

Social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses: A qualitative study among social workers in primary care settings in Namibia

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DECLARATION

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I declare that “*Social workers’ perceptions of their role in providing palliative care to patients with life-limiting illnesses: A qualitative study among social workers in primary care settings in Namibia*” is my work and that all the sources that I have used or quoted have been acknowledge by means of complete references.



SIGNATURE

(Mrs Rachel J Freeman)

08 March 2018

DATE

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SUMMARY

This study explored social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses in six hospitals across Namibia. A qualitative grounded theory approach was used in which in-depth interviews were conducted with twenty (20) social workers. Several key findings are presented: First, the emerging constructivist grounded theory of social workers' multi-dimensional roles in providing palliative care includes identities of advocate, assessor, broker, counsellor, educator, facilitator, patient liaison, mediator, discharge planner and manager of in-country referrals. Second, several participants' uncertainties of what palliative care entails offered insight that they are in need of palliative care education and training. Third, healthcare professionals do not understand the role of the social workers and therefore social workers receive inadequate support from them. Fourth, there is a lack of in-service training and continuous education in palliative care. Fifth, there are inadequate practice opportunities in palliative care for undergraduate social work students. Finally, the well-being of social workers is another concern with limited debriefing opportunities available. Further research needs to be conducted and policy guidelines established to identify ways to improve the field of palliative care social work. In achieving this, formal education and palliative care practice opportunities for social workers need to be established, providing continuing education and establishing a Centre of Excellence on palliative care provision. This study argues that the social work profession is well positioned to draw upon its values, culture and experiences (particularly from their clients) to get involved in creating a constructivist grounded theory of social workers' roles in providing palliative care.

Keywords: *Life-limiting illnesses, Namibia, palliative care, primary care settings, role of social worker, and social work*

TABLE OF CONTENTS	PAGE
DECLARATION.....	ii
ACKNOWLEDGEMENTS	iii
SUMMARY	v
TABLE OF CONTENTS PAGE	vi
LIST OF TABLES	xv
LIST OF ACRONYMS AND ABBREVIATIONS	xvi
GLOSSARY.....	xviii
CHAPTER 1: ORIENTATION TO THE RESEARCH PROBLEM.....	1
1.1 INTRODUCTION TO THE STUDY.....	1
1.2 BACKGROUND AND SOCIOLOGICAL SIGNIFICANCE	2
1.3 RESEARCHER’S INTEREST IN THE RESEARCH: FROM PERSONAL JOURNEY TO PROFESSIONAL INPUT	11
1.4 PROBLEM STATEMENT	13
1.5 THE RESEARCH QUESTION.....	15
1.6 THE AIMS AND OBJECTIVES OF THE STUDY	15
1.6.1 Examine social workers’ perceptions of their role in providing palliative care to patients with life-limiting illnesses.....	16
1.6.2 Examine social workers’ understanding of palliative care	16
1.6.3 Investigate conditions that hindered social workers’ abilities to provide palliative care	17
1.6.4 Investigate conditions that strengthened social workers’ abilities to deliver palliative care	17
1.7 THE RATIONALE FOR THE STUDY	17
1.8 OPERATIONALISATION OF CONCEPTS.....	20
1.8.1 Life-limiting illnesses.....	20
1.8.2 Palliative care.....	21
1.8.3 Patients	21

1.8.4	<i>Social work</i>	22
1.9	OUTLINE OF CHAPTERS	23
	CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK	25
2.1	INTRODUCTION AND BACKGROUND TO THE STUDY	25
2.2	CONTEXTUALIZATION OF SOCIAL WORK AND PALLIATIVE CARE ..	28
2.2.1	The three historical periods of social welfare and social work development in Namibia	28
2.2.2	The indigenous human service systems in the pre-colonial era of Namibia	29
<i>i.</i>	<i>Indigenous Human Services in the Pre-Historical Period-BC to 1485 in Namibia</i>	<i>30</i>
<i>ii.</i>	<i>Indigenous Human Services in the Period of Bantu Expansion: 1400-1800 in Namibia</i>	<i>31</i>
<i>iii.</i>	<i>The role of indigenous human service systems in an independent Namibia</i>	<i>32</i>
2.3.	SOCIAL WELFARE AND SOCIAL WORK DURING THE SOUTH AFRICAN COLONIAL ERA	32
<i>i.</i>	<i>The legal Social Welfare system during the Colonial Rule</i>	<i>33</i>
<i>ii.</i>	<i>Social Work Education under the Colonial Rule</i>	<i>35</i>
2.4	SOCIAL WELFARE AND SOCIAL WORK SYSTEMS IN AN INDEPENDENT NAMIBIA	36
2.4.1	Information on the context of social work service users (Patients)	41
2.4.2	Social work education and training in an independent Namibia	42
2.5	THE GLOBAL CONTEXT OF PALLIATIVE CARE	46
2.6	THE CONTEXT OF PALLIATIVE CARE IN AFRICA	48
2.7	THE CONTEXT OF PALLIATIVE CARE IN NAMIBIA	51
2.8	DEMAND AND NEED FOR PALLIATIVE CARE	53
2.9	SOCIOLOGICAL SIGNIFICANCE OF STUDYING SOCIAL WORKERS IN PROVIDING PALLIATIVE CARE	56
<i>2.9.1</i>	<i>Understanding social workers' perceptions of their roles in providing palliative care</i>	<i>58</i>
<i>2.9.2</i>	<i>Social workers' understanding of palliative care</i>	<i>61</i>
<i>2.9.3</i>	<i>Conditions that hinder social workers' abilities to provide palliative care</i>	<i>63</i>
<i>2.9.4</i>	<i>Conditions that strengthen social workers' abilities to deliver palliative care</i>	<i>66</i>
<i>2.9.5</i>	<i>Social work education and training on palliative care</i>	<i>67</i>

2.10	THE RELEVANCE AND APPLICABILITY OF SYMBOLIC INTERACTIONISM IN THE STUDY	70
2.10.1	Ecological Systems Perspective.....	74
2.10.2	Theory On <i>Death and Dying</i> by Kubler-Ross.....	77
2.11	SUMMARY	78
CHAPTER 3: THE RESEARCH METHODOLOGY.....		81
3.1	INTRODUCTION.....	81
3.2	APPLYING GROUNDED THEORY	81
3.2.1	<i>The origins of grounded theory.....</i>	<i>82</i>
3.2.2	<i>Constructivist grounded theory.....</i>	<i>83</i>
3.2.3	<i>Rationale for choosing constructivist grounded theory.....</i>	<i>84</i>
3.3	THE CHOSEN RESEARCH DESIGN.....	85
3.4	METHODOLOGICAL FRAMEWORK.....	86
3.5	ACCESS, NEGOTIATION AND SAMPLING TECHNIQUES.....	88
3.5.1	<i>Preparation and negotiation to conduct the study.....</i>	<i>88</i>
3.5.2	<i>Permission to conduct the research.....</i>	<i>88</i>
3.5.3	<i>Sampling</i>	<i>89</i>
3.6	DATA COLLECTION AND ANALYSIS	90
3.6.1	<i>Data Collection Procedures</i>	<i>90</i>
3.6.2	<i>Data Analysis and Interpretation.....</i>	<i>91</i>
3.7	ISSUES OF TRANSFERABILITY	93
3.8	REFLECTION ON THE ROLE AND POSITION OF THE RESEARCHER ...	93
3.8.1	<i>Going there: Undertaking the research.....</i>	<i>95</i>
3.9	ETHICAL CONSIDERATIONS.....	96
3.9.1	<i>Confidentiality and Anonymity</i>	<i>97</i>
3.9.2	<i>Voluntary participation and Informed consent.....</i>	<i>98</i>
3.10	SUMMARY	98
CHAPTER 4: PRESENTATION OF THE FINDINGS AND ANALYSIS		100
4.1	INTRODUCTION.....	100
4.2	PRESENTATION OF THE FINDINGS AND DATA ANALYSIS	104

4.3	SOCIAL WORKERS' PERCEIVED ROLES IN THE PROVISION OF PALLIATIVE CARE	106
4.3.1	<i>Role as counsellor.....</i>	<i>109</i>
4.3.2	<i>Role as facilitator / liaison.....</i>	<i>113</i>
4.3.3	<i>Role as educator</i>	<i>115</i>
4.3.4	<i>Role as broker.....</i>	<i>117</i>
4.3.5	<i>Role of assessment of patients.....</i>	<i>118</i>
4.3.6	<i>Role as advocate</i>	<i>119</i>
4.3.7	<i>Managing in-country and international referrals.....</i>	<i>121</i>
4.3.8	<i>Role as discharge planner</i>	<i>122</i>
4.3.9	<i>Role as mediator /intermediary</i>	<i>123</i>
4.4	SOCIAL WORKERS' UNDERSTANDING OF PALLIATIVE CARE	124
4.4.1	<i>Social workers' definition of palliative care.....</i>	<i>124</i>
4.4.2	<i>The definition of palliative care according to the World Health Organization</i>	<i>128</i>
4.4.3	<i>Gap in knowledge according to participants' understanding of palliative care.....</i>	<i>129</i>
4.5	SOCIAL WORKERS' PERCEPTIONS AND EXPERIENCES IN PROVIDING PALLIATIVE CARE	129
4.5.1	<i>Perceptions of the proportion of social work focusing on palliative care.....</i>	<i>130</i>
4.5.2	<i>Perceptions, experiences and satisfaction with the management of palliative care services.....</i>	<i>133</i>
4.5.3	<i>Perceived confidence in the provision of palliative care.....</i>	<i>137</i>
4.5.4	<i>Perceptions and satisfaction with the provision of palliative care services.....</i>	<i>139</i>
4.5.5	<i>Perceptions and satisfaction with the role of the social worker in the provision of palliative care</i>	<i>141</i>
4.5.6	<i>Perceptions and experiences about interactions with patients and family.....</i>	<i>142</i>
4.5.7	<i>Perceptions and experiences about interactions with the multi-disciplinary team... </i>	<i>145</i>
4.6	CONDITIONS THAT HINDER SOCIAL WORKERS' ABILITIES TO PROVIDE PALLIATIVE CARE	148
4.6.1	<i>Roles of the social workers not understood by other health care professionals</i>	<i>149</i>
4.6.2	<i>Lack of palliative care training; in-service training; continuous education and research on palliative care in the Namibian context.....</i>	<i>151</i>
4.6.3	<i>Communication barriers.....</i>	<i>152</i>

4.6.4	<i>Referrals from doctors and nurses to social workers not mainstreamed</i>	154
4.6.5	<i>Explaining Medical jargon used by doctors</i>	157
4.6.6.	<i>Shortage of specialized palliative care social workers and social workers' workloads</i>	160
4.6.7	<i>Well-being of social workers</i>	163
4.6.8	<i>Lack of Supervision; Debriefing and Support from management</i>	164
4.6.9	<i>Lack of appreciation for the role of the social worker in providing palliative care</i>	165
4.6.10	<i>Lack of bed space in the hospital</i>	165
4.6.11	<i>Limited resources</i>	166
4.7	CONDITIONS THAT STRENGTHEN SOCIAL WORKERS' ABILITIES TO DELIVER PALLIATIVE CARE	168
4.7.1	<i>Palliative care social work education; in-service training; continuous education; research and a national palliative care policy</i>	168
4.7.2	<i>Collaborating with the multi-disciplinary team</i>	172
4.7.3	<i>The role of the social worker in palliative care provision</i>	172
4.7.4	<i>Mainstreaming of referrals of palliative care patients to social workers</i>	173
4.7.5	<i>Designated palliative care social worker</i>	173
4.7.6	<i>Networking with other stakeholders</i>	174
4.7.7.	<i>Strengthening the skills of palliative care social workers</i>	176
4.8	SOCIAL WORK EDUCATION AND TRAINING IN PALLIATIVE CARE..	178
4.8.1	<i>Experiences on undergraduate social work education and training in the palliative care module</i>	179
4.8.2	<i>Lack or limited under-graduate palliative care curriculum</i>	182
4.8.3	<i>Internship experiences on palliative care in the Bachelors of Arts (Honours) in social work</i>	183
4.8.4	<i>Continuous education and training on palliative care</i>	186
4.8.5	<i>Continuing education and training topic suggestions</i>	187
4.9	BIOGRAPHICAL DETAILS OF THE RESEARCH PARTICIPANTS	190
4.9.1	<i>Sex and religious affiliation of participants</i>	190
4.9.2	<i>The ages of the participants</i>	191
4.9.3	<i>The ethnicities of the participants</i>	191
4.9.4	<i>Years of experience as a social worker</i>	192

4.9.5	<i>Educational and training backgrounds</i>	192
4.10	SUMMARY	193
CHAPTER 5: ~ ‘Being here’ - Creating a constructivist grounded theory of social workers’ multi-dimensional roles in providing palliative care.....195		
5.1	INTRODUCTION.....	195
5.2	MULTI-DIMENSIONAL ROLES OF THE SOCIAL WORKERS IN PROVIDING PALLIATIVE CARE	200
5.2.1	<i>Role as counsellor.....</i>	202
5.2.2	<i>Role as facilitator and liaison.....</i>	203
5.2.3	<i>Role as educator</i>	204
5.2.4	<i>Role as broker.....</i>	205
5.2.5	<i>Role of assessment of patients.....</i>	206
5.2.6	<i>Role as advocate</i>	206
5.2.7	<i>Managing in-country and international referrals.....</i>	208
5.2.8	<i>Role as discharge planner</i>	208
5.2.9	<i>Role as mediator or intermediary.....</i>	209
5.3	SOCIAL WORKERS’ UNDERSTANDING OF PALLIATIVE CARE.....	210
5.4	SOCIAL WORKERS’ PERCEPTIONS AND EXPERIENCES ABOUT PROVIDING PALLIATIVE CARE	214
5.4.1	<i>Perceptions of the proportion of social work focusing on palliative care.....</i>	214
5.4.2	<i>Perceptions, experiences and satisfaction with the management of palliative care services.....</i>	215
5.4.3	<i>Perceived confidence in the provision of palliative care.....</i>	220
5.4.4	<i>Perceptions and satisfaction with the provision of palliative care services.....</i>	221
5.4.5	<i>Perceptions and satisfaction with the role of the social worker in the provision of palliative care</i>	222
5.4.6	<i>Perceptions and experiences about interactions with patients and family.....</i>	223
5.4.7	<i>Perceptions and experiences about interactions with the multi-disciplinary team... </i>	224
5.5	CONDITIONS THAT HINDER SOCIAL WORKERS’ ABILITIES TO PROVIDE PALLIATIVE CARE.....	226
5.5.1	<i>Roles of the social workers in the provision of palliative care are not understood by other healthcare professionals.....</i>	227

5.5.2	<i>Lack of palliative care training; in-service training; continuous education and research on palliative care in the Namibian context</i>	228
5.5.3	<i>Communication barriers</i>	229
5.5.4	<i>Delayed referrals from doctors and nurses to the social workers</i>	230
5.5.5	<i>Explaining medical jargons used by doctors with patients</i>	231
5.5.6	<i>Shortage of specialized palliative care social workers and workloads of the hospital based social workers</i>	231
5.5.7	<i>Well-being of the social workers</i>	232
5.5.8	<i>Lack of supervision; debriefing and support from management</i>	233
5.5.9	<i>Lack of appreciation for the role of the social worker in providing palliative care</i> .	234
5.5.10	<i>Shortage of bed space in the hospital</i>	235
5.5.11	<i>Other conditions that hinder social workers' abilities to provide palliative care</i>	235
5.6	CONDITIONS THAT STRENGTHEN SOCIAL WORKERS' ABILITIES TO DELIVER PALLIATIVE CARE	236
5.6.1	<i>Palliative care social work education; in-service training; continuous education; research and a national palliative care policy</i>	236
5.6.2	<i>Collaborating with the multi-disciplinary team</i>	238
5.6.3	<i>The role of the social worker in the provision of palliative care</i>	239
5.6.4	<i>Mainstream of referrals of palliative care patients from doctors and nurses to social workers</i>	240
5.6.5	<i>Designated palliative care social worker</i>	<u>241</u> 241 235
5.6.6	<i>Network with other stakeholders</i>	241
5.6.7	<i>Strengthen the skills of palliative care social workers</i>	241
5.7	SOCIAL WORK EDUCATION AND TRAINING IN PALLIATIVE CARE .	242
5.7.1	<i>Experiences on undergraduate social work education and training in the palliative care module</i>	242
5.7.2	<i>Limited undergraduate palliative care curriculum</i>	242
5.7.3	<i>Clinical placements on palliative care in the Bachelors of Arts in Social Work Degree</i>	243
5.7.4	<i>Continuous education and training on palliative care</i>	244
5.7.8	<i>Continuous education and training topic suggestions</i>	245

5.8	THE SOCIOLOGICAL SIGNIFICANCE OF SOCIAL WORKERS' ROLE IN PROVIDING PALLIATIVE CARE	246
5.8.1	<i>Patients with life-limiting illnesses</i>	248
5.9	INTERPRETATION OF THE FINDINGS ON IMPLICATIONS FOR PRACTICE	250
5.10	CONCLUSION	252
CHAPTER 6:	CONCLUSIONS AND RECOMENDATIONS	254
6.1	<i>RECOLLECTING THE STUDY OBJECTIVES</i>	255
6.2	SUGGESTIONS ON HOW TO IMPROVE THE FIELD OF PALLIATIVE CARE SOCIAL WORK	260
6.2.1	<i>National Policy on Palliative Care</i>	260
6.2.2	<i>Undergraduate training; in-service and continuing education and conferences in palliative care for social workers</i>	261
6.2.3	<i>Palliative care internship & clinical placements sites</i>	261
6.2.4	<i>Designated palliative care social workers</i>	262
6.2.5	<i>Research in palliative care</i>	262
6.2.6	<i>Mainstreaming of palliative care patient referrals to social workers</i>	263
6.2.7	<i>Awareness and education on palliative care</i>	263
6.2.8	<i>Supervision and debriefing opportunities</i>	<u>263</u> 264
6.2.9	<i>Other suggestions on how to improve the field of palliative care</i>	264
6.3	STRENGTHS AND LIMITATIONS OF THE STUDY	264
6.4	RECOMMENDATIONS ON HOW TO STRENGTHEN POLICY, PRACTICE AND RESEARCH	<u>266</u>267
6.4.1	<i>National policy and guidelines on palliative care</i>	268
6.4.2	<i>Undergraduate training; in-service and continuous education for social workers on palliative care</i>	<u>268</u> 269
6.4.3	<i>Palliative care clinical placements opportunities and sites</i>	269
6.4.4	<i>Designated palliative care social workers</i>	270
6.4.5	<i>Further Research</i>	270
6.4.6	<i>Mainstreaming of palliative care patient referrals to the social workers</i>	<u>271</u> 272
6.4.7	<i>Awareness and education on palliative care</i>	272
6.4.8	<i>Supervision and debriefing opportunities</i>	273

6.5 FINAL REMARKS.....	<u>273274</u>
LIST OF SOURCES	277
APPENDICES	315
APPENDIX 1: DEMOGRAPHIC INFORMATION	315
APPENDIX 2: INFORMATION LETTER & CONSENT FORM.....	316
APPENDIX 3: INTERVIEW GUIDE.....	321
APPENDIX 4: UNISA ETHICAL CLEARANCE	325
APPENDIX 5: APPROVAL OF RESEARCH FROM MHSS	326
APPENDIX 6: EXAMPLE OF TRANSCRIBED INTERVIEW WITH PARTICIPANT 3.....	327
APPENDIX 7: BIOGRAPHIC PROFILES OF THE PARTICIPANTS	375
APPENDIX 8: SUMMARY OF THE DEMOGRAPHICS OF THE PARTICIPANTS.....	389
APPENDIX 9: SUMMARIZED CHARACTERISTICS OF THE PARTICIPANTS.	390

LIST OF TABLES

Table 2.1:....The four central components of Symbolic Interactionism (adapted Blumer, 1969)

.....	<u>71</u> 69
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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
APCA	African Palliative Care Association
APCSW	Association of Palliative Care Social Work
ART	Antiretroviral Therapy
CGT	Constructivist Grounded Theory
CEUs	Continuous Education Units
CSWs	Chief Social Workers
HIV	Human Immunodeficiency Virus
GDP	Gross Domestic Product
GT	Grounded Theory
HDI	Human Development Index
HCPs	Healthcare Professionals
HPCNA	Health Professions Council of Namibia
IASSW	International Association of Schools of Social Workers
ICESCR	International Convention on Economic, Social and Cultural Rights
IFSW	International Federation of Social Workers
MA	Master of Arts
MDGs	Millennium Development Goals
NASW	National Association of Social Workers
NCDs	Non-Communicable Diseases
NEMLIST	Namibian Essential Medicines List
MDT	Multi-Disciplinary Team
MHSS	Ministry of Health and Social Services
PC	Palliative Care
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNAM	University of Namibia
UNISA	University of South Africa
USAID	United States Agency for International Development
WHA	World Health Assembly
WHO	World Health Organization

WHPCA World Hospice and Palliative Care Alliance

GLOSSARY

Categories:	group of concepts that are used to create a theory
Carer / caregiver	terms used interchangeably to describe someone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support
Codes	identifying anchors that allow key points of data to be gathered
Concepts	collection of codes of similar content that allows data to be grouped
Constant Comparison	constantly comparing incoming data with data, codes and categories to determine ‘fit’
Induction	a type of reasoning that emerges from the data
Palliative Care	an approach that improves the quality of life of the patients and their families facing the problems associated with life-limiting illness.
Reflexivity	the researcher’s scrutiny of her/his own experience, decisions and interpretations

Rigour	ensuring and demonstrating processes employed to explain all factors that have been followed and adhered to in order to avoid bias and threaten the validity of the research findings
Symbolic Interactionism	a theoretical perspective which assumes people construct selves, society and reality through interaction and they assign their meaning to it.
Theory	a collection of explanations that explain subject of research
Theoretical Sampling	sampling is focused on people, places and events which will illuminate the data emerging
Theoretical Sensitivity	the ability to recognize and extract from the data elements that are relevant to the emerging theory

CHAPTER 1: ORIENTATION TO THE RESEARCH PROBLEM

1.1 INTRODUCTION TO THE STUDY

This study investigates social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses in primary care settings namely; six hospitals across Namibia. Unlike previous research that centres on developed or western countries, the focus of this study is base in an African country, Namibia and therefore adds to the literature because it focuses exclusively on social workers' own perceptions of their role in providing palliative care to patients with life-limiting illnesses in Namibia. The study utilises a grounded theory qualitative approach. This approach seeks to present in-depth information on the core role/s in the narratives by those carrying out the roles, rather than simply to approach information clinically as a series of tasks (i.e. simply by describing what their role is in caring for patients with life-limiting illnesses). In that sense, a constructivist grounded theory ethnographic study is present here as I entered the workspaces of and observed those participating in the study, which essentially is about them and how they interpret their own work. In-depth face-to-face interviews with twenty practicing social workers at six public hospitals in Namibia were carrying out using an audio tape-recorder. I first sought to examine how these social workers perceived their role in providing palliative care to patients with life-limiting illnesses and then I explored social workers' understanding of palliative care. Third, I investigated, in the interviews, conditions that hindered or strengthened social workers' abilities to deliver palliative care based on their experiences. Finally, I sought to gain, through this in-depth investigation, insights into how social work education and training in Namibia influenced the social workers' competencies to deliver palliative care.

This introduction chapter serves to contextualize and situate the research in its context and to provide an overview of the thesis. The next section provides background information on palliative care in social work. I am exploring its' sociological significance as a phenomenon and offering my own experiences as a trained social worker and how my interest in examining social workers' perceptions of their role in

providing palliative care to patients developed into research. I discuss the problem statement, the research questions, the aims and objectives of the study, the rationale of the study, the operational definitions applicable to the study and finally I provide a brief outline of the theoretical framework.

1.2 BACKGROUND AND SOCIOLOGICAL SIGNIFICANCE

Emerging out of the need to record and produce scholarly work, which contextualizes the development and evolution of palliative care social work in Namibia it is important to link the micro level interactions to the broader political, social and structural context by getting a glance on the overview of Namibia's political and socio-economic situation. In order to have a better understanding of the social worker's role providing palliative care, the next section provides a sociological explanation, which links the questions of palliative care to the broader historical background of an apartheid colonial segregated healthcare system and the highly unequal nature of the Namibia society.

1.2.1 An Overview of Namibia's political and socio-economic situation

The past, present and the future have important connections. It is thus necessary to explore the roots, foundations, fundamental policies and processes to social work palliative care by providing an overview on major developments in Namibia's political and socio-economic situation that culminated in palliative care social work. Namibia emerged from a history of colonialism. Namibia is Africa's last colony, liberated on 21 March 1990. In 2017, Namibia celebrated 27 years of independence. After 1990, the country became an independent, democratic and unitary state, whose governance is based on democracy, rule of law, solidarity and justice. At independence, the country expressed her commitment towards the welfare of all its citizens at constitutional level in Chapter 3 of the Namibia Constitution, which deals with human rights and freedoms (Republic of Namibia Constitution, 1990). As a country its history passed through several distinct stages, such as the pre-colonial era (1400-1800); the Christian Missionary Era (1805-1840); the German rule (1884 -1915); the South African rule (1915-1990) and post-colonial period (1990-present).

Formerly known as German South West Africa before independence, the country upon gaining independence was proudly named after the Namibian Desert, which covers about one fifth of the country. The name Namibia derives from a Nama/Damara word meaning, "shield" or protector used, which long protected the Namib Desert interior from access by sea. Vast in distance, this thinly populated and largely arid country shares borders with Angola and Zambia (north), Botswana (east), South Africa (south), and the Atlantic Ocean (west) (SWA /Namibia Information Service Today 1980:4). The size of Namibia's territory comprises of 824,268 km² with a population of 2.2 million (National Statistics Agency, 2011). Namibia is a land of diversity with eleven different ethnic groups; namely *OvaHerero*, *Aawambo*, *vaKavango*; *Namas*; *Damaras*; *Caprivians*; *Basters*, *Coloureds*, *Germans*, *Afrikaners* and *San* people. The largest ethnic group being the *Aawambo* (Owambo) people make up fifty one percent of the population and the ten other ethnic groups make up forty nine percent of the Namibian population. Every ethnic group has its own distinct language, cultures and traditional practices that are unique to each group. The country's official language is English, but less than 7 per cent of Namibians speak it as a first language (National Statistics Agency, 2011).

In reversing the legacy of apartheid, Namibia at independence opted to align social welfare provision with the country's new Constitution based on liberal democracy. In line with this the country signed and ratified several African and international conventions to advance human rights and human dignity, which emphasise democratic participation, social justice and a human rights approach in the promotion of people's social wellbeing; and the protection of vulnerable and marginalised groups. Social workers in Namibia are responsible for the provision of social welfare and social work services in improving the quality of life and social well-being of those in need of care and assistance. The profession social work is concerned with people in societies with particular needs across all ages, classes, religious and ethnic groups. In short, social work is a profession that serves the needs of society. In this context, social workers perform their roles within a human rights framework, which promotes the social and economic empowerment of clients.

Social workers facilitate the empowerment of individuals, groups and communities which emphasis collaboration on micro, meso and macro levels of interactions and interventions (Patel, 2005: 207). The profession social work can be consider both generic and specialised since the focus is on broad social problems, such as poverty, gender-based violence and alcohol abuse, among others. In addition, most social workers' caseloads include working with people with life-limiting illnesses, who fear their loss of health and simultaneously face the high risk of a premature death and are in need of specialist care called palliative care. Kramer, Paroureke and Hovland-Scafe (2003) identified that social workers deal with patients with life-limiting illnesses in a range of settings, which include hospitals, private home-based care, hospices, emergency rooms, intensive care units, paediatric settings, etc. However, Kramer *et al.*, (2003) found that many social worker textbooks did not include material on palliative care and end-of life care even though it is relevant to all social workers and important to different specialized social worker roles (Kramer, *et al.*, 2003).

The end of colonial rule in 1990 - left Namibia with fragmented social welfare and social work systems, which resulted in Namibia's traditional and indigenous systems and institutions of social welfare service provision disrupted and destroyed in the process. Hunt (2009) states that families are fragmented, traditional values, and support systems have been eroded and the sick, the elderly and grieving orphans can no longer rely on immediate family members to provide for them. The colonial social welfare and social work systems with a strong Christian influence were deeply rooted in the legacy of apartheid. Consequently, the social welfare system and social work inherited from the apartheid South African colonial administration lacked in inclusiveness (including palliative care) and in promoting the well-being of all Namibians. Although, like in South Africa, many welfare policies during the South African rule did not specifically exclude black people, however, the government's allocation of welfare resources were based on racial differentiation with the "white" administration on top of all others. The South African apartheid rule, divided Namibia into eleven ethnic administration departments where whites had their own administration, followed by the coloured administration and various black ethnic group administrations.

For example, Bernstein and Gray (1997) state that just like in South Africa, public assistance was not provide to Africans even if they qualified for such assistance, the same was true for Africans in Namibia where only limited state help was available for them. However, Namibia has since independence in 1990 made great strides in promoting the social well-being of its people and it is often herald as one of Africa's greatest success stories for its stable democracy, peace and stability and progressive social welfare policies and institutions. This enormous socio-economic progress has been accompanied by equally vital changes in the social welfare field in terms of systems and organisational structure; the size of social work professional membership; the educational systems of all professions in the human service; the sophistication of their practice methodologies and social work as a profession within this wide ambit of socio-economic development. The country is rank as an upper middle-income developing country rich in resources (Jauch & Kaapama, 2011). The country has recorded steady economic growth over the last two decades, despite the fact that its socio- economic situation is ruin by unacceptably high levels of unemployment, poverty and inequalities. This social inequality, which has historical roots, contributes to a high rate of unemployment, poverty and lack of access to primary healthcare among many Namibians. To this effect Jauch, Edwards and Cupido (2011: 243) attribute inequality in present day Namibia to the South African colonial regime, which left Namibia with a highly dualistic society, comprised of the extremely rich and the extremely poor. Globally, Namibia is considers as suffering the highest income inequalities, despite its upper middle-income country status. The National Statistics Agency (NSA, 2012) provides statistical confirmation to support the levels of poverty and inequality in Namibia. According to the National Statistics Agency (NSA, 2012) the income per capita households where Khoisan is the main language spoken, is N\$6,631 compared to the N\$150, 730 in households where German is the main language. These figures highlight massive income disparities as individuals in a German-speaking household on average have a level of income that is 23 times higher than in a Khoisan speaking housed (NSA, 2012:14). Key social problems facing Namibia include HIV and AIDS, poverty, vulnerable children, gender based violence (GBV), unemployment and substance abuse, etc. However, according to International Labour Organisation (ILO, 2014) poverty has declined in the official estimates from 69.3 per cent in 1993/94 to 28.7 per cent in 2009/10.

Recognising the intrinsic connectedness of the total institution of social welfare and the profession of social work, it needs to be noted that the profession developed out of the need for agents to carry out the welfare programmes that were developed to address people's living conditions throughout the country. However, like other countries in Africa, Namibia faces certain socio-economic problems, which require some adjustment in social welfare and social work provision. As a country, Namibia recognises this reality, and addressing socio-economic inequalities is a critical priority area for Vision 2030, Namibia's Policy Framework for Long-Term National Development (Republic of Namibia, 2004b: 7). Vision 2030 recognizes that government alone cannot deal with socio-economic inequalities and that there is a need for collaboration with civil society and all members of the Namibian community (Republic of Namibia, 2004b: 9-10). In government's recognition that they cannot deal with the socio-economic inequalities alone, it is important to recognize the vital role the social work profession plays in addressing these challenges. In line with this, Palattiyil, Sidhva and Chakrabarti (2016) point that social workers are increasingly involved in global social issues impacting human development and well-being.

While palliative care has a relatively long history in North America and Europe, it has only recently been introduced to sub-Saharan Africa where thousands of patients suffer from life-limiting illnesses in Namibia alone. Although palliative care social work has a relatively short history in Namibia, it is seen as having an important complementary role within the hospice movement (Dunlop & Hockley, 1998). The hospice movement initiated by Dame Cicely Saunders (1967), herself a social worker, nurse and doctor, is an approach that took account of the patients' 'total pain', which highlighted not only the physical aspects of the pain, but also the psychological, emotional, social and spiritual dimensions of distress (Saunders 1993). Saunders (1967), who initiated the modern hospice movement, published her first paper on hospice care (Clark, 1999 & Clark, 1998a) and in 1967, she opened the St. Christopher's Hospice in South London (Clark, 1998b). Advances in medicine have led to better pain control and pain relief and this, together with a clearer understanding of the impact of death and dying on all concerned, has helped to provide a more holistic approach to the dying person (Reith

and Payne 2009). Palliative care as an approach has since come to be considering a specialist area in social work (Sheldon, 2000; Cadell, Johnston, Bosma & Wainwright, 2010). It is a multi-professional practice in which pain control and symptom management is combined with the concern for social, psychological and spiritual problems that arise for a patient diagnosed with a life-limiting illness and for their families. Worldwide, palliative care is considered a human right and an obligation under international human rights law (International Covenant on Economic, Social and Cultural Rights, Article 12, 1976 and (Brennan, 2007 & Gwyther, 2009). It is provided through various services such as social work, home-based care, hospices and palliative care teams in primary care settings, such as social worker, nurses, doctors, and other healthcare professionals. Ensuring the accessibility of palliative care, is not just an ethical obligation of health systems, it is also an obligation under international human rights law (International Covenant on Economic, Social and Cultural Rights, Article 12, 1976) and a humane response to human suffering. In addition, the World Health Assembly (WHA 67.19, 2014) has recognized that palliative care is explicitly part of the comprehensive services required for giving dignity to those with a life-limiting illness (WHA 67.19, 2014).

Palliative care developed from services for a wide range of patients who have life-limiting illnesses (World Health Organization, 2016). These life-limiting illnesses include non-curable communicable diseases (such as HIV and AIDS) or non-communicable diseases (such as cancer, cardiac arrest, diabetes, respiratory failure or multiple sclerosis). Patients affected by either type of life-limiting illnesses have contact with health professionals in the health care setting. Many patients' contact is with professional social workers, who in most cases in Namibia do not necessarily practice as palliative care social work specialists. Despite this, professional social workers at micro level make an invaluable contribution to the patient and the family's experiences at meso and macro levels. The social worker's role in the provision of palliative care is an important component in improving the quality of life of patients and their families with life-limiting illnesses, particularly, in being able to provide this specialised palliative care treatment.

Social workers are key professionals in assessing the psycho-social needs of patients with life-limiting illnesses providing moral, psychological and emotional support. Bomba, Morrissey and Leven (2010: 75) state that social workers provide an essential link between patients, families and medical providers, in general, because, “*the social worker has the skills to work with individuals in diverse environments, understand their social ecological contexts, and help them make meaning of their decision-making experiences*” (Bomba *et al.*, 2010). The social worker acts as an essential member and intermediary between the patients, families and the medical team. Social workers work with patients facing life-limiting illnesses, death, grief and bereavement. Social workers therefore play a fundamental role within the multi-disciplinary team. According to Gonzales (2014), a multi-disciplinary team is defined as a group of professionals from various disciplines including physicians, nurses, social workers, physiotherapists and nutritionists, working together to provide care to patients and families. Despite the importance of the multi-disciplinary team approach, social workers in Namibia do not have a formal role in working with physicians, patients and families.

In the first ever, global resolution on palliative care in 2014, the World Health Assembly (WHA 67.19, 2014) called upon the World Health Organization (WHO) and Member States to “*improve access to palliative care as a core component of health systems with an emphasis on primary health care and community or home-based care*”. Palliative care is explicitly recognized as part of the comprehensive services required for the non-communicable diseases in the WHO Global Action Plan (2013-2020) for the Prevention and Control of Non-Communicable Diseases. In Africa, there is a growing recognition of the importance of addressing life-limiting illnesses and advancing the palliative care provision (<http://www.hospicepalliativecaresa.co.za/pdf/consensus-statement.pdf> and Powell, Ali, Luyirika, Harding, Radbruch & Mwangi-Powell (as quoted in APCA, 2016, accessed January 2016). In Africa, palliative care originated over 30 years ago and it has made significant improvements over the last decade including an enlarged number of service providers (Grant, Brown & Leng *et al.*, 2011; Lynch, Connor & Clark, 2013 & Powell, Mwangi-Powell & Kiyange *et al.*, 2011). The WHO (2002) defines palliative care as an approach that improves the quality of life of patients who face life-limiting illness.

This is done through the relief of suffering by means of early identification and treatment of pain and other problems including physical, psychological, emotional and spiritual from the time of diagnosis to the end of life as well as in bereavement after the passing of the family member. The WHO (2016) states that palliative care for children is perceived as distinct from palliative care for an adult, and it is defined as *"the active total care of the child's body, mind and spirit, and also involves giving support to the family"*. It begins when an illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. My research topic is interesting and relevant not only to the subfield of the sociology of healthcare, but also to social work and the sub-discipline of social-psychology as it examines the social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses.

Pescosolido (2006: 193) states that, *"when integrating sociological studies into the field of health sciences, the diversity of theoretical and methodological insights cater for a diversity of empirical knowledge"*. Further, Clarke (2001: 7-8, 26) argues that the discipline of sociology provides different perspectives for trying to understand the social world: *"Each perspective gives us a different slant on social behaviour and hereby adds to our knowledge of the nature, structure and content of social relationships and patterns of social interaction"*. Based on these arguments by Pescosolido (2006) and Clarke (2001), it makes my study multi-, inter- and transdisciplinary relevant. Pescosolido (2006) further continues to explain how:

- social, psychological, economic, and cultural factors predispose individuals to health and illness
- diseases are often a reflection of current theories, diagnostic procedures, trends and resources in medicine, as well as cultural understandings
- the quality and quantity of treatment are not tagged solely to some clear disease profile, and are not consistently amenable to a single set of treatments
- the eventual outcomes of health, illness, and healing are shaped by extra-medical or extra-treatment factors, such as palliative care.

Pescosolido's (2006) discussion above justifies the location of the study in the field of sociology of healthcare provision. With reference to the first point above, life-limiting illnesses are not held in isolation, but are affected by a patient's social, psychological and economic situation. The second point above emphasises the social aspect of culture, which needs to be integrated into the Namibian social services and medical systems, since many patients seek traditional and cultural remedies to maintain their health. A patient's culture also contributes to the manner in which illness is accepted and treated. A patient with a life-limiting illness is not isolated; instead, this illness affects the patient's social life, emotional, financial, and family life. The third point notes that life-limiting illnesses affect a person's quality of life, since life-limiting illnesses are complex illnesses and are incurable. Patients constantly need to seek medical and psychosocial care in order to manage it. Life-limiting illnesses are not restricted to the medical system, but are judged and maintained by social factors, which include culture and aspects of family support.

Clarke (2001: 26) emphasises my argument above:

“a sociologically orientated or social model of illness challenges the biomedical approach to disease by roundly rejecting the notion of mind-body dualism, dismissing the idea that illness can be reduced to disordered bodily functioning and urging health-care professionals to take account of the wider social and cultural milieu in which diseases are diagnosed and treated” Clarke (2001: 26).

The conceptual contribution of this study examines social workers' perspectives of their role in providing palliative care to patients with life-limiting illnesses. This study attempts to explore whether social workers based in hospitals are taking an active role in providing palliative care? If they are taking an active role, how do they perceive these roles and what conditions strengthened their abilities to deliver palliative care and how can the social work profession continue to improve how it provides palliative care in these settings? It continues to examine social worker's understanding of palliative care. The study investigates conditions that hindered social workers' abilities providing palliative care. If social workers are not providing palliative care in the primary care settings in Namibia, what are the conditions that hinder their abilities to do so?

The study aims to gain insight into how social work education and training influence social workers' competency to deliver palliative care. Do they feel inadequately prepared or lack an understanding of how to provide palliative care? By investigating how social workers' perceive their role, this study identifies ways to improve the science of palliative care social work. Social workers' perspectives and lived experiences in dealing with and providing palliative care need to be taken into account in order to develop treatment plans to help solve the individual patient's healthcare issues. I adopted a qualitative constructivist grounded theory framework that produced rich data.

1.3 RESEARCHER'S INTEREST IN THE RESEARCH: FROM PERSONAL JOURNEY TO PROFESSIONAL INPUT

I am a social worker with 22 years of practical experience and a social work educator at a tertiary institution with social work teaching experience. I am based in Namibia and therefore focused my study in Namibia, but there is more to this as explained below. My interest in exploring this research topic was inspired by a personal experience with death and dying seven years before the conceptualization of my study. This was when my dad received his diagnosis of lung cancer in the final year of my Master of Arts (MA) studies (2010). During this time, I watched my dad dying from lung cancer within two months after he received the diagnosis. I was shocked by his late diagnosis, the advanced stage of his illness and at the same time overwhelmed by my MA studies. I was unable to comprehend the challenges he and my family faced because of his life-limiting illness. My dad's fear about cancer and his belief that cancer is equal to death, as well as the social stigma attached to this life-limiting illness contributed to his delay in seeking medical attention. His hopelessness at the point of diagnosis, his pain and suffering moved me to find out more about the social workers' role in the provision of palliative care. Over the past several years, I have gathered bits and pieces about what my dad's struggles with a life-limiting illness were, even beyond the diagnosis. Shortness of breath, chest pains, difficulty to walk, tiredness and dizziness were no strangers to my dad. My mother at that time recounted stories of him coughing up blood and passing out, which were concrete physical problems that caused him much suffering and reducing this suffering was a priority.

I later came to realize that he did not only require physical pain control interventions, but required comprehensive palliative care interventions beyond his physical pain management. For two months after his cancer diagnosis, I witnessed the emotional weight he felt every time he needed to go to the hospital. Leaving his family to stay for long stretches of time in the hospital was not something he looked forward. His spiritual battles of pleading to God to relieve the pain and suffering continue to remind me of his experience with a life-limiting illness. Denial by some of my significant others that death is a natural course of life made it challenging and difficult to accept the reality that my dad needed palliative care. I learned through his experiences that our family's needs often times included ones beyond those of the physical difficulties. My dad and his family required palliative care, which addressed the emotional, social, spiritual and cultural needs as well. Today, my dad and my family's resilience in overcoming those barriers are some of the memories that I truly cherish since his passing, even sometimes without knowing it. I try to carry his strength with me every day. The impact from my dad's experiences on my professional life did not surface until 2012 when I started to work as a contract social work lecturer at the University of Namibia where I was tasked by the African Palliative Care Association (APCA) to assist with the drafting of a palliative care training manual for the third year social work students. I soon came to realize that I did not have much knowledge on palliative care social work. With my natural curiosity about my dad's care and my lack of knowledge in the area of palliative care social work, I believed it would be a good fit for this particular study. After much consultation, I was able to narrow down my research topic to explore social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses. While focusing on social workers, it allowed me to distance myself slightly from the experiences of my dad, which kept my emotions in check. It also exposed me to similar kinds of care he encountered. The work of Cicely Dame Saunders, who found the Christopher's Hospice in London in 1967, further stimulated me. Saunders (1967) established the importance of regularly giving morphine to patients with cancer pain and achieved control of pain for the vast majority of people with no risk of addiction. Saunders (1967), first a nurse, then a social worker, and thirdly a doctor, also established a philosophy of medicine that had been in danger of disappearing.

This philosophy was one that saw patients in all of their aspects and dimensions, which are the concern of the doctor, the nurse and the social worker, not just seeing the disease alone (Saunders, 1967). My interest continued to grow in the need to develop an informed understanding of social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses. In order to explore this further, I applied a grounded theory framework, which was developed by Glaser and Strauss (1967), and subsequent works of Glaser (1967 & 1998), Strauss and Corbin (1990) and Charmaz (2002, 2006 & 2009). In addition, I investigated conditions that hindered or strengthened social workers' abilities to deliver palliative care. I also foregrounded how social work education and training influence social workers' competencies in providing palliative care. Through undertaking this study, in-depth insights were gained from the individual social worker's point of view of his or her contribution in palliative care to patients. Knowing that there was already a substantial body of work carried out in developed countries not only on generic social work, but also on specialized palliative care social work, I wished to explore the lack of research in the Namibian context, which satisfied my preference for research that was of practical value. I became aware that palliative care social work had become an important provision for patients with life-limiting illnesses.

1.4 PROBLEM STATEMENT

Despite the recognition of the importance of providing palliative care to patients with life-limiting illnesses, and the essential role of social workers in the provision thereof in developed countries (Burford, 1981; Christ & Sormanti, 1999; Csikai & Bass, 2000; Heyman & Gutheil, 2006; Rose & Shelton, 2006; Dubus, 2010; Forrest & Derrick, 2010; McCormick, Curtis, Stowell-Weiss, Toms, & Engelberg, 2010; Hartman-Shea, Hahn, Kraus, Cordts, & Servansky, 2011 & McCormick, 2011), this study found that there is a lack of research within the Namibian context. A review of the relevant literature revealed that in Namibia, no studies have been conducted on social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses in primary care settings. The review found an absence of context-relevant Namibian literature sources, which indicated a degree of silence with regard to social workers' role in the provision of palliative care.

It is unclear whether this absence of research in Namibia is caused by a lack of understanding (by governmental institutions, the Health Professions Council of Namibia (HPCN) and hospital administrators) and appreciation of the role social workers can play in this setting. The study found a lack of research evidence on conditions that hinder or strengthen social workers' abilities to deliver palliative care in Namibia. A further study therefore needs to be conducted on how the perceptions of the social workers' role in providing palliative care impacts the way care is delivered. It was important to understand what social workers in the hospitals in Namibia are doing when a need for palliative care exists. Namibia at the time of this study did not have a National Palliative Care Policy and Practice Standards and Guidelines. There is no legislature in Namibia that addresses the social workers' role in providing palliative care to patients with life-limiting illnesses. Therefore, the study's primary aim was to examine social workers' perceptions of their role providing this care. As a social work educator at the University of Namibia, I identified the following gaps in the work of social workers especially in the areas where no formal Palliative Care Policy, Practice Standards and Guidelines exist and where no formal training on palliative care in the social work curriculum existed at the University of Namibia prior to the year 2012. The fact that no such study has been conducted on social workers' perceptions of their role in providing palliative care, not only indicated a gap in education and training for aspiring social workers, but also indicated a gap in practice opportunities in palliative care for the undergraduate social work programme. This gap in research is especially true in the Namibian context. The fact that no such study has been conducted in Namibia also indicated the need for a grounded theory research approach in order to explore social workers' perceptions of their role in providing this care. By examining how social workers perceived their role as palliative care providers, this research generated new data and theoretical insights in the area of social work, particularly in Namibia. This study in sum is important in identifying ways to improve the field of palliative care social work in Namibia. The field of palliative care social work can be improved through interventions, such as awareness and education on the multi-dimensional roles of the social worker in providing palliative care; more appreciation and optimisation of the roles of the social workers in the multi-disciplinary team. To improve palliative care practice opportunities in the undergraduate social work program as well as to contribute to the improvement of on-the-job training for social workers currently practicing in

primary care settings. Policy guidelines and further research are necessary to improve the field of palliative care social work. The qualitative approach to the research questions specifically addressed this information gap. Chapter 3 discusses additional justification for selecting this approach.

1.5 THE RESEARCH QUESTION

This research journey was guided by the following central research question that is exploratory and descriptive:

How do social workers in primary care settings in Namibia perceive their role in providing palliative care to patients with life-limiting illnesses?

The following related sub-questions investigated:

- 1.5.1 How do social workers understand palliative care?
- 1.5.2 What conditions hinder social workers' abilities to deliver palliative care to patients with life-limiting illnesses?
- 1.5.3 What conditions strengthen social workers' abilities to deliver palliative care to patients with life-limiting illnesses?
- 1.5.4 How does social work education and training in palliative care contribute to social worker's competency in the provision of palliative care to patients with life-limiting illnesses?

1.6 THE AIMS AND OBJECTIVES OF THE STUDY

The primary aim at the outset of this study was to first explore social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses. As already mentioned, my intention was to capture the essence of that role as perceived by those carrying it out, rather than simply to approach it as a series of tasks like a shopping list. In support of the primary aim of this study, the study objectives included second, to examine social workers' understanding of palliative care. Third, I carried out an investigation into conditions that hindered social workers' abilities in their role to deliver palliative care.

Fourth, I sought to investigate conditions that strengthened social workers' abilities in their role to deliver palliative care. Finally I carried out an investigation on how social work education and training in palliative care contributed to their competencies to deliver palliative care.

The following specific research objectives included:

1.6.1 Examine social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses

In examining social worker's perceptions of their role in providing palliative care to patients with life-limiting illnesses, this study gained insight into how social workers perceived their roles. It is important to understand how social workers approach their work in the provision of palliative care in their various roles and responsibilities. In achieving this, broad research questions were used and no limiting hypothesis with a purposive sample of social workers. The study contributed to new knowledge by means of analysing and using the findings to inform palliative care delivery, in particular raising awareness on the important multi-dimensional roles of social workers in providing palliative care social work and its benefit to improve the quality of life of patients with life-limiting illnesses. In light of this, findings from the study generate a constructivist grounded theory on the roles of the social workers in providing palliative care, which contribute meaningfully to future research as well as to illuminate this area of the social workers' contribution to social development. The study intended to enrich existing knowledge of social workers' in their role of providing palliative care, with a focus on Namibia and to make an academic contribution to new knowledge in terms of use of methods, delivering substantive data and providing theoretical insights.

1.6.2 Examine social workers' understanding of palliative care

The second objective sought to examine social workers' understanding of palliative care.

1.6.3 Investigate conditions that hindered social workers' abilities to provide palliative care

The third objective of the study sought to uncover conditions that hindered the social worker's ability to provide palliative care. I did this by creating a space through narrative conversations where social workers could speak freely about conditions that hindered their abilities to provide palliative care.

1.6.4 Investigate conditions that strengthened social workers' abilities to deliver palliative care

The fourth objective of the research journey sought to investigate conditions that strengthened social workers' abilities to deliver palliative care. I did this by creating an opportunity where the participants could speak freely about conditions that strengthened their ability to provide palliative care.

1.6.5 Gain deeper insight into how social work education and training influenced social workers' competencies to deliver palliative care

The final objective investigated how social work education and training influenced social workers' competencies in providing palliative care. The study contributed to new knowledge by means of using the findings to inform palliative care training and education programmes, in particular raising awareness on the importance of palliative care social work and its benefit to improve the quality of life of patients with life-limiting illnesses.

1.7 THE RATIONALE FOR THE STUDY

In this sub-section, the rationale for this study is explained by a need for a sociological analysis of social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses. In 2009, the Ministry of Health and Social Services (MHSS) in collaboration with the African Palliative Care Association (APCA) conducted a national Palliative Care Situational Analysis in all the 13 regions (currently 14 political regions) of Namibia.

The situational analysis (MHSS, 2009) was to determine the state of palliative care service provision in Namibia in order to generate the baseline data against which future scale-up in the coverage and quality of palliative care services could be monitor and assess. This situational analysis was conducted to guide policy makers and implementers in developing a palliative care policy and guidelines and to assist in the development of effective palliative care service delivery strategies. Findings from the MHSS (2009) Palliative Care Situation Analysis Report recommend “... *social workers to be trained in palliative care so that they can provide adequate care, particularly in the areas of psycho-social support, social welfare, spiritual care and positive living, as these are often neglected areas of care*”(MHSS, 2009). Findings from this report (MHSS, 2009) also revealed that the unavailability of a National Palliative Care Policy, Practice Standards and Guidelines in Namibia is a barrier in the provision of care. The Palliative Care Situation Analysis Report thus recommends for “*the Government of Namibia, MHSS and other palliative care stakeholders to facilitate the review and development of a palliative care – friendly legislation, regulations, policies and guidelines to ensure that palliative care services are accessible to the majority of patients who need them in the country. As such, there should be a comprehensive and critical review of policies and guidelines to identify existing gaps and barriers to palliative care delivery*”. (MHSS, 2009:60). Palliative care is one of the many neglected public policy issues. The growing unmet needs of patients with life-limiting illnesses and their families are fuelling growth in palliative care despite the lack of official status of public policy in Namibia. Policy issues have long been the focus of intense societal debate, as providers, policy makers, legislators and the public have considered essential questions concerning the patient’s quality of life (Roa, Alongi, Anderson, Jenkins, Stokes & Kane, 2005). Consequently, this study articulates the benefits public policy in palliative care provides to the social worker. For example, it provides the social worker the perfect opportunity to advocate at both the micro and macro level. Being aware of these benefits and influences public policy plays in the delivery of palliative care allows the social worker to be an effective advocate for the client and family living with a life-limiting illness. Having a public policy on palliative care in Namibia in place can benefit standards of practice for palliative care and hospice care through professional social work, nursing and medical regulatory bodies.

Attilio, Otis-Green and Dahlin (2008) state that “*while social workers are essential participants in all domains, social workers have a unique perspective and ability to enhance the social and community aspects of a care plan*”. Although specialist social work provision happens in a range of settings, its provision like palliative care is not delivered by all social workers in Namibia. Social workers in Namibia do not have a formal and specialized role in providing palliative care. Further, the provision of palliative care is not uniform throughout Namibia. This study therefore strongly advocates for adoption and implementation of appropriate healthcare policies key to providing palliative care. Policies may include a national healthcare policy, an essential medicines policy and a palliative care policy, which need to include providers’ roles and responsibilities regarding palliative care.

In Namibia, there is a lack of scientific research evidence on social workers’ perceptions of their role providing palliative care to patients. As a starting point in addressing this deficiency, the rationale for this study is to enable social workers to describe their perceptions and experiences of their role in providing palliative care. In addition, social workers play an important role in the provision of palliative care to patients with life limiting illnesses. According to the National Association of Social Work (2003), social workers are concerned with enhancing the quality of life and promoting well-being for individuals, families and caregivers. When confronting issues related to life-limiting illnesses and palliative care, social workers have multi-dimensional roles as counsellors, educators, researchers, advocates and community leaders. Social Workers should manage life-limiting illnesses holistically by starting from diagnosis of the disease throughout the disease trajectory, end-of-life care and bereavement (dealing with loss). Social workers are able to assess the needs of the patient and the family, as well as appreciate the medical provider’s perspective and thereby aid in developing appropriate medical intervention in the provision of palliative care. In this regard, this study is important as it sought to uncover conditions that hindered or strengthened social workers’ abilities to provide palliative care. The study sought to gain deeper insight into how social work education and training influenced social workers’ competencies to deliver palliative care.

This qualitative study is important in gaining a broad understanding of social workers' perceived roles when palliative care is necessary in primary care settings. For example, palliative care social work should be integrated into the existing health care structures at all levels of health care services delivery, however, this can only be achieved with clear policies and guidelines in place. Consequently, this study benefits the practice of palliative care in recommending interventions for palliative care policies, palliative care social work provision, training, education and health planners who are implementing and planning palliative care services for the needy patients. In light of all these points, there is an important context in which my own initial findings about social workers' perceptions of their role in providing palliative care to patients may make an academic contribution to knowledge in the area of palliative care social work in Namibia and beyond, breaking new grounds for further research.

1.8 OPERATIONALISATION OF CONCEPTS

This area of the thesis is confounded by problems of definition and the semantics of whether conditions are life-limiting or life-threatening. The latest contribution by WHO (2014) proposed that a life-threatening illness is one where there is a possibility that a medical intervention might prove successful (even if the treatment poses a threat to life). Life-limiting illnesses are those conditions for which there is currently no available cure and the condition is likely to lead the patient to die prematurely. For the purpose of this study, the following concepts following are defined as:

1.8.1 Life-limiting illnesses

For the purpose of this thesis, the term "life-limiting illness" is conceptualized as any medical diagnosis that prohibits or hinders one's life. This paper focused on life-limiting illnesses that affect both adult and paediatric patients. As defined by WHO (2014), life-limiting illnesses are diseases marked by progressive deterioration and ultimately result in death for these patients. Life-limiting illnesses could be an illness, from which there is no reasonable hope of cure and from which a person is expect to die. These conditions are severe and have enormous effects on both the patient suffering from the illness and the family.

They are often refer to as life-limiting conditions, or terminal illnesses. The choice to use the term life-limiting illness is an attempt to be consistent with the language of social work research in this area and that of the National Association of Social Workers (2003).

1.8.2 Palliative care

The term palliative care derived the Latin concept of *pallium*, which means a cover or cloak (Phillips, Ajrouch & Hillcoat-Nallétamby, 2010). In a broad sense, the concept of palliative care describes a form of care, which offered to individuals whose illness or disease can be relieved, but not cured. Health professionals in primary healthcare settings and in hospices most commonly use the term palliative care. The World Health Organization (WHO, 2002) defines palliative care as an approach, which improves the quality of life of patients and their families facing life-threatening illness through the prevention and relief of suffering by early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling;
- Will enhance quality of life, and may positively influence the course of an illness.

1.8.3 Patients

The World Health Organization (2011) defines a patient/s as a person or persons who is/are the recipient/s of health care. They can include hospital or patients with cancer bearing pains or trials calmly or without complaint.

1.8.4 Social work

Literature defines social work in many ways but in this thesis I am referring to social work as a helping profession, which utilizes professional approaches to help the vulnerable groups in society, such as people living with a life-limiting illness (cancer, HIV and AIDS) children, women, persons with disabilities the elderly and to empower people to solve their own social problems (Chitereka, 2009 & Mupedziswa, 2005). The International Federation of Social Workers (IFSW, 2010:5) defines social work as “*a profession that promotes social change, problem-solving in human relationship and the empowerment and liberation of people to enhance wellbeing*”. Other definitions of social work also important to note include that by Horner (2012:3), “*it is a profession that promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being. Utilizing theories of human behaviour and social systems, social work intervenes at the point where people interact with their environment. Principles of human rights and social justice are fundamental to social work*”. According to Schenck, Mbedzi, Qalinge, Schultz, Sekundu and Sesoko (2015), the International Association of the Schools of Social Work (IASSW) in 2014 have agreed on the following definition of social work: “*Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance well-being*” (Schenck *et al.*, 2015: 8-9). The IFSW (2010) states that the social work profession utilizes theories of human behaviour and social systems where social workers intervene at the points where people interact with their environments. Human rights and social justice are the two basic principles that are fundamental to the practice of social work.

1.9 OUTLINE OF CHAPTERS

Chapter 1 provided the context and background, the study's sociological relevance and contribution of the study in an African, i.e. Namibian context together with the aim and research questions I have developed. It introduced the problem statement, the rationale and objectives.

Chapter 2 provides an overview of current research on social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses. While most research projects begin after a thorough literature review has been completed (Bryman, 2008), my study did not begin with a detailed review of literature. I believed that a detailed literature review prior to data collection would hinder or jeopardized a transparent approach to the research. I therefore delayed a detailed literature review until analysis of data had taken place (Glaser, 1978). A more comprehensive, thorough literature review was conducted towards the later stages of analysis as the theory emerged. This served to weave into the theory generation and provided more data to compare (Glaser, 1998 & Rintala *et al.*, 2014), as well as provided a vehicle for engagement. Thus, the critical review of related studies only occurred after the new, grounded theory developed (Glaser, 1998). This chapter, however, introduces the theory of symbolic interactionism as the theoretical framework, which lends constructive insight into the participants' part and my part in the study, which proceeds from the foundational tenets of a traditional grounded theory approach.

Chapter 3 outlines the research methodology adopted for this study. In this chapter, I described how the study was executed and the chapter gives a concise description of the grounded theory method based on the early work of Glaser and Strauss (1967) and subsequent works (Glaser, 1967 & 1998), Strauss and Corbin (1990) and Charmaz (2002 & 2006). This chapter explains the research design and sampling procedure and data collection methods with attention placed on the qualitative field interviews. The chapter continues to discuss ethical considerations where the ethical principles and protocols are adhering to throughout the study. The last part of the chapter concludes with a reflection on the role and position of the researcher.

Chapter 4 presents and analyses the key findings of the study. In this chapter, I discuss and analyse the findings of the study in accordance with the research questions and the objectives. The data was analyzed for themes using the technique of constant comparative analysis in the grounded theory method. A thematic analysis was used to sort and categorize the data collected adhering to the grounded theory approach. Themes were group into categories and a conceptual framework was developed.

Chapter 5 provides a more detailed discussion and interpretation of the findings.

In the final chapter 6 of the study, I discuss the general research conclusions and recommendations. The chapter focused on the strengths and limitations of the study, and implications for policy, programme, practice and further research.

CHAPTER 2: LITERATURE REVIEW AND THEORETICAL FRAMEWORK

2.1 INTRODUCTION AND BACKGROUND TO THE STUDY

This chapter aims to provide an overview of current research relating to social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses. Despite much research been carried out in developed countries on the social workers' role in providing palliative care to patients with life-limiting illnesses, (Altilio, 2011; Bartlett, 1975; Bomba, Morrissey & Leven, 2010; Dubus, 2010; Encyclopedia of Social Work, 2012; Forrest & Derrick, 2010; Goldsmith, Wittenberg-Lyles, Rodriguez & Sanchez-Reilly, 2010; Harper, 2011; Hartman-Shea, Hahn, Kraus, Cordts & Sevransky, 2011; Higgins, 2011; McCormick, 2011; McCormick, 2010; Morrissey, 2005; Nadicksbernd, Thornberry & von Guten, 2011; O'Mahoney, McHenry, Blank, Snow, Karakas, Santoro, Selwyn & Kvetan, 2010; and Palos, 2011), there is a lack of research within the Namibian context. Attempting to include all of this previous research through a critical literature review prior to data collection and analysis will not only result in preparing the researcher for preconceived ideas, but it may result in compromising the methodological integrity in the use and development of a grounded theory approach in the study. Grounded theory advocates for the generation of a new theory from rich data, which consists of interrelated concepts, rather than testing existing theories.

This chapter introduces symbolic interactionism as the theoretical framework, which was apply to explore twenty social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses in primary care settings in Namibia. However, in extending the literature review, this chapter includes a brief acknowledgement of empirical studies such as Ecological Systems Theory (Bronfenbrenner, 1994) and the Theory On *Death and Dying* (Kubler-Ross, 1969/2008). My study does not begin with a detailed review of the literature relevant to the topic, (Charmaz, 1995, 2006, & 2009). Instead, the study begins the data collection with a preliminary reading of existing literature relevant to the perceived role of the social worker in providing palliative care to patients with life-limiting illnesses.

Preliminary reading included related studies on (Ecological Systems Theory by Bronfenbrenner (1994) and the Theory on *Death and Dying* by Kubler-Ross (1969/2008) in other parts of the world in order to place this study in its context. A critical review of literature was delay until analysis of data had taken place (cf. Glaser, 1998) and afterwards a new constructivist grounded theory on the roles of the social workers' in providing palliative care was developed. This approach allowed me as the researcher to commence my study "*with as few predetermined ideas as possible*" and to "*remain open to what is actually happening [in reality]*" (Glaser, 1978: 3).

Although my study uses the grounded theory approach which was introduced as a methodology by sociologists Glaser and Strauss in 1967 (Merriam, 2009) and further explained in chapter 3, I consider my thesis a constructivist grounded theory approach given my involvement in this study as the researcher and simultaneously being "the primary 'instrument' of data collection and analysis." I will, for example, interpret and discuss the data from my own reflections and I "*assume an inductive stance and will strive to derive meaning from the data*" collected (Merriam, 2009:29), which is a more recent advancement in using grounded theory (Charmaz, 2006). I classify my research as a constructivist grounded theory study based on my involvement as the researcher in the data collection and data analysis in this study; because constructivist grounded, theory recognizes that the theory, which designed, is grounded in the perceptions and experiences of the participants. Nevertheless, the researcher helps co-construct the theory based on her or his interactions with the participants (Charmaz, 2006). Furthermore, I intentionally co-create a theory using the grounded theory method as well as ideas that emerge by introducing the theory of symbolic interactionism particularly of Dewey, Blumer and Mead (Blumer, 1969). The symbolic interactionism theoretical framework lends constructive insight into the participants' part and my part in the study, which proceeds from the foundational tenets of a traditional grounded theory approach. Symbolic interactionism as stated by Blumer (1969) underpins three important aspects; namely that: 1) human beings act towards things on the basis of the meanings that those things have for them personally; 2) meaning is derived from, or arises out of social interaction and 3) meanings are modified through an interpretative process and therefore meaning is created (and recreated) from each different experience.

As the researcher in this study I, not only co-created the constructivist grounded theory on the role of the social workers in providing palliative care which emerged from the data, but as a social worker, a social work educator and researcher, I also brought with me these experiences and exposures to the research. As a result, I have documented the need for palliative care integration into the healthcare system of Namibia through policy development and implementation, further research, in-service and continuing training on palliative care, palliative care practice opportunities in the undergraduate social work education at the University of Namibia.

My prior knowledge, experience in palliative care social work, social work education and training, as well as my social work practice experience, which I brought to this study, cannot be completely be eradicated. It instead, lends itself to a symbolic interactionism theoretical lens appropriate in co-creating the constructivist grounded theory on the role of the social worker in providing palliative care that emerges from this study. Given my involvement as the researcher in data collection and analysis as well as my prior knowledge and experiences as a social worker and palliative care educator, lends itself to co-create the theory, which emerged from the data, similar to the term “constructivist” grounded theory approach. As I sought to examine social workers’ perceptions of their role in providing palliative care to patients with life-limiting illnesses, an analytical lens on symbolic interactionism allowed me to co-create a focused grounded theory from the participants’ perceptions and experiences. The study applied broad questions through individual, face-to-face interviews to collect data. Chapter 3 of my thesis provides a more in-depth explanation of how the grounded theory methodology was use to execute the study.

The following section discusses the contextualization of social welfare social work and palliative care within Namibia. The section continues to discuss why global demand and need for palliative care outstrips supply. Further, it discusses the sociological significance of the topic and literature review driven by the conceptualization of the research question. Although this chapter concludes with a discussion on constructive symbolic interactionism as the theoretical framework used to guide the research process, it was important to review and acknowledge different theoretical perspectives,

such as the Ecological Systems Perspective (Bronfenbrenner, 1994) and the Theory on *Death and Dying* by Kübler-Ross (1969/2008).

2.2 CONTEXTUALIZATION OF SOCIAL WORK AND PALLIATIVE CARE

This section starts with a discussion on the contextualization of social welfare social work and palliative care within Namibia. It continues to identify the three periods in the Namibian history as far as the development of social work and palliative care over the centuries are concerned. These three periods can clearly be demarcated as the time of the indigenous human services, the period under colonial rule, and the current period after independence. The section further provides an overview of the challenges and opportunities for social welfare and palliative care social work in Namibia today. Finally, this contribution will fill the existing gap of written work on social welfare social work and palliative care in Namibia.

In the next section, I will discuss the three historical periods of social welfare and social work development in Namibia.

2.2.1 The three historical periods of social welfare and social work development in Namibia

Social welfare and social work in Namibia have undergone various changes influenced by the country's socio-political landscape, ranging from the pre-colonial period, Christian Missionary Era, the colonial era and post-colonial, which altogether played an important role in the transformation and development of a Namibian social welfare and social work system. In the following section, I will address these various stages in the social welfare development in Namibia, namely the indigenous human service systems in the pre-colonial era, the indigenous Human Services in the Pre-Historical Period-BC to 1485, the indigenous Human Services in the Period of Bantu Expansion: 1400-1800 and the role of indigenous human service systems in an independent Namibia.

2.2.2 The indigenous human service systems in the pre-colonial era of Namibia

Kamwanyah (2016) states that contact with Christian missionaries (1805-1840), and subsequent German colonial rule (1804-1915) and then South African Rule (1915-1990), not only introduced the indigenous people of Namibia, previously known as German South West Africa to foreign rule and domination, but also disrupted and undermined Namibia's traditional and indigenous systems and institutions of social welfare and human service provision. That is to say that Namibia, as we know this country today, is heavily influenced by the Christian Church, with over 90 per cent of Namibians subscribing to the Christian faith as Anglicans, Lutherans, Roman Catholics, African Methodist Episcopalians (AME) Orora, Seventh Day Adventists, Jehovah's Witnesses, Dutch Reformed church and Pentecostal (Diescho, 2014). The early missionary churches through the efforts of the first missionary societies, such as the London Missionary Society, Wesleyan Methodist Missionary Society, Rhenish Missionary Society, and Finnish Missionary Society, who roughly arrived in Namibia in 1805 evangelized and converted the indigenous people of Namibia to Christianity through the Gospel of God, a process that heavily influenced the social identity of the indigenous people (Buys & Nambala, 2003). The missionary provided evangelization education, spiritual services and medical services, which were some types of social work services, to the indigenous people as a religious duty to help the poor and the unrepentant. Therefore, the missionaries used evangelization, education, medical and social services to win the hearts and minds of the indigenous people and sway them away from their traditional practices and value systems, including the provision of their traditional social welfare services. At the same time the arrival, respectively, of both German settlers and South African rule in the country later would further undermine the indigenous systems of human services. According to Kamwanyah (2016) the German and South African colonial system of social welfare provision were informed by apartheid and stereotypical views, which attributed social issues and challenges affecting the indigenous majority in Namibia to personal and moral failing of their own, instead of seeing them as broader structural and institutional contributory factors. The provision of social services and programmes were mainly clinical, individualistic and symptom-driven, instead of addressing the underlying causes of social welfare problems.

Therefore, professional social work education and practice in Namibia maybe closely tied to the country's missionary and colonial history, but it did not necessary start with colonialism. What colonialism did was to undermine, disrupt and destroy Namibia's traditional and indigenous systems/institutions of social welfare service provision. Consequently, the missionary church and the subsequent colonial rules of German and South African social welfare systems and social work failed in recognizing, incorporating and utilizing the available wealthy indigenous human service helping systems that characterised pre-colonial Namibia. Like the rest of the African continent, prior to the contact with colonial rule, pre-colonial Namibia had a very a rich political and social welfare systems such as extended family; and other mechanisms under which assistance were provided to the needy and vulnerable. For example, the vaKavango people use the concept of *ndjambiNzambi*, in collectively cultivating each other's field in order to ensure every community member, especially those who lack means or resources to cultivate for themselves. This puts them on an equal basis with everybody in the community as far as cultivation is concerned (Kamwanyah, 2016). Namibia is a vast country and has 11 ethnic groups, with varying social, economic and political situations. Therefore, generalisation of the indigenous human service system is difficult and may not give the true picture of each indigenous system of social welfare. However, one cannot shy away from the reality of certain conditions and situations that are common to the pre-colonial Namibian indigenous systems of human services. The significant portion of this pre-colonial Namibian existence is that people lived in small-scale, clan-base and egalitarian societies in which members of the community depended on each other for their well-being. Discourses about pre-colonial Namibian human services may be link to three broader historical events. These are:

i. Indigenous Human Services in the Pre-Historical Period-BC to 1485 in Namibia

In the pre-Historical Period-BC to 1485, for example, “*the San people-!Kung, /Xam, ≠Khomani, Nusan (N/u), Khwe (Khoi, Kxoe), Naro, Hai//om, Tsoa, Auen, Ju''hoan, Kua and G/u and G/ana*” - were the first inhabitants of Namibia who hunted and gathered food from the grasslands, painted rocks, and collectively took care of each other.

This they did by moving from place to place in search of food, water and a protective shelter for every member. Their existence was serene, simple and in harmony with nature in the sense that they consumed according to what ‘one needs, not what one wants’ (Kamwanyah, 2016)”. The concept here is that the well-being of each member depends on being non-materialistic and a simple life that does not destroy nature, but conserves it for the wellbeing of everybody, including the future generation. In this type of society, greed was not common as each member consumed not more than what he or she needed.

ii. Indigenous Human Services in the Period of Bantu Expansion: 1400-1800 in Namibia

The San people’s simple way of taking care of each other was followed by the period of *Khoisan and Bantu – Namas, Damaras, Ovaherero, Aawambo, vaKavango, Mafwe / Subia / Lozi* expansion. According to Kamwanyah (2016), the Bantu and the Khoisan worked the soil, cultivated the fields and herded cattle. Theirs was a stateless society in which the elders were respected, revered and enjoyed hierarchical advantages over the young ones, in which the elders played the important roles of counselling, coaching and mentoring the rest of the community member. They primarily communicated with God - Kalunga, Nyambi, Mukuru, and Nyambe - through ancestors, instead of through prayer”. That is the belief that those who have passed on do not completely disappear from the earth, but continue to take an interest in the wellbeing of the living (Kamwanyah 2016). Therefore, an ancestor as a medium to reach God had the power and ability to influence life-changing events such as births, sicknesses, deaths, seasonal changes and everything that cannot be explain by human reason. Communal ethos characterized their existence in the sense that one’s well-being was nothing without the existence of the other. That is the ability to imagine life from the perspective of others, which is a collective responsibility of taking care of each other in action, which is the notion of *Ubuntu* or “*I am because we are*” common throughout Africa. A society cannot function fully if one of their own is struggling, hence the taking care of each mechanism built in their political and social system such as the extended family

arrangement and the collective cultivation arrangement of *Ndjambi/Nzambi* (Kamwanyah, 2016).

iii. The role of indigenous human service systems in an independent Namibia

Today, the indigenous human service systems in independent Namibia through extended families and social and family network continue to work parallel to government public assistance programmes in providing social protection to many Namibians, especially in rural areas where resources and facilities are very rare, and poverty is rampant. In fact, Namibia's poor, especially the previously disadvantaged blacks, largely depend on their employed relatives for social security in terms of food, shelter, health care and education because they lack government social protection. In conclusion, to this section, the pre-colonial system of helping was not curative or medically oriented, but more socially rooted in the African *Ubuntu* of taking care of each other.

2.3. SOCIAL WELFARE AND SOCIAL WORK DURING THE SOUTH AFRICAN COLONIAL ERA

According to Rose-Junius (2016) social workers, medical doctors and nurses in the then South West Africa during this colonial period shared their concerns for the quality of life of people in the remote areas of the country. Rose-Junius (2016, who was heavily involved in the setting up of social welfare systems in Namibia, working with other health professionals and training social workers), recalls how medical staff went out in the districts, staying in tents and setting up the most basic medical services also in tents to attend to health problems which were brought to their attention. Medical services during this period were address by government through the building of state hospitals in various towns in the country. In Windhoek, being the capital of the country, there were two separate state hospitals serving white patients and other (ethnic groups) respectively. Large state hospitals were built in the northern part of Namibia (Oshakati and Eenhana); in the southern part of the country (Keetmanshoop); central north (Rundu) and far northeastern (Katima Mulilo).

Although hospitals served all the patients in those respective areas, they were cared for in separate wards. State and private clinics were erect in towns and rural areas where the poor who could not afford hospital fees have been cared for (Rose-Junius, 2016).

i. The legal Social Welfare system during the Colonial Rule

According to Rose-Junius (2016), Namibia previously known as South West Africa, was colonialize by South Africa and it was based on the South African Legal System and the Roman Dutch Law, which was applied in the country. There were some acts (also called Ordinances) available to regulate welfare service in South West Africa (Namibia now) during the colonial Era. The main statutes governing the work of social welfare services in Namibia were; the National Social Welfare Act, Act No.25 of 1956, the National Welfare Act, Act No. 79 of 1965, as amended in South Africa prior to Namibia's independence, the Children's Act, Act No. 33 of 1960, Act on the Prevention and Treatment of Alcoholism and Ant-Social Behaviour, 1965. These Acts regulated friendly societies, which are associations of persons established to provide relief to children, the aged, the sick widows and so forth. The National Welfare Act, Act No.79 of 1965, as amended in South Africa, established a National Welfare Board of Namibia, which provided for the registration and control of certain welfare organisations. The Aged Persons Act, Act No. 81 of 1967 prior to Namibia's independence provided for the protection and welfare of certain aged and debilitated persons. The Blind Persons Act, Act No. 26 of 1968 concerned the promotion of the welfare of blind persons. The Criminal Procedures Act, Act No 51, 1977, the Children's Act, Act No. 33 of 1960, were some of the legal statutes governing the court system and the total social welfare scene during the colonial rule. According to Aisindi (2013), the social work profession has developed as a scientific discipline since the early 1950s. At this time, churches mainly facilitated and carried out social work. During the 1950s Churches and Non-Governmental Organisations (NGOs) specialised in specific services were established (Maree 2012a). The Dutch Reformed Church introduced social work for the first time in Namibia by appointing the first social worker, Mrs. CM Truter, in 1953 in a town called Tsumeb. The social worker provided services to members of its congregation and the broader white community.

The Roman Catholic, Lutheran, Anglican and various other denominations were more involved in all Namibian cultures that needed some form of assistance. This system only changed after independence. The Catholic AIDS Action (CAA) became the leader in the field of home-based care addressing HIV and AIDS in the country. It was also the Catholic Churches, who over time built hospitals and brought doctors and nurses, mostly nuns from Germany to serve in towns and in the most remote areas of the country. The Catholic and Lutheran denominations, having the financial support of Germany, played leading roles in building schools and hostels to secure education, specifically for the families who could not afford school fees and accommodation away from their places of residence. The Ministry of Health and Social Services registered private welfare agencies during the colonial era in various towns of the country by and they functioned under the supervision of this respective Ministry. These welfare agencies worked very well, because they knew the local social needs and cultural practices.

While under the South African Apartheid Regime, Namibia was (known as South-West Africa) considered as a fifth Province of South Africa. There was a South-West Africa Administration, which rendered services to all ethnic groups. The Department of Welsyn en Pensioene (Welfare and Pensions) in South Africa, with a branch office in Windhoek, which is the capital city of Namibia, in 1969, took over Welfare services. During the same time a Department of Bantu Administration and Development was establish for black people in Windhoek. A separate Department of Social Welfare was established, but with sub-departments to serve all the different ethnic groups, and again in 1980, a Directorate of National Health and Welfare in Afrikaans '*Direktoraat van Naionale Gesondheid en Welsyn*' was establish to coordinate social services of all the ethnic administrations or second tier governments as they were referred too. The ethnic administrations were an indication that social workers were appointed in the administrations where they served their own ethnic groups and they had to develop social services related to the culture and tradition of the specific ethnic group they served. Social workers started working within the culture of the eleven different ethnic groups. This resulted in unequal distribution and welfare benefits among the various population groups in Namibia.

The white needy communities enjoyed better welfare services, followed by the coloured community, while the majority black populations left the most marginalised. For example, while a coloured family received R200-00 foster grant per child, foster care grant for a black child was R25-00 per month.

ii. *Social Work Education under the Colonial Rule*

This study continued to look at the education and training of social workers under the colonial Era in Namibia and found that the educational situation during the time before independence was characterised by an unequal access to education and training at all levels of the education system (Ministry of Education, 2013). There was fragmentation of education along racial and ethnic lines and a lack of democratic participation within the education and training system. Rose-Junius (2016) narrates that originally, Namibian social workers were trained in South Africa at Minnie Hofmeyer College since there were no tertiary institutions in Namibia. They were trained at University of Cape Town, Stellenbosch, Witwatersrand and the University of South Africa (UNISA) - which is a distance training Institution. The University of the Western Cape, which opened in Belville South, Cape Town in 1960, catered for the so-called non-white students (or the mixed raced population group) from South Africa and any other countries mostly in and around Southern Africa which included Namibia. The University of the Western Cape was a university college of the University of South Africa (UNISA) with students who received Degrees, such as Psychologist, Teachers, and Dentists were trained at these institutions. The University of South Africa (UNISA) established the Academy for Tertiary Education in the early 1970s in Windhoek, Namibia, as a university college of UNISA. I was one of the social work students trained in the social work programme at the Academy for Tertiary Education of Namibia shortly after independence (1990-1992), which in later years transformed into the University of Namibia in 1992. While its curriculum started as a three-year BA Degree in Social Work, it advanced to a four year training degree around 1991 with no inclusion of palliative care education and training as a module in the social work curriculum.

The training of Welfare workers already commenced in 1975 at the Augustinium Training College and was initiated by the then Department for Education and Training. The minimum requirement then was a Standard 8 certificate, although a matriculation certificate was preferred. It is estimate that 37 Welfare workers completed their welfare course by 1979, and employed mainly in the south and in traditional areas. The training prepared them mainly for court work and home visits leading to assessing the needs of the poorest people in the country. They functioned like the friendly visitors in the early American Social work. In later years immediately after independence through the newly proclaimed University of Namibia, the trained welfare workers were appointed as social workers by the Ministry of Health and Social Services.

The next section presents the development of social work in Namibia to shed more light on social and economic advancement and social work.

2.4 SOCIAL WELFARE AND SOCIAL WORK SYSTEMS IN AN INDEPENDENT NAMIBIA

Freeman (2016) narrates that shortly after independence in 1990, political transformation was experience at all levels and in the fields of social welfare and social work systems. This meant that the Namibian government after independence in 1990 committed to a constitutional responsibility in the establishment of a Ministry of Health and Social Services where upon social workers and social welfare workers from all diverse ethnic groups were employ under the Directorate Social Services. This Directorate under the auspices of the Ministry of Health and Social Services is a governmental institution, who is task to offer social welfare services to the people of Namibia. The Namibian social welfare and social work landscape changed dramatically, shifting from a clinical approach to broader issues of nation building and socio-economic development. This arrangement created many challenges and issues for the social welfare and social workers and the realities of managing social services for a nation soon took up time, consultations, investigations and lengthy reports.

A study done by Kaseke (1995) reveals that the Directorate was experiencing poor interpersonal relationships; tensions and conflicts prevented social welfare and social workers from working together. These issues were ascribed to the fact that the social welfare and social workers from different ethnic groups were brought together without any proper groundwork. *“These tensions and conflicts were more evident in Windhoek and perhaps these are due to the fact that at independence, social workers who had been working for the different administration authorities were suddenly put together without any meaningful preparatory work taking place”* (Kaseke, 1995: iv).

The Ministry of Health and Social Services (MHSS) has ever since been the main employer of social workers in Namibia. After Namibia’s independence, social welfare was re-organised and consolidated by giving a comprehensive sole mandate to the Ministry of Health and Social Services as the ministry in charge of welfare services (Chiwara, 2015). The MHSS addresses the inequalities and discrimination in access to services in meeting the basic needs of people through a social development approach. The Constitution (1990) provides a strong backdrop for equal access to social welfare and social work services in Namibia. In addition, the Namibian government also developed the National Development Plans (NDPs), which also place social welfare provision at the centre of service-delivery. Post-independence Namibia’s social welfare approach differs from the social welfare model during the colonial and apartheid eras, which focussed on institutionalising polices for whites and a residual system for blacks. At present, the Namibian government instituted various governmental ministries and departments such as the Ministry of Labour and Social Welfare, which is mandate under the Pension Act of 1992 to administer pension grants. The Social Security Commission established under the Social Security Act, Act No. 34 of 1994 and its core aim is to provide a foundation of social protection on the principles of solidarity for workers in Namibia and their dependents. The Directorate of Child Welfare Service under the auspices of the Ministry of Gender Equality and Child Welfare mandated to promote and protect the well-being of all Namibian children below the age of 18 years was establish. Ministry of Poverty Reduction and Social Service, focus on eradicating poverty. Ministry of War Veterans established to address vital social welfare needs in the country.

Social workers currently work in a number of the above-mentioned government ministries; NGOs such as Regain Trust, Catholic AIDS Action, ChildLine/Life Line; Red Cross, etc. and international organisations such as United Nations Children's Fund (UNICEF), United Nations Development Programme (UNDP); United Nations Fund for Population Activities (UNFPA); United States Agency for International Development (USAID) etc. and in private practices. There have been several legal reforms aiming at addressing gender inequalities, gender based violence; poverty in strengthening social protection, improving care co-ordination, confronting underdevelopment and economic inequality, therefore changing the landscape of social welfare and social work in the country. For example, legal reforms include the Local Authorities Act, Act No. 23 of 1992, which applied affirmative action for women to participate in local government elections, including a number of statutory bodies such as the Social Security Commission, the Namibia Sports Commission and the National Council for Higher Education. The Labour Act, Act No 6 of 1992 prohibits discrimination in any respect of employment on basis of sex, marital status, family responsibilities and sexual orientation. The Married Persons Equality Act, Act 1 of 1996 eliminates the discriminatory Roman-Dutch law concept of marital power previously applicable to civil marriages in Namibia. With the shocking levels of gender-based violence in Namibia, the Parliament passed the Combating of Rape Act, Act 8 of 2000, a very progressive law. Law reform on rape, followed by the Combating of Domestic Violence Act, Act No. 4 of 2003 covers a range of forms of domestic violence, including sexual violence, harassment, intimidation, economic violence and psychological violence. It also covers violence between husbands and wives, parents and children, boyfriends and girlfriends and close family members. Another major family law reform was the Maintenance Act, Act No.9 of 2003, which made significant changes to the child maintenance system. The Children's Status Act, Act No. 6 of 2006 deals with the position of children born outside of marriage and provides simple procedures for appointing a guardian for any child whose legal custodian or guardian has died. All these law reforms show that Namibia is seriously committed to improve the quality of life and well-being of its citizens.

Internationally, Namibia in 1997, adopted a social development focus in line with the UN Copenhagen Agreement (1997). The Namibian government after independence set its agenda and objectives out in its developmental objectives of the Millennium Development Goals (MDGs) (United Nations, 2013:13). Namibia is signatory to several UN Conventions and Charters, such as the UN Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), and the UN Convention on the Rights of the Child, with no reservations. Regionally, Namibia has also adopted the Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa. In order to combat the social challenges facing Namibia, the government introduced free primary health care, no-fee paying schooling and social grants. The Namibian government in 2004 recognised the role that social work plays in achieving the Sustainable Development Goals (Government of Namibia, 2004) and passed the Social Work and Psychology Act, Act No. 6 of 2004. This act makes provision for the establishment and constitution of a professional Council for the social work and the psychology profession, known as the Health Professions Council of Namibia (HPCN) (Republic of Namibia, 2004). This Act determines the powers, duties and functions of the HPCN. The Health Professions Council of Namibia has the responsibilities to regulate the registration of persons practicing social work, psychology, nursing and of persons practicing allied professions; to set out the ethical code of conduct, specify the education, tuition, training and qualifications of practitioners; prohibit the practicing of such professions without being registered; and provides for matters incidental thereto. It is a requirement for all social workers and social work students to register with the HPCN on an annual basis. Social work students are required to register from year one and pay a once off minimal student fee until they complete their studies. However, to date the country has yet to develop a unique social welfare and social work system that is authentic to the Namibian situation. Instead, the country's social welfare and social work systems in terms of principles, philosophy and practice, predominantly mirror colonial-apartheid practice and to some extent reproduce similar patterns of clinical, casework and symptom-driven response interventions.

Namibia in addition, faces a human resource crisis in the public health sector, which is characterised by a shortage of health professionals, high vacancy rates for all categories of staff, high attrition rates (mostly due to resignations), lack of a human resources

retention strategy, staff burn-out (and incomplete implementation of the Employee Assistance Programme) and inadequate capacity at local health and social academic institutions to produce the required number of needed health workers Ministry of Health and Social Services (MHSS, 2012). There are three health workers per 1,000 population in Namibia, above the World Health Organisation (WHO) recommendation of 2.5 health workers per 1000 population. Specific health worker-population ratios include 1:13,519 for social workers; 1:2, 952 for doctors; 1:704 for registered nurses; 1:10,039 for pharmacists; and 1:28,562 for health inspectors, among others. Namibia has a critical shortage of social workers split in various government institutions, NGO's and Faith-Based Organisations as well as the few in private practice. As on the 31st of March 2017, there were 689 registered social workers by the Health Professions Council of Namibia (HPCN, 2017) serving a population of 2, 2 million. It is evident that Namibia has a serious shortage of social workers. *“The severe shortage of social workers requires urgent attention. It has serious implications on the effective implementation of services”* (MHSS, 2014). This shortage of social workers has been a tenacious challenge in all the 14 political regions of Namibia. For example, in the Erongo Region, only three social workers were dispersed to serve a population of 150 809 (Conteh, 2008). This study therefore argues that the critical lack of qualified social workers hinders the effective and efficient service delivery to the vulnerable groups of communities and especially, palliative care to people with life-limiting illnesses. The shortage of social workers is experience in almost all fields of social work, for example, it is identify as a main hindrance in caring for orphans and vulnerable children in Namibia. A report by the Parliament Standing Committee on Gender and Family Affairs says the absence of social workers has a serious impact on identifying the needy children and inspecting their living conditions (Namibia Broadcasting Cooperation [NBC], 2013). These figures, however, ignore a shortage in the public sector, which has barely two health workers per 1000 population. Moreover, within the public sector there are chronic shortages of frontline workers including social workers, doctors and nurses. The country depends very much on the recruitment of expatriate doctors. There is a direct relationship between the ratio of health workers to the population and survival of women during childbirth and children in early infancy. In Namibia, the health worker shortage has been a major impediment to attaining the health Millennium Development Goals (MDGs).

Therefore, it is my belief that for Namibia to address the myriads of socio-economic challenges, its social welfare and social work systems must be robust and holistic in nature and geared towards addressing structural and institutional inequality as well.

2.4.1 Information on the context of social work service users (Patients)

Generally, service users of social welfare service and palliative care are vulnerable and orphaned children (OVC), people with life-limiting illnesses such as HIV and those affected by AIDS in need of care, the youth in conflict with the law, families, senior citizens and people living with disability. Social workers in all the various organisations cover a range of social services in trying to meet the psycho-social needs of their service users (patients). These include medical social work, mental health, substance abuse, statutory work, gerontology, gender-based violence, correctional social work, aftercare and reconstruction services among many others and these services are rendered through the social work methods of casework, group work, community work, research and management. For social workers to respond competently to the needs of the service users and to maintain quality service provision there are some statutory requirements that social workers need to adhere to. All the statutory requirements under the Social Work and Psychology Act, Act No. 6 of 2004 under the Health Professions Councils of Namibia (HPCN) and Namibia Social Workers' Code of Ethics command supervision for social workers. Social Work and Psychology Act, Act No. 6 of 2004 (Namibia, 2004) demands that a social worker may only be supervised on his or her work by another registered social worker. The same applies to student social workers and the act further requires final year social workers students to do their internship at registered welfare organisations that have social workers so that they can perform under the supervision of a qualified social worker. However, with the severe shortage of social workers in Namibia, the reality is that there are instances where social workers function without or with minimal supervision. In some cases, social workers have to accept supervision from non-social workers. This state of affairs is adverse and has negative demeanour on the social work practice.

2.4.2 Social work education and training in an independent Namibia

Namibia has four universities of which two are semi-state; namely the University of Namibia and the Namibian University of Science and Technology. The other two are private owned; namely International University of Management and Welwitchia University. In 1992, the University of Namibia (UNAM) was established by an Act of Parliament on 31 August 1992 as recommended by a Commission on Higher Education. It is the largest and leading national institution in the country. The Department of Social Work was established in 1983 and is housed in the Faculty of Humanities and Social Sciences of the University of Namibia, which currently the only institute to offer the four-year Bachelors of Arts (Honours) in social work in Namibia (Matthews, Muinjangu, Nashandi & Rukambe, 2015). The University of Namibia (UNAM) and the Social Work and Psychology Council have played major roles in the professionalization of social work as a profession in Namibia. The Social Work and Psychology Act, Act No. 6 of 2004 constitutes the council for the registration of social workers and psychologists aiming to ensure professionalism among practitioners in the given fields. In Namibia, registration is needed in order to legally practice social work (Social Work and Psychology Act, Act No.6, 2004). Social workers are required to keep abreast with their professional development through the earning of Continuous Educational Units (CEUs) to ensure that professionals in Namibia are current with the latest developments in the profession offered by registered Continuous Professional Development (CPD) providers under the Health Professions Council of Namibia. Twenty-seven years after independence a lot has changed (with the establishment of the Social Work, Psychology and Sociology Departments at the University of Namibia (UNAM) who provide training for social work. UNAM also upgraded a group of welfare workers to social workers. The social work department also offers post-graduate degrees (Master of Arts and Doctoral) as well as a Certificate in HIV and AIDS, a Diploma in HIV and AIDS Management and Counselling through the Centre of Open, Distance and e-learning (CODEL). The social work curriculum of the University of Namibia complies with the University of Namibia's quality assurance requirements and the Namibian Qualifications Authority (NQA) Standards.

Schenck *et al* (2015:12), state that in order to perform as a social worker, “*one needs education and training in a wide range of areas and disciplines, such as values, ethics, diversity, human behaviour, health, social pathologies, Sociology, Psychology, Anthropology, Economics, and Developmental studies to effectively deal with the developmental challenges faced by individuals, groups, families and the larger community*”. In response to this, the Department Social Work at the University of Namibia reviewed its social work curriculum, to move away from the colonial-apartheid curriculum, towards a robust, and more uniquely Namibian model of social work practice. The department relies heavily on stakeholders to ensure that the training prepare students to be competent social workers who will contribute to the realisation of the objectives of the National Development Plans (NDPs). Stakeholders from the industry are actively engaged in the curriculum process. To this effect, the department hosts consultative stakeholder meetings twice a year to tap from the expertise and input of stakeholders in relation to prevalent social issues in the country. Various government ministries, multi-national organizations, private companies, parastatals, non-governmental and faith-based organizations, which employ social workers, subsequently are demonstrating support for this workforce through funding bursaries to students who study social work at UNAM. In consultation with the stakeholders and the advisory committee issues such as palliative care, mental health approaches, gender-based violence, and monitoring and evaluation have been included in the social work programme. The social work department offers a BA Honours Degree in Social Work; Master of Arts in Social Work and Doctoral Degrees in social work. The department produced its first doctorate graduate in 2016. The revised (2016) social work curriculum and internship programme offer work integrated learning components that transform students to become practitioners who can render social services to the diverse Namibian society. Professional exposure and experimental learning are offer through a Field Education Programme where students have the opportunity to work directly with community partners, getting valuable on the ground experience, while offering countless hours of capacity to those organisations.

The Namibia Qualifications Authority Act (Namibia, 1996) enacted the Namibia Qualifications Authority (NQA) with the following objectives to:

- Set-up and administer a national qualifications framework;
- Be a forum for matters pertaining to qualifications;
- Set the occupational standards for any occupation, job, post, or position in any career structure
- Set the curriculum standards required for achieving the occupational standards for a given occupation, job, post, or position in a career structure;
- Promote the development of, and to analyse, bench marks of acceptable performance norms for any occupation, job, post, or position;
- Accredite persons, institutions and organisations providing education and courses of instruction or training of meeting certain requirements;
- Evaluate and recognise competencies learnt outside formal education; to establish facilities for the collection and dissemination of information in connection with matters pertaining to qualifications;
- Inquire into whether any particular qualification meets the national standards;
- Advise any person, body, institution, organisation or interest group on matters pertaining to qualifications and national standards for qualifications (Namibia, 1996).

The Department of Social Work expects students to possess a number of essential skills, values and standards of professional conduct in order to work with diverse populations and a range of issues within the profession. These essentials include physical, cognitive, emotional, and character requirements necessary to participate fully in all aspects of social work education and the practice of social work. The social work program for this reason conducts screening of students upon application, as well as an on-going review of students throughout the program in order to assess students' ability to possess and develop these essential skills, values, and standards, which also includes in-the-classroom, in their field placements, and in the professional practice. To ensure that students receive high quality and relevant education, and that the academic qualifications are widely recognized, the department develops its credits, exit levels and outcomes as well as assessment criteria in accordance with the requirements as set by

the University Centre for Quality Assurance and Management (CEQUAM). The Bachelors of Arts Social Work training program has been praised for its strong practical component which complements the theoretical part, because it gives students an opportunity to integrate theory and practice; in other words, to put theory into practice. The Social Work Department is a member of the Association of Schools of Social Work in Africa (ASSWA) as well as the International Association of Schools of Social Work (IASSW). Over a short time, social work in Namibia has and continues to develop into a well-established field. The social work programme in the Department of Social Work in the Faculty of Humanities and Social Sciences at UNAM, became popular over the years and attracts students from all over Namibia, Southern Africa, and internationally (USA, Sweden, Finland and Germany). In most cases, after graduation, these international students choose to remain in Namibia. The UNAM social work student population increased over the past years from an average of 18 first year students in the early 1990s to as many as 60 first years in 2009 (Ananias & Lightfoot, 2009). The University of Namibia roughly educates approximately two hundred and five (205) social work students per year. The post-independence social work programme aims to provide students with the necessary knowledge, skills and understanding to deal positively with problems that arise in the interaction between people and their environment and to empower those involved to deal with their problems in a self-reliant way. The students should acquire theoretical knowledge, professional skills and adhere to the ethical code of the profession. At the end of the education, the students should be able to perform in all the methods of the social work profession, which include social work with individuals, groups and communities, as well as research and management. These methods need to be apply according to the integrated model of social work. The methods are tailor to the specific needs of a client, group or a community system. Social workers in Namibia serve as counsellors (e.g., in adoption cases, bereavement, domestic violence, vocational and rehabilitation, hospice, mental health, substance abuse, youth services); they practice as service co-ordinators and case managers (e.g., in health care, child welfare, housing, human resources, public affairs, student life, employee assistance programs; as therapists (e.g., child, adolescent, marriage and family). They serve as administrators in public and private human service agencies; as community development workers, public policy analysts; and in juvenile and adult justice systems, to name a few.

They work in governmental agencies, private institutions, as well as in voluntary welfare organisations and non-governmental organisations. Based on this background, the development of social work education at the university is an important part of social work professionalization.

Collectively, therefore, it may be argue that since gaining independence, there are many opportunities and avenues shaping and changing the landscape of social welfare and social work (including palliative care) in Namibia to respond to the welfare needs of the citizens effectively and efficiently. Yet, as Compton (1989:16), observes: “--- *today the profession of social work is much more than the agent of the welfare system. It is charged both with the delivery of services to individuals, families and groups and with attending to the institutional structure within which such services are offered*”.

2.5 THE GLOBAL CONTEXT OF PALLIATIVE CARE

Developments in palliative care and social work intervention within the field of life-threatening illnesses are trace through the history of the hospice movement and the development of specialist palliative care social work (Small, 2001). Palliative care social work as a specialized field has developed rapidly since the late 1960s. The pioneering work of Cicely Saunders (1967) was influential in drawing attention to the end-of-life care needs of patients with advanced life-threatening diseases, such as cancer. Saunders (1967), the founder of the modern hospice movement in the United Kingdom, recognized the full amount of distress caused by cancer in its terminal phase. Saunders (1967) incorporated elements of emotional, psychological, financial and spiritual (as well as physical) pain, which resulted in the need for a holistic approach to the treatment of life-limiting illnesses such as cancer, which connects well with the tenets of social work (Reith & Payne, 2009). In the 1970s, palliative care began to define as a subject of activity and came to be tantamount with the physical, social, psychological and spiritual support of patients with life-limiting illnesses.

Palliative care services have developed in many settings and have often been closely relate to oncology, but the worldwide need for this type of care remains much greater than the available provision. Palliative care social work is globally required for a wide range of diseases with life-threatening illnesses (WHO, 2016). According to Goldman, Hain and Liben (2012, as quoted in the Oxford Textbook of Palliative Care for Children, 2012) life-threatening illnesses or conditions pose a grave threat of mortality for all human beings and for which medical treatment may result in a cure, but may also fail (Oxford Textbook of Palliative Care for Children, 2012).

The World Health Organization (WHO, 2016) globally estimates that in 40-60% of all diagnoses and deaths caused by life-limiting illnesses need palliative care. Each year an estimated 20 million people are in need of palliative care in the last year of their life with many more requiring palliative care prior to the last year of their life. Of these people in need, 78% live in low- and middle income countries and Namibia is no exception. For children, 98% of those needing palliative care live in low- middle-income countries with almost half of them living in Africa (WHO, 2016). In 2014, the Global Atlas on Palliative Care at the End-of- Life (2014) estimates that only 14% of people needing palliative care at the end-of-their life actually receive it (Global Atlas on Palliative Care at the End-of- Life, 2014). WHO (2016) states that the majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), followed by cancers (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%) just to mention a few. Non-communicable diseases (NCDs) kill 38 million people each year globally (WHO, 2016). The majority of these deaths occur in low-and middle-income countries. Cancer is the most common cause of death in developed countries, but it is difficult to estimate precisely the burden of cancer mortality in developing countries (such as Namibia), due to lack of and/or poor quality of available data. However, it is estimated that 10% of deaths in developing countries are due to cancer, and that cancer incidence is increasing (WHO, 2002). Palliative care social work is thus required for these patients with a wide range of life-limiting health related problems. In order to put into perspective social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses this chapter explores the literature that refers to the context and the roles of palliative care social workers in general.

It examines the specific role and work of social workers with patients with life-limiting illnesses and their families, and their role in a multi-disciplinary team. As mentioned previously in chapter 1, social workers' role in providing palliative care in primary care in Namibia, is poorly address in the literature with no empirical studies available. Therefore, the choice of this study on constructivist grounded theory approach is to provide recent information and tap into an under-researched area of social work in Namibia.

2.6 THE CONTEXT OF PALLIATIVE CARE IN AFRICA

Studies by Mwangi-Powell, Downing, Powell, Kiyange and Ddungu (2015), and Wright and Clark (2006) found that palliative care services commenced in Africa over 30 years ago with the founding of the Island Hospice and Bereavement Services in Harare, Zimbabwe. The African Palliative Care Association (APCA), a non-profit organization with its head office currently based in Kampala, Uganda, was provisionally establish in November 2002 and formally established in Arusha, Tanzania in June 2004. Acknowledging the genesis of modern palliative care within the United Kingdom, APCA strives to adapt it to African traditions, beliefs, cultures and settings, all of which vary between and within communities and countries on the continent. As such, in collaboration with its members and partners, APCA provides solutions to African problems, articulating them with what is the recognized regional voice for palliative care. APCA's vision is to ensure access to palliative care for all in need across Africa, whilst its mission is to ensure palliative care is widely understood, underpinned by evidence and integrated into all health systems to reduce pain and suffering across Africa. According to Mathers & Loncar (2014, as quoted by APCA, 2016: 11), Africa is characterized by an increasing rate of communicable diseases (such as HIV and AIDS), and a high burden of non-communicable diseases (such as cancers, cardio-vascular diseases, diabetes, respiratory diseases). This is especially evident in sub-Saharan Africa, who has increased the need for a well-developed understanding of and integration of palliative care social work services. According to Hunt and Maasdorp (2011, as quoted in Altilio, et.al, 2011:555) "*home-based care (HBC) is one of the models of palliative care that has been promoted to deliver cost-effective and comprehensive palliative care since the beginning of the HIV and AIDS epidemic*

across Africa. HBC has rapidly been adopted by many communities in sub-Saharan Africa due to health facilities being overburdened by the demand for HIV and AIDS care and support services". These researchers (Hunt & Maasdorp, 2011, as quoted in Altilio, et.al, 2011:555) state that in bringing palliative care directly into the home, has an impact on roles, relationships and attitudes toward death and dying, and this impacts on the role of the palliative care social worker.

UNAIDS (2014) estimated that by 2013, 24.7 million people in the sub-region were living with HIV and AIDS, which is 70.7 percent of the global disease burden (UNAIDS, 2014). Jemal *et al.* (2012), find that regionally cancer is a developing public health problem, as in 2008 there were 715 000 new cases and 542 000 cancer-related deaths in Africa, projected to nearly double (1.28 million new cases and 970 000 deaths) by 2030 due to the population growth and aging (Ferlay, Shin, Bray, Forman, Mathers & Parkin, 2008) with 36 percent of cancers infection-related, twice the global average (Parkin, 2006). Furthermore, in 2010 there were 259 500 new cases and 2.1 million tuberculosis (TB)-related deaths (United Nations Millennium Development Goals Report, 2012), with the continent accounting for 80 percent of all TB cases among people living with HIV (WHO, 2012). Given the statistical picture on the infectious and NCD disease burden, it is estimate that while globally the number of adult and child patients in need of end-of-life palliative care is 20.4 million, in Africa it is estimate that this figure is 1.8 million, 346,203 of which are for cancer (Connor & Bermedo, 2014). Despite increasing longevity and greater cancer survival rates, the word 'cancer' still confers a special status: 'cancer has become the metaphor for the feared death' (McNamara, 2001:30)—which can be seen "to affect anyone, regardless of class, status or financial resources" (Beresford *et al.*, 2007: 23). Access to palliative care services is not equally availed. Even in the developed world, older people and people from ethnic minority groups represent poorly in hospices and specialist palliative care units (Evans *et al.*, 2011) and the reporting and diagnosis of pain and other symptoms known to be problematic amongst people with dementia and other mental health problems. Consequently, African palliative care services operate within resource-constrained settings and palliative care social work in particular needs to attend to the psycho-social impact of poverty on the health of patients.

Such communities have limited access to the basics of food, portable water supply, sanitation, transport accommodation and shelter. These rapid changes in the family and social structures characterize the important role of the social worker in the provision of palliative care.

Key to specialist palliative care social work is the ability to see and assess people in totality (physically, emotionally, psychologically, mentally and spiritually) in order to understand the connections of their lives. In addition, palliative care social work seeks to act on, rather than ignore, the limitations and discrimination they experience in society (Association of Palliative Care Social Workers, 2006:6). Indeed, Beresford *et al.*'s (2007) research into the generalist focus of social work intervention within palliative care services strongly advocates that this approach is valued by service users—patients and caregivers alike (Reith & Payne, 2009:17). Crucial to the success of national programmes, which seek to improve the quality of care at the end-of-life through palliative care, is the promotion of broader societal change, principally through raising public awareness on the importance of palliative care social work. Social work throughout its history interacted with community models of support and, in some parts of the world; this is its primary model (Adams, 2008). This community focus, combined with a rediscovery of the importance of health for well-being and the social work task (Bywaters & Napier, 2009) suggests that public health initiatives are natural allies for social work. The profession of social work itself has experienced a radical change in the wake of the high burden of life-limiting illnesses, which make palliative care in social work and in its contribution to society a pressing need in the Southern African region and particularly in Namibia where this study is confined. Palliative care in social work has come to be considered a specialist area of social work with a relatively short history (Sheldon, 2000; Cadell *et al.*, 2010). The Association of Palliative Care Social Workers (APCSW, 2006) defines specialist palliative care social work as follows:

“Social work is seen as an integral part of the multi-disciplinary team within the palliative care offering a holistic service to patients and families. Specialist palliative care social workers offer a wide range of support to patients and families from practical help and advice around income maintenance, debt counselling, help with housing and accessing other services, through to

advocacy, individual counselling and group support. This will include bereavement work with adults and children both as individuals and in group settings. Key to specialist palliative care social work is the desire and ability to see people as whole people and not as a set of problems, to understand the connections of their lives and to seek to act on, rather than ignore the complaints and discrimination they experience in society (APCSW, 2006:6).

In 2011, a review of developments undertaken by the World Hospice and Palliative Care Alliance (WHPCA) and WHO (2014) revealed that Sub-Saharan Africa has shown the most notable changes in palliative care service development, with nine countries moving from group 1/2 (with no known activity or capacity building) to group 3a (with isolated provision of palliative care services). Further to this, Harding et al. (2003) reported “*a need among care providers for methodological robust research and despite some notable research studies, the evidence base informing the delivery of effective and appropriate care on the continent remains in its infancy*” (Harding et al., 2003). In a review of the status of palliative care in ten Southern African countries, including Namibia, (APCA, 2016) some of the key obstacles to the development of palliative care in Africa resonate with those in the United Kingdom (Richards, Corner & Clark, 1998) and include: the lack of a research culture; lack of research skills and knowledge among health care professionals; lack of agreement on outcome measures, shortage of research funding, the dominance of the biomedical model; the absence of national palliative care research, palliative care policies, including those pertaining to home-based care and the absence of strategic research vision (Powell et al., 2008), leave a guidance vacuum in the field.

The next section documents the modern history of such care within a Namibian context.

2.7 THE CONTEXT OF PALLIATIVE CARE IN NAMIBIA

Namibia has a population of 2.3 million people and its’ classification by the World Bank is that of an ‘upper middle income’, with a ‘medium’ HDI ranking (i.e.127) (Namibia Demographic and Health Survey, 2014).

In 2009, Namibia's population in poverty headcount ratio was 24% (i.e., living on \$1.25 per day), with 7.7% of its GDP allocated to health, with \$423 per capita total expenditure on health in 2013 and a per capita government expenditure of health in 2011 of \$208. Namibia, according to APCA (2016) reported to use the WHO (2002) definition of palliative care, while the reported palliative care activity for Namibia ranks at group level 3a, which indicates an isolated provision of palliative care services in the primary care settings. The isolated provision of palliative care in Namibia is characterized by the development of palliative care activism that is sparse in scope and not well supported. It is characterized by source of funding that is often donor dependent; limited availability of morphine; a small number of hospice based palliative care services that are often home-based in nature and relatively limited to the size of population generalized palliative care provision. The country provides limited palliative care services for patients with HIV and AIDS or cancer diagnosis (APCA, 2016). Namibia is reported to provide palliative care services for prisoners and in non-specified other community settings (APCA, 2016). The country is one of the hardest hit countries globally with respect to the HIV epidemic with a prevalence ranging from 4 to 33%, averaging 13.5% (Namibia Demographic and Health Survey, 2014). APCA (2016) found that Namibia has no national palliative care association and palliative care is directly coordinated by the Ministry of Health and Social Services. The country has a draft palliative care policy in place and is in the process of renewing the national palliative care task force. Palliative care is integrated with the Community-Based Health Care Policy. The community-based organizations can be demarcated as Faith-Based organisations and Informal or Community Based Initiatives. Faith-Based Organisations are mostly church initiatives to render services to needy church members as well as community members. One good example is the Catholic Aids Action (CAA) Trust, who resorts under the auspices of the Namibian Catholic Church. CAA Trust has grown to be one of the largest organisations, responding to the plight of HIV and AIDS nationwide. The majority of organizations (such as church initiative and community-based initiatives), delivering elements of palliative care at the local community level in Namibia are almost entirely dependent on donor support from foreign governments and non-governmental organizations. Thus, with the lack of donor funding, CAA had close down most of its satellite offices in the country.

Another example is Church Alliance for Orphans (CAFO) in Namibia, a network of faith-based and community-based projects providing services to orphans and other vulnerable children. Due to the high rate of HIV-infection, Namibia has also seen the rise of many informal or community based initiatives trying to provide social service to especially children and families infected and affected by HIV and AIDS. These are initiatives by individual community members, who build shelters, day care centres or soup kitchens. The Helping Hand Welfare Organisation for example, provides support services for victims of gender-based violence and abuse, the sick, the needy, and anyone in need of a helping hand. It also runs a day-care centre for abused, neglected or needy children. In addition, counselling is offer for women, children, couples as well as families. The country has a national HIV and AIDS programme and a national cancer control programme, but the national cancer control programme does not have a structure in place yet. Namibia is in the process of developing a national cancer control plan and a multi-stakeholder's strategy on non-communicable diseases. The country supports the inclusion of palliative care medicines on the Namibia Essential Medicines List (NEMLIST) to ensure drug availability for pain management. Codeine and brufen have been added as essential pain medication as part of the country's initiative that considers the access to essential medicines as a human right and there is a system in place for monitoring and evaluating palliative care health policies. Morphine, for example, is now accessible at clinic levels and nurses can re-prescribe. Although Namibia has no dedicated budget line for palliative care in the health budget or dedicated research resources, active involvement of the Ministry of Health and Social Services has facilitated the integration of palliative care into healthcare delivery in primary care settings (APCA, 2016).

2.8 DEMAND AND NEED FOR PALLIATIVE CARE

The demand and need for palliative care remain vital in contributing to the quality of life of patients, both adults and children. The quality of life, the humaneness of what makes us human are all relevant arguments for the demand and need for palliative care from the point of diagnosis, to end-of-life and bereavement.

Global ageing together with the demand and need for palliative care forces us to widen the lens and to think of its meaning in the broader context of globalization itself, what, for example, will the impact and consequence of ageism in the forms of access to treatment in general and particular to palliative care means? Harper (2006) refers to population ageing as the gradually global phenomenon demanding for palliative care because most European and American countries in the world are now experiencing the shift in age structure. With population aging and advances in medical technology prolonging life, social workers are increasingly called into this specialized field, called palliative care, because their knowledge, skills and professionalism lend them in a unique position to increase their skills and knowledge in palliative care. The implications for global aging and palliative care demand in developed countries are altering patterns of health, welfare, housing and transport consumption needs, transformations in the age-based configuration and financial patterns of saving and consumption sparked by an increasing percentage of individuals with higher levels of disposable income, which may have further implications if demand and need for palliative care, which range from the fear of being a burden in the form of elevated health and pension costs, to the need for policy makers to question whether population ageing *per se* is at the source of these needs or whether they in fact reflect on political unwillingness or inability to adopt policies and institutions and to respond positively and creatively to the advantages that ageing populations represent (Harper, 2006).

This study argues that the demand, need and opportunity for the social workers' role in providing palliative care settings increases as are the issues and dilemmas presented in practice due to longer life spans, medical advances in technology and the implications of such technology for clients, families and systems providing care. In contrast, a common feature of many sub-Saharan countries, in particular, is the role of the HIV and AIDS epidemic and cancer incidences which shape the development of palliative care, particularly if this impacts the generation of adult workers as it does in sub-Saharan Africa. Several countries in the sub-Saharan Africa region (Namibia, Botswana, Swaziland, Lesotho and Zimbabwe) have some of the highest HIV and AIDS rates in the world with limited infrastructures to manage life-limiting illnesses and dying

patients within the mainstream health systems, which outstrips supply. The number of patients with cancer, HIV and AIDS continue to rise and with them, the burden of palliative care needs remains a challenge. These issues (cancer incidences and HIV and AIDS) facing the region, impact on the demand, need, provision and character of palliative care. Health systems in many countries fall sadly short of adequately supporting patients living with life-limiting illnesses. For example, Namibia's increased prevalence of communicable diseases (Namibia Demographic and Health Survey, 2014) and the high burden of non-communicable diseases in the absence of a national palliative care policy, make palliative care a national demand and need. Namibia's low urbanisation means services often need to provide to low-density populations across vast rural areas (Namibia averages two people per km²). Many health professionals prefer to work in urban areas, so rural health provision often is left to community- and home-based volunteers, able to deliver care that is only supportive in nature (African Palliative Care Association website data www.africanpalliativecare.org). Namibia continues to face shortage of healthcare professionals (MHSS, 2014) and access to palliative care services, especially in rural areas. Palliative care can greatly increase if more healthcare professionals become train and permitted to deliver aspects of holistic care, including prescribing of morphine.

This study argues that the need and demand for social workers to serve and advocate for vulnerable populations, such as patients with life-limiting illnesses is enormous and addressing health disparities in palliative care is an increasingly essential part of practice area for social work. Social workers are challenge by time and funding limitations to provide the services to clients in demanding practice settings. Yet, social workers need to have opportunities to contribute and participate in research, policy making, education, and practice initiatives for this specialization in social work. This study argues that there is a dire demand and need for more palliative care social work. The primary aim for this study therefore is to explore social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses in primary care settings in Namibia. It examines social workers' understanding of palliative care. Although much research were carried out in developed countries on social workers' role in providing palliative care, previous research has not been conducted in a Namibian context.

The main aim of the study is therefore on this under-researched area in Namibia. This study addresses this gap in research in the context of Namibia by shedding light on social workers' roles in providing palliative care. It investigates those conditions that hinder or strengthen social worker's abilities to provide palliative care. It seeks to reveal deeper insights into how social work education and training (aspects also covered in chapter 5) influence social workers' competencies in their roles of providing palliative care. The intention of the study is to illuminate the lack of research on the role of social workers in providing palliative care in primary care settings in Namibia.

2.9 SOCIOLOGICAL SIGNIFICANCE OF STUDYING SOCIAL WORKERS IN PROVIDING PALLIATIVE CARE

The researcher approached both the preliminary reading and a literature review (of this chapter) with an open mind. The purpose of the literature review aligned with the research objectives and the concepts that derived from the data analysis. Dey (1999) points out that research should be approach with an open mind, and previous knowledge should be use to inform our analysis, but not direct it (Dey, 1999). Likewise, Cutcliffe (2000:1481) alludes to the benefit of conceptual awareness if the literature is explored before the research on which the remaining "emergent theory can be built". In their study, Corbin and Strauss (2008) cautioned against blocking "*creativity and familiarity*", but welcomed "*enhanced sensitivity to subtle nuances in data*" (Corbin & Strauss, 2008: 37). Following this recommendation, I conducted a preliminary reading on existing literature on the role of social workers in providing palliative care to patients with life-limiting illnesses. I started data collection with a preliminary reading on the role of social workers providing palliative care. The preliminary readings included: Altilio, 2011; Bartlett, 1975; Bomba, Morrissey & Leven, 2010; Dubus, 2010; Encyclopedia of Social Work, 2012; Forrest & Derrick, 2010; Goldsmith, Wittenberg-Lyles, Rodriguez & Sanchez-Reilly, 2010; Harper, 2011; Hartman-Shea, Hahn, Kraus, Cordts & Sevransky, 2011; Higgins, 2011; McCormick, 2011; McCormick, 2010; Morrissey, 2005; Nadicksbernd, Thornberry & von Guten, 2011; O'Mahoney, McHenry, Blank, Snow, Karakas, Santoro, Selwyn & Kvetan, 2010 and Palos, 2011.

These readings enhanced my understanding of social workers' perceptions of their role in providing palliative care in order to place the study in context (Glaser, 1998). I used the preliminary reading of literature to support and continuously compare data and then integrate into theory (Glaser, 1992). This served to highlight what is already known about social workers' perceived role in providing palliative care to patients with life-limiting illnesses and thereby inform the direction of this research (Hutchinson, 1993 & Walls *et al.*, 2010). Birks and Mills (2011:22) refer to this as "a limited and purposive review which can assist the researcher". The preliminary scan of the literature was considered essential in order to inform the original purpose for ethical approval of this study and to ensure similar work had not been undertaken previously in Namibia (McGhee *et al.*, 2007).

In this chapter, I acknowledge my expertise within this area, which was the reason in further exploring any gaps in knowledge. The early literature review did not hinder or jeopardize a transparent approach to my research, but instead afforded me the opportunity to study pertinent, previously unexplored areas related to palliative care social work within a Namibian context. I used the preliminary reading to help place my study in a theoretical context. A critical literature review was conducted towards the later stages of the analysis as the theory emerged. The critical review of related studies only occurred after the new grounded theory was developed (Glaser, 1998). It served to weave into the theory generation and provided more data to compare (Glaser, 1998) as well as providing a vehicle for engagement (Walls *et al.*, 2010). The initial review was widespread whereas the later review was much more focused on emerging themes and took on a much different angle, a process Charmaz (2006) describes as "*travelling to new substantive terrain and scaling unimaginative theoretical heights*", which, if "*thorough and sharply focused*" can "*strengthen your argument and add credibility*" to the study (Charmaz, 2006: 166). The literature reviewed was used as data (Walls *et al.*, 2010). As each new core category or theme evolved, the literature was searched to explore possible connections and relationships. This was an exciting period in time as thoughts and ideas unfolding proved accurate, consistent or otherwise with existing literature. The harmony between conducting a preliminary reading to establish previous studies and the later review to add data to the emerging theory provided me with an appropriate balance and understanding of the literature (Giles *et al.*, 2013).

The later literature review for the study was inform by the themes found in the data collected on social workers' perceptions of their roles in providing palliative care in Namibia as discussed below:

2.9.1 Understanding social workers' perceptions of their roles in providing palliative care

I reviewed research studies closely related to my present study for five central purposes. First, I wished to understand social workers' perceptions of their roles in providing palliative care. Second, I wanted to examine social workers' understanding of palliative care. Third, and fourth, I wanted to identify gaps in the literature regarding conditions, which may hinder or strengthen social workers' capabilities to provide palliative care. Finally, I wanted to gain insights into how training and education on palliative care influence social workers' competencies in this area. All five perspectives informed and supported my study and its research design.

First, the sociological importance in undertaking this study is to understand how social workers perceive their roles in providing palliative care to patients with life-limiting illnesses, as social workers are concerned with enhancing the quality of life and promoting the well-being for individuals, families and caregivers (NASW, 2003). Palliative care claims its approach to be 'holistic', and this study asks how do the social workers perceive their roles in providing palliative care to patients with life-limiting illnesses in understanding and operationalizing the concepts of 'holistic' and in shaping services. As palliative care services are widening the role of the social worker within this care must become clearly articulated. When confronting social problems of patients with life-limiting illnesses, social workers are required to perform multi-dimensional roles as counsellors, educators, advocates, mediators, facilitators, community leaders and researchers and therefore need to be train and equipped to competently and sensitively respond to the needs of these patients. There is a growing impetus towards greater involvement of social work and social services in the field of palliative care. In this regard, this study hopes to contribute to its sociological significance.

Since the inception of social work practice in hospitals in 1905 in the United States, the social work profession has been a link between the patient and the environment (Varghese, 2016). The social work profession in hospitals has faced many challenges due to changes in the health care environment. A literature review from the National Association of Social Workers (2010) characterizes palliative care social work as diverse and includes; facilitating advance care planning; advocacy on behalf of the patient and the family; leading community education and facilitating psych-social education. Palliative care social work includes working with people with life-limiting illnesses such as Non-Communicable Diseases (cancer, diabetes, etc.) and communicable diseases (for example Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS)). Non-Communicable Diseases are non-infectious and non-transmissible diseases. They are long in duration and generally slow progression diseases with the four most prevalent globally being cancers, cardiovascular diseases, chronic respiratory diseases and diabetes. The WHO Resolution (2014) records *“that many more people will require palliative care in the future given the overall ageing of the global population and the increased prevalence of non-communicable diseases”* (WHO, 2014). Although the rationale of palliative care provision certainly includes giving painkilling medicines in the need to relieve pain and other distressing symptoms, it goes further to include efforts to enhance the quality of life and even influence the course of the illness in a positive way (WHO, 2016). WHO (2014) contemplates *“the provision of palliative care to be an ethical responsibility of health systems and called on all health care professionals (including social workers) throughout the world to fulfill an ethical duty to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured”* (WHO, 2014).

According to Watts (2013), the social worker has an integral role to perform within the multi-disciplinary palliative care team. Social workers, alongside nursing, medicine and other clinical and complementary therapies have a key role in conducting psychosocial assessments on patients’ palliative care needs. As a professional social worker who focusses on behavioral patterns, emotions and relationships, I argue that social workers play an invaluable role in the multi-disciplinary team in the provision of palliative care.

The stress accompanied by the diagnosis of a life-limiting illness, concerns about daily care and medical demands made on the patient and the caregivers causes additional emotional pain and if not adequately addressed, hampers the patients' quality of life and complicates the grieving process. Reith and Payne (2009) found that death and dying involve loss and transformation, and for many patients this can be an overwhelming experience where they require counseling to manage their feelings and come to terms with this. The focus of social work practice in this area includes family and social network responses upon receiving a diagnosis of a life-limiting illness and facing end-of-life. Although the social workers' roles vary across service providers, a fundamental aspect of palliative care social work includes assisting individuals and their families to manage change and loss at each stage of the illness trajectory. Within this framework, the social worker is in the position to facilitate the therapeutic process to promote emotional healing and closure for the patient and the family. Worth (2001) states that social workers are key professionals contributing to the practice of palliative care delivery in a range of settings, including hospital, hospices and the community.

According to the WHO (2016), palliative care social work starts with a multi-dimensional assessment of physical, emotional, social, spiritual and cultural needs, values and preferences of patients and families. Social workers in this regard have an important role to perform in the provision of psychosocial care, which involves addressing the psychological, emotional, social and financial well-being of patients and family members (WHO, 2016). Social suffering includes stigma, discrimination, extreme poverty, religious prejudice, or lack of adequate food, clothing or shelter (WHO, 2016). For those no longer able to support themselves and their families financially, palliative care social workers serve as a broker to provide information and to link them with sources of funding (WHO, 2016). Bereavement support is another core component of palliative care social work. Patients and their families often need emotional support to face the losses associated with dying and bereavement, and some bereaved family members develop complicated grief, requiring bereavement counseling from social workers (WHO, 2016). Engaging in providing psychosocial support is demanding for trained palliative care social workers since social workers have an important contribution to make in helping to improve the quality of life for patients with a life-limiting illness.

In this regard, I would argue that social workers are one of the key professional groups among health care professionals who are well placed to provide comprehensive psychosocial support, counseling and palliative care to patients with life-limiting illnesses.

2.9.2 Social workers' understanding of palliative care

In the second purpose to inform my study and its research design, I reviewed the literature to examine social workers' understanding of palliative care. Psycho-social support provided by social workers is an important need in the provision of palliative care. Patients with life-limiting illnesses and their caregivers go through great stress, health professionals, including social workers have an important supportive role in assessing, and addressing the needs of patients diagnosed with life-limiting illnesses. In this regard, social workers, nurses and doctors treating these patients need to have a clear understanding of what constitutes palliative care. They should be adequately trained and prepared to help patients manage their stress. However, palliative care as a concept and discipline in itself is not well understood commonly, across different contexts and within the African context.

In sub-Saharan Africa and particularly in Namibia, the concept of palliative care is not well developed. Largely, it is confined to isolated specialist centres. The literature review aims to examine the related sub-questions including: how do social workers understand palliative care? Why is social workers' understanding of palliative care important? According to the WHO (2002), palliative care provision is an essential component of a comprehensive package of social work services for people with life-limiting illnesses, because of the variety of symptoms patients can experience. Palliative care social work is an important means of relieving and addressing symptoms that result in undue suffering and frequent visits to the hospital or clinic. Lack of social workers' understanding of palliative care can result in untreated symptoms that can hinder an individual's ability to continue his or her daily activities. WHO (2016) finds that the lack of understanding and knowledge about palliative care in general is another major barrier limiting the appropriate access to palliative care.

In this regard, social workers' understanding of palliative care is an integral part of holistic care, which aims to improve the quality of life of patients with life-limiting illnesses. According to WHO (2015), palliative care is explicitly recognized as a human right by the United Nations Human Rights and Open Society Foundations (2011, as quoted in Freeman, Luyirika, Namisango and Kiyange, 2016:2) under the International Convention on Economic, Social and Cultural Rights (ICESCR) Article 12.1 (1996). The goals of palliative care are to achieve the best possible quality of life for patients and their families, to facilitate adjustment to the many losses they will face, and to attain a dignified death, with minimum distress, in the patient's place of choice. APCA (2016) found that Namibia uses the World Health Organization's (WHO, 2002) definition of palliative care which defines palliative care "as an approach that improves the quality of life of patients (adults and children) and their families facing the problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual".

However, the MHSS (2009, as quoted in Freeman *et al.*, 2016) found that forty percent of the health care professionals in Namibia (including social workers, doctors, nurses, academics and other health care professionals) repeatedly encounter a lack of understanding of what palliative care is and how it enhances the work in these professions. The situation analysis by the MHSS (2009) found that palliative care is often either seen as synonymous with the end-of-life (i.e. dying) and hospices and all the associated negative connotations of death. Or it is associated only with the relief of physical pain. Findings from the national situation analysis (MHSS, 2009) revealed a low level of knowledge for the definition of palliative care. Forty percent (40%) of the respondents in the study (MHSS, 2009) were unable to provide any definition of palliative care. While of those who did provide a definition, only five percent (5%) were able to elaborate on the different dimensions of palliative care, according to the definition by the World Health Organization (WHO, 2002). This finding is similar to the fifty one point three percent (51.3%) of health care workers (i.e. nurses, doctors and pharmacists) in the MHSS (2009) study, who reported that they provided palliative care with the majority of forty seven point four percent (47.4%) only concentrating on pain

and symptom management as essential elements, neglecting the other components of holistic palliative care (MHSS, 2009). Few people comprehend the holistic nature of palliative care, while even fewer understand its effectiveness in improving care outcomes, most importantly the quality of life to patients and their caregivers (MHSS, 2009). Additionally, palliative care is often confused with home-based care, which is only one model of delivery (MHSS, 2009). While there are many challenges that hinder palliative care development in the country, a key challenge is the lack of understanding, knowledge and accurate information around palliative care in Namibia. This exploration therefore hopes to gain deeper insight into how social workers understand palliative care and perceive their role in the provision thereof. This study includes social worker's perceptions, beliefs and lived experiences of palliative care provision and its' applicability from diagnosis through to death and bereavement. This study examines the latter by using broad questions in in-depth interviews with social workers.

2.9.3 Conditions that hinder social workers' abilities to provide palliative care

The third purpose of reviewing related studies concerns my intention to identify the gaps in the literature, such as conditions, which may hinder social workers' capabilities to provide palliative care. This I hope to achieve by examining social worker's perceptions through their narratives when collecting information on their roles in providing palliative care. It is important to understand social workers' responsibilities when palliative care is need. Are they taking an active role in providing palliative care? If they are not taking an active role, what conditions hinder their abilities to do so? If social workers are not providing palliative care in the primary care settings in Namibia, is it because they were not train to fulfill an ethical duty to alleviate pain and suffering? The importance of social workers to society includes their applied and hands-on experience in assessing social problems and alleviating some of these through their presence and recommendations to broader social structures and institutions. In this sense, social workers are an invaluable workforce in society and provide social support amidst various social problems.

People with life-threatening illnesses who are close to death may experience a humane transition as can their families after these persons pass on because of the intervention in palliative care by social workers. According to Holliman, Dziegielewski and Data (2001) social workers in hospitals face several challenges, together with providing biopsychosocial needs with discharge planning skills. Yet, palliative care social work as a specialized field has limited recognition in Africa, and in Namibia, it is not yet formally recognize as a specialized field. Many social workers in Namibia are not train as palliative care social workers and they are not aware of the active clinical aspects of palliative care. However, there is a growing recognition in Africa of the importance of addressing the NCD agenda and advancing palliative care service provision (Powell, Ali, Luyirika, Harding & Radbruch, 2013). Yet, palliative care social work is rarely accessible in resource-limited settings (Connor 2012; Farmer 2010; Harding 2005 & Lamas 2012) and Namibia is no exception.

While some hospital administrators in Namibia view social work positions as “welfare service providers”, others view social work as a profession that helps patients and health care in general, dealing with patients’ complex social and health care needs. Varghese (2016) argues that the contributions of social workers become unclear and remains unnoticed as it mixes with other disciplines that are also involved in the discharge planning process. In the case of Namibia, it is unclear whether the absence of context-relevant literature, which indicates a degree of silence surrounding this topic, is caused by a lack of understanding and appreciation by governmental institutions, the Health Professions Council of Namibia and hospital administrators) of the role the social worker can play. These challenges are due to multiple related conditions including, lack of social work in-service training; continuous professional education on palliative care; lack of skills and knowledge among healthcare professionals to provide palliative care. It includes professional isolation; lack of agreement on outcome measures, key definitions and concepts on palliative care; the absence of national strategies for palliative care research; a shortage of research funding; lack of opioid availability; and decentralization of key services from the central hospital level to the health centre or patient home.

These challenges result in patients with advanced chronic illnesses typically being discharged from the healthcare system and returning home with no referral to the social worker and no follow-up treatment when they are most likely to have severe symptoms, and when their families are under the greatest stress (Harding, 2009 & Vogel, 2011). However, Dziegielewski (2004) suggests that social workers can accept the challenges and move forward to create an evolution in new practice techniques, becoming a crucial member of the multi-disciplinary palliative care team. According to Larochelle et al. (2009), it is often the responsibility of the physician to communicate the diagnosis, prognosis and treatment of a life-limiting illness to patients. Yet, the medical terms for life-limiting diagnoses used by physicians are perplexing to the patients, because words such as “carcinoid” and “neuroendocrine” are difficult to understand. Physicians, for reasons of patient confidentiality, work individually with the patient and families, who in most cases result in lack of communication among the multi-disciplinary team. The lack of communication between medical doctors, nurses and social workers leads to further confusion for patients and families as they work to understand the medical diagnosis and prognosis in order to make appropriate treatment decisions.

In Namibia, the specific health worker-population ratio includes 1:13, 519 for social workers, among others (MHSS, 2014). As it rolls out the provision of palliative care which is a rather labour intensive discipline, there is a need for Namibia to assess the human resource needs (with the focus on social work) to inform the appropriate planning for human resources for palliative care at national level. At the time of this study, there is a shortage of information on human resources for social work as it relates to palliative care in Namibia. This makes it challenging to provide a basis for determining required numbers and quality of training as well as attrition of human resource for palliative care in Namibia. Recommendations from this study will help in the development of a harmonized management system of a consolidated human resource development plan for social workers in Namibia and similar settings in Africa.

2.9.4 Conditions that strengthen social workers' abilities to deliver palliative care

The WHO's (2002) public health approach recommends four strategies for strengthening palliative care service provision and research systems in health, including capacity building in strengthening education and health research, policy implementation and drug availability. Although at the time of this study, there was no national policy for palliative care in the country, the MHSS has been addressing the topic in recent years, owing to the fact that eighty percent (80%) of the cancer patients are diagnosed at advanced stages of the disease, when no other options apart from palliative care can be provided. Since 2006, there has been a focus on capacity building of the palliative care providers through various training programmes in other countries, namely Uganda and on measures to make morphine tablets available for the palliative patients in Namibia. In 2009, the MHSS conducted a situational analysis of palliative care in Namibia in conjunction with the African Palliative Care Association and the financial support of USAID, published in November 2009. Following this action, in July 2010, the MHSS organized a two-day national workshop on palliative care. At this workshop, all stakeholders (including non-governmental) reached a consensus in putting together a document to be used in the development of palliative care guidelines and ultimately, the Palliative Care Programme. At the outset, the strategy is to encompass HIV and AIDS in addition to cancer and to promote home-based care.

This study is important in seeking to understand social workers' responsibilities when palliative care is necessary. Are they taking an active role in providing palliative care? If they are not taking an active role, what conditions hinder their abilities to do so? In response to these questions, the literature review revealed that palliative care is integrated into the social work education and training curriculum of the Faculty of Humanities and Social Sciences at University of Namibia (APCA, 2016). The Social Work Department of the University of Namibia (UNAM), in close collaboration with and support from the African Palliative Care Association (APCA) embarked upon specialist palliative care training for practicing social workers in Namibia, which took place during the week 04-08 March 2013.

It was the first time in the history of Namibia that a group of twenty- nine social workers from public and private sector were train in palliative care. The country has a national training curriculum for pre-service introductory training for community home-based caregivers developed on palliative care, but there is no dedicated research group (with no experiences in international research) and it has no palliative care standards, norms or guidelines or dedicated directory.

2.9.5 Social work education and training on palliative care

The final purpose of this literature review is to gain insights into how social work education and training on palliative care contribute and influence social workers' competencies in the provision of palliative care. According to Stjernsward, Foley and Ferris (2007), palliative care education and training is one of the four pillars of the WHO Public Health strategy in the provision of palliative care and is crucial, not only for effective integration of palliative care in society, but also to change the experiences of patients with palliative care needs. The WHO 67th World Health Assembly (2014) focuses on integration of palliative care and highlights the need to include it as an integral part of education and training across the spectrum of care. The past two decades has seen a rapid increase in awareness on the importance of educating social workers in palliative care to address effectively the patients' needs. The provision of comprehensive palliative care demands social work practitioners with appropriate knowledge, skills, confidence and competencies in the provision of compassion and care for all. The need to act in this capacity has been especially pronounced by the growing recognition in Africa and Namibia of the importance of addressing the non-communicable disease (NCD) agenda and the Human Immunodeficiency Virus (HIV) pandemic (APCA, 2016). The need for palliative care education and training for social workers in Namibia remains vital in improving the quality of life for both adult and paediatric patients and their families. This research therefore investigates whether social workers feel inadequately prepare? Or do they lack an understanding of how to provide palliative care? According to the African Palliative Care Association (2009), it is important that palliative care education and training be look at as a continuum, which begins at undergraduate level through to specialist training into continuing education.

Downing, Defilipi, Garanganga and Opio (2006) state that it is important to ensure that palliative care education and training of service providers not only focus on knowledge and skills, but also on attitudes, beliefs and values. The same authors (Downing, *et al.*, 2006) found that clinical placements are a fundamental education strategy in palliative care education and training. It is imperative that palliative care education and training also include a clinical component as well as an element of ongoing mentorship and supervision (Downing, Finch, Garanganga and Opio, 2006). Continuous education in palliative care is a critical component in the professional development of care providers' knowledge and skills in order to improve and refresh their existing knowledge. Professional palliative care development aims to ensure that patients receive the best competency-based care possible. A Situation Analysis on Palliative Care in Namibia by the MHSS (2009: 60) recommends, "*social workers be trained in palliative care to competently provide adequate care and support to patients with life-limiting illnesses*". MHSS (2009) highlights the need for palliative care training that empowers social workers with knowledge and skills in areas of psychosocial support, emotional, spiritual and social welfare, which are just as important as physical well-being.

For education in social work to be competency-based and effective, appropriate training methodologies have to be applied to support social work students to have the appropriate knowledge and to be able to translate this knowledge into skills and competencies. Such education and training should lead to a change in attitudes, beliefs and values, which result in the social work graduates being able to do their job effectively. To this end, the Social Work Department in the Faculty of Humanities and Social Sciences at the University of Namibia developed and integrated palliative care as part of a six months' module in the four year Bachelors of Arts Degree in the Social Work Programme in 2012. Namibia currently has only one educational institution for the training of social workers, namely the University of Namibia (UNAM). The Department of Social Work was established in 1983 and is housed in the Faculty of Humanities and Social Sciences of the University of Namibia. The social work department conforms to the academic requirements guided by Senate and the policies and guidelines of the Health Professions Council of Namibia (HPCNA) and Social Work and Psychology Act, Act No. 6 of 2004

(HPCNA, 2010 & UNAM, 2014). The Bachelors of Arts Degree in Social Work is a degree by course work including a six-month internship, a research component and three days of palliative care clinical attachment. As stated earlier, undergraduate training in palliative care for social work students has been institute only in 2012. The integration and teaching of palliative care social work in social work made history in Namibia and in Africa, because it is now introduce as a compulsory part of the third year undergraduate level social work curriculum at the University of Namibia. The first six months' module of palliative care social work education and training was developed in 2012, and has since (2014) expanded to three days' clinical placement under the supervision of practicing social workers at two public hospitals (Windhoek Central and Katutura) in Namibia. The Department of Social Work at the University of Namibia provides palliative care social work by a social work lecturer in close consultation and collaboration with practicing social workers in Namibia. The social work lecturer with the assistance of the African Palliative Care Association has been instrumental in leading the palliative care social work curriculum development at the University of Namibia. Practicing social workers in Namibia are also key stakeholders in providing palliative care education, training and supervision to the third year social work students during the three days clinical placement. A variety of teaching and learning methods are used in palliative care social work education and training at the University of Namibia. At the social work undergraduate level, several teaching methods ensure engaged and active learning. These include lectures, small group tutorials, interviews, role-plays and interaction with patients, particularly for learning clinical assessment, communication and relationship building skills or bedside learning under the supervision of a multi-disciplinary team. It is expected from students to keep personal learning journals during their palliative care clinical placements, where they draw on their experiences to illustrate and enrich case-based learning as a successful teaching method. Documenting reflective learning in a journal is an effective teaching and learning method. Students must be given the time and space to think about, and document what they are learning. It is a privilege as a palliative care social work teacher, to read these intimate and insightful reports. Student support and debriefing groups also remain an effective teaching and learning method. Palliative care education and training in Africa has developed from small beginnings (Wee & Hughes, 2007).

In Namibia, palliative care social work education and training is now a formal part of the undergraduate social work training accredited by the Health Professions Council and the Namibian Qualifications Authority in Namibia. However, affordable palliative care social work textbooks in an African context remain a challenge. Most of the resource centres only have key texts such as the *Oxford Textbook of Palliative Social Work*.

Further developments have included recognition and support from the national government to provide palliative care training to social workers within the hospitals and clinics in Namibia (MHSS, 2009) as this will improve the access for patient and families facing the diagnosis of a life-limiting illness. Harding et al. (2013), highlight that improving cancer care is in part dependent upon research evidence. In order to improve palliative care provision in Africa, there is a need to make palliative care knowledge accessible to all service providers, as well as educators. This research journey therefore uses the narratives and memos from the participants in this study to create a context in which the participants will be able to voice their personal experiences of how education and training in palliative care influences their competencies providing palliative care.

2.10 THE RELEVANCE AND APPLICABILITY OF SYMBOLIC INTERACTIONISM IN THE STUDY

The literature review includes a few empirical studies on the application of symbolic interactionism in palliative care. This gap represents an opportunity for my study to apply a symbolic interactionist perspective, which examines the social workers' perceptions of their roles in providing palliative care. Symbolic interactionism relates closely to the value system and mission of the social work profession and discipline. This qualitative study is guided in its theoretical underpinning by the symbolic interactionist sociological perspective developed in the 1960's by Dewey, Mead and Blumer (Blumer, 1969).

According to Mendieta (2015:38) *“symbolic interactionism provides a methodology that connects language to action as individuals communicate verbally and then take action. Language and action in the provision of palliative care by social workers in the primary care settings provide data that can be captured by face-to-face interviews and recorded interviews”*.

As mentioned in this chapter, the three tenets of Blumer’s (1969:2) symbolic interactionism suggest that:

- *“human beings act towards things on the basis of the meanings that those things have for them personally*
- *meaning is derived from, or arises out of social interaction and*
- *meanings are modified through an interpretative process and therefore meaning is created from each new experience”*.

Table 2.1 below explains the central tenets of symbolic interactionism. This was preferred to a detailed discussion here in order to highlight the most relevant aspects for this study and in the interest of brevity where a less detailed literature review is preferable to this qualitative grounded theory approach.

Table2.1: The four central components of Symbolic Interactionism (adapted Blumer, 1969)

PEOPLE – individuals and collectively respond to the meaning they attach to objects that make up their world	PROCESS – people are making signs to each other and interpreting each other’s actions
SOCIAL ACTS – individually or collectively they construct a process in response to a given situation which is confronting them	COMPLEX INTERLINKAGES – the constant movement and dynamic nature of organizations, institutions and networks

Blumer (1969) states that the interaction between individuals inform meaning according to a specific situation and that meaning is interpreted within the minds of the participants, which results through social interaction and it is the outcome of an interpretive process.

He states that the *“interpretive process requires that the individual communicates with himself and it is during this communication that the individual selects, checks, suspends, regroupes and transforms the meanings in the light of the situation in which he is placed and the direction of his action”* (Blumer, 1969:5). In the context of this study, interpretation was not the result of selecting predefined meanings but the result of a formative process where meaning undergoes use and constant comparison and revision as explained in chapter 3 of this thesis (Mendieta, 2015). Analysis of the action taken by the participants in this study in their roles as social workers providing palliative care, (Blumer, 1969), shed light on their perceived roles, on the conditions that hinder or strengthen their roles and insight into how social work education and training influenced their capabilities and competencies to deliver palliative care. Symbolic interactionism allows the opportunity to draw out meaning from the verbal exchanges and actions taken between the actors as they occupy temporal roles. According to Chenitz and Swanson (1986), the hierarchal nature of symbolic interactionism refers to as a useful framework for the purpose of research:

- Micro – understanding individual behavior and interactions
- Macro – understanding the context, setting and conditions across a full range of variations
- MACRO- shared meaning between groups and societies in order to understand the interpretation of self.

Charmaz (2006) further explains that people do not robotically react to stimuli, but they respond in a careful way, indicative of the situation they face with, thus meaning arises out of and influences actions. The emphasis is on the lived experiences of the individual and their interpretation of the world around them (Jeon, 2004). The language used in communication is often constructed through symbols and objects which have significance and meaning in interactions and interpretations derived from previous experience. This all contributes to the development of the person’s individual identity (Carlson, 2013). Interaction within the world in which we live would not be possible without a form of language, which can be multi-faceted (Corbin, 2003).

The aim of palliative care social work is to improve the quality of life of patients diagnosed with a life-limiting illness and to enrich society through orienting and empowering individuals and communities toward societal changes and new life styles. Social work is a profession and discipline that sees individuals and society supplementing and complementing each other and believes in complex, positive interactions of individuals and communities in solving human problems. From a symbolic interactionist position, while trying to understand the patient in the context of his or her ecology, different approaches should be utilized as well, because different theoretical approaches help us realize and appreciate different realities. In this study, I consider symbolic interactionism as the most applicable theoretical framework as there was an interest to examine from the perspectives of the social workers' their roles in providing palliative care. The study considers symbolic interactionism in investigating the conditions, which hinder or strengthen their abilities to provide this care and how social work education and training influence their competencies in the provision of palliative care.

The research exploration centered on the participants' (as well as my own) interpretations of events and the meaning attached to them which were influenced by their lives and previous experiences. This study was set at a micro level, as it could only be generalizable to a specific population, although the contextual nature was relevant to the cohort of social workers in different care settings. My comprehension of symbolic interactionism and the individual's meaning of 'self' assisted me in understanding and analyzing the data. My study did not only present the tenets of symbolic interactionism, but establishes a theoretical foundation for pursuing further research to better understand how social workers in close collaboration with other healthcare professionals in the multi-disciplinary team affect the outcomes of the patients in their care. An approach based on symbolic interactionist will make social work practice more powerful.

In extending the literature review, I acknowledge the different theoretical perspectives such as, Ecological Systems Perspective by Bronfenbrenner (1994), *Theory On Death and Dying* by Kubler-Ross (1969/2008) which is briefly discussed in the section below.

2.10.1 Ecological Systems Perspective

The ecological perspective by Bronfenbrenner (1994) links individuals to their environment on the ground that “*human behaviour is to be understood within the social environment in which the behaviour takes place*” (Norlin, Chess, Dale & Smith, 2003: 36). This perspective views the individual and his or her environments as forming an ecosystem, which consists of the individual, all the systems with which the individual has reciprocal relationships, the wider environment in which the individual acts, and all the mutual interrelationships that occur between the individual and the various subsystems (Weiss-Gal, 2008:65). The ecological perspective is centre on the transactions of the person-in-environment, including the person’s ability to adapt to and cope with their environment (Zastrow & Kirst-Ashman, 2004). Those transactions occur at four levels, the microsystem, mesosystem, ecosystem, and macro system (Bronfenbrenner, 1994). As I examined the roles of the social worker in the provision of palliative care, it was important to understand how the social workers perceived their roles in providing palliative care to patients within their ecosystem, which is the hospital and their interactions with patients, families, and the multi-disciplinary health care team. It was important to examine social workers’ understanding of palliative care and what factors have influenced their ability provide palliative care. The study also investigated factors that strengthened social workers’ abilities to deliver palliative care. It sought to gain insight into how education and training influenced social workers’ competencies in delivering palliative care. It was important for this study to consider “*the centrality of understanding people as they relate to their environment, and the reciprocal relationship of people to their environment*” (Beder, 2006: 4), which are integral to palliative care social work practice. Each person is a microsystem, interacting interpersonally with other microsystems (Bronfenbrenner, 1994). In the hospital environment, the social worker interacts with other microsystems that are the patients, families, and the multi-disciplinary team members.

The social workers bring their own experiences, education and training to those interactions. As a result, it is important to understand the perceptions of social workers regarding their role providing palliative care. Specifically, to understand what they do value in their role and what experiences have shaped their ability to perform that role. In addition, it is important for the social worker to understand that each person brings his or her own perspective and experience, which shapes how they behave and react in providing palliative care. People have internal resources, which are the psychological components that aid the person in their transactions with the environment (Germain, 1981). A person's age, sex, culture, physical condition, emotional state and prior experience influence their perceptions (Germain, 1981). Patients and families react differently than medically trained staff, because they do not have the experience and knowledge of medical terminology and diagnoses that is common to nurses and physicians. Social workers need to be aware of that difference and guide the patients and families as they make healthcare decisions, as well as to educate the other healthcare professionals on the views and perceptions of the patient and the family.

The mesosystem is the interaction between a microsystem and a larger unit, such as the multi-disciplinary team and the family (Broffebrenner, 1994). In this regard, it is important to understand how social workers identify with the team and the family, the communication patterns between the two, and the role of the palliative care social worker as a member of the multi-disciplinary team and working with the family. In addition, it is important to understand how the social worker interacts with the family unit.

The exosystem includes the interaction between the microsystem and the organisation, such as the hospital (Broffebrenner, 1994). The hospital may dictate the size and composition of the social worker's caseload therefore it is critical to examine the influence and attitude of the organization towards the palliative care social worker (Roer-Strier & Rosenthal, 2001). One "*can consider the institution not, only as an entity in and of itself, but also a business of all the individuals and groups that comprise it*" (Higgins, 2001: 35).

Lastly, the macro system is the interaction between the microsystem and the broader cultural, economic, and historical context (Broffebrenner, 1994). It is *“the influence of history, values, laws and regulations, aspects of social policy, and customs from the culture of origin and from the host culture”* (Roer-Strier & Rosenthal, 2001: 218). Social workers providing palliative care must have a broader understanding of how society looks at end-of-life. *“Every society and faith system has developed some way of integrating the reality of end-of-life into their belief systems and ways of life”*. (Silverman, 2004: 128) and it is important for the palliative care social worker to be aware of differences in beliefs on end-of-life. Individuals are part of a community and a social network. In that community, power, privilege, and common beliefs influence individual values (Ungar, 2002). The community influences the physical and social environments through cultural norms, values, beliefs, knowledge and technology (Gitterman & Germain, 1976). As people develop and evolve, the person adapts to both their physical and social environment (Germain, 1981). The unwritten rules of society are not absent in the healthcare settings. Rather, societal norms influence how care is provided and which choices patients, families, and health care providers ultimately make. Often social workers are face with guiding families through the decision of when to provide or not provide aggressive care at a patient’s end-of-life. Social workers must work to determine what society is pressuring someone to do versus what the needs and wants of the patient truly are, as patients, families, and medical practitioners make choices for care in socially charged medical conditions. Social workers must work to mediate between the patient’s right to self-determination and the medical team’s belief of the proper treatment for the patient. The social worker acts as an educator to the patient and staff, a facilitator during the meetings and conversations about potential treatment options, and an advocate for the patient. The purpose of palliative care social work is to help foster healthy and independent transactions between individuals and their environment (Ungar, 2002).

The symbolic interactionism method aligns with the approach adopted in this research. The theoretical frame recognizes the researcher’s active role in shaping data and analysis and the constraints that historical, social and situational conditions impose upon actions. Grounded theory methods become generalized, reconstructed and contested, and as Charmaz has acknowledged, can be use in flexible ways.

The flexibility of these methods allowed for multiple perspectives to be explored, alternative interpretations generated and the analysis of these within the context of broader structures. The result was a critical understanding rather than a simple description of the experience.

2.10.2 Theory on *Death and Dying* by Kubler-Ross

Kübler-Ross in 1969 developed a Theory on *Death and Dying* (Kübler-Ross, 1969/2008). According to Phillips, Ajrouch & Hillcoat-Nalletamby (2010), Kübler-Ross experienced a lot of resistance from the health professionals when she started her work, which set out to listen to the dying, which indicated the degree to which death and dying was a taboo topic to discuss from health professionals point of view. It was not strange to experience such resistance, because health professionals were not train to deal with dying patients beyond the clinical needs, and them simultaneously having to confront their own mortality. Phillips, Ajrouch & Hillcoat-Nalletamby (2010), state that because of the fact that HCPs were not trained beyond dealing with the clinical needs, the emotional and spiritual needs of the those who were about to take the retiring step from life to death were being ignored. After extensive interviews with end-of-life patients, Kubler-Ross (1969/2008) identified the five stages of grief: denial, anger, bargaining, depression and acceptance. These five steps have helped HCPs in their respective fields today to attain a level of understanding when working with the dying and their families, which also contributes to their competencies in being more able to assess and provide psycho-social and spiritual support. The Theory on *Death and Dying* (Kübler-Ross, 1969/2008) challenged the earlier notion that end-of-life care takes place only during the last few weeks of life.

According to the researchers (Phillips, Ajrouch & Hillcoat-Nalletamby, 2010:163) “*end-of-life model has emerged, where supportive measures are offered from the point of diagnosis rather than at the point of decline*”. The end-of-life model acknowledges the individuality of each patient, and factors such as the nature of the condition, living arrangements, social circumstances, psychological well-being, cultural matters and spiritual beliefs (Department of Health, 2008).

2.11 SUMMARY

An initial literature review was conducted in order to review the existing literature prior to the final decision regarding the broad research questions and areas of interest. A subsequent literature review was conducted as the theory began to emerge and be constructed. A wide range of articles and books were reviewed, key words and phrases adopted. Literature on palliative care social work was examined to ensure adequate breadth and depth to the literature review. The researcher's existing knowledge, experiences and the information from the early literature review was combined to create the aim of the study and the research questions. This chapter argues that a primary task for contemporary social work is to assign appropriate value and meaning in optimising the multi-dimensional roles of the social worker in the provision of palliative care. This is the only way to make palliative care social work *real* in the lives of the patients with life-limiting illnesses in the primary care settings. Social work is well positioned to help develop palliative care provision in Namibia. The social work profession is well placed to draw upon its values, culture and experience and to get involved in developing models of palliative care and create a constructivist grounded theory of the social workers' roles in providing palliative care.

The evolution of palliative care social work can be strengthened and taken to the next level by creating a constructivist grounded theory of the social workers' roles in providing palliative care. Symbolic interaction among patients with life-limiting illnesses, their families, the multi-disciplinary team, managers and hospital administrators can be strengthened and taken to the next level in order to optimize the roles of social workers to better serve these patients and their families. The use of a grounded theory approach and symbolic interactionism framework can start moving palliative care social work research from reporting statistics and costs to advancing theoretical understanding and theory evolution. Symbolic interactionism provides a methodology that connects meaning, interaction and interpretation to the roles and actions, which individuals take while fulfilling the responsibilities of the roles they are occupying.

This study therefore challenges the social work profession in Namibia, and beyond in considering whether the roles of the social workers in the multi-disciplinary team in providing palliative care is optimize and whether this needs to be re-thought. It investigates conditions that hinder or strengthen social workers' abilities to provide palliative care to patients with life-limiting illnesses. It looks at the benefits of palliative care social work education and training that contribute to social workers' competencies in the provision of palliative care.

A critical literature review allowed me to gain a broader understanding of the roles of the palliative care social worker from an individual social worker's perspective, exploring how social workers perceive their roles in providing palliative care and what conditions hinder or strengthen their abilities in that role. The study envisages informing the reader on what changes are needed with an effort to enhance palliative care social work practices and training. In doing this, I wish to achieve a detailed exploration of how the Namibian social work education and training influence social workers' roles and competencies in providing palliative care to patients with life-limiting illnesses. This is important in order to create new spaces for deeper insight of what is palliative care, the importance thereof and understanding the roles of the social workers in the provision of palliative care. The study wishes to determine whether social work training is preparing social workers for their roles in providing palliative care. The study will observe and relate how social workers fulfil these roles in their interactions with the patients, the family members as well as with members of the multi-disciplinary team, but from the point of view of the social worker.

In doing this, the research provides a detailed exploration of how twenty regional social workers perceive their role to be in providing palliative care to patients with life-limiting illnesses in order to add to existing knowledge. This exploration will connect what social workers are doing to what they could be doing in providing palliative care that aims to improve the quality of life of patients with life-limiting illnesses. This is achieved by using broad questions, in-depth interviews with a purposive sample of social workers.

In my application of the symbolic interactionist framework in this study, I demonstrate and acknowledge that researchers co-create grounded theories, to be use to advance its contributions to qualitative studies and numerous academic arenas.

CHAPTER 3: THE RESEARCH METHODOLOGY

3.1 INTRODUCTION

In the preceding chapter, I reviewed literature concerning social workers' perceptions of their roles in providing palliative care to patients with life-limiting illnesses and discussed the symbolic interactionism perspective as the theoretical framework applicable to this study. In this chapter, I provide an overview and rationale of adopting the qualitative research methodology. In addition, I describe how the study was executed and the chapter gives a concise description of the grounded theory method based on the early work of Glaser and Strauss (1967), and subsequent works of Glaser (1967 & 1998); Strauss and Corbin (1990) and Charmaz (2002, 2006 & 2009). This chapter discusses the research design and sampling procedure and the data collection methods with attention place on qualitative field interviews. It discusses ethical considerations where ethical principles and protocols are adhered throughout the study. The last part of the chapter concludes with a reflection on the role and position of the researcher.

3.2 APPLYING GROUNDED THEORY

The study embraced grounded theory as a qualitative method examining social workers' perceptions of their roles providing palliative care to patients with life-limiting illnesses. The grounded theory methodology was applied to place my study in an appropriate theoretical context. Grounded theory aims to generate theory from face-to-face field interviews (in this study) on real life experiences (inductive theory) as they are occurring in a given situation. In grounded theory studies there are no existing hypothesis and it is considered a dynamic process which aims to make sense and attach meaning to human relationships (Charmaz, 2006; Corbin & Strauss, 2008; Hallberg, 2006; Birks & Mills, 2011). These meanings may be through symbolic interaction (interactions happen between individuals) and is influence by personal knowledge, experience and external factors (Cowley, 1991).

Grounded theory is concerned with the ‘pragmatic application of results’ (of research) as opposed to the absolute ‘truth’ as this may not exist (Annells, 1996). Grounded theory permits the gathering of rich data and allows initial analysis, which guides further data collection and allows flexibility (Strauss & Corbin, 2008). Both the initial and later review of literature aim to answer the main research question that seeks to investigate: How do social workers in primary care settings in Namibia perceive their roles in providing palliative care to patients with life-limiting illnesses? The literature review was guided by the following related sub-questions, namely: How do social workers understand palliative care? What conditions hinder social workers’ abilities to provide palliative care to patients with life-limiting illnesses? What conditions strengthen social workers’ abilities to deliver palliative care to patients with life-limiting illnesses? How does social work education and training in palliative care contribute to social workers’ competency in the provision of palliative care to patients with life-limiting illnesses? The study applied the grounded theory methodology, as it gives credit to qualitative research approaches for gaining deeper insights and generating theory on social workers’ perceptions (Goulding, 2005).

3.2.1 The origins of grounded theory

Marshall and Rossan (2010) refer to the grounded theory method “*as an interactive enquiry process between the researcher and the participants. It values participants’ perspectives and is primarily descriptive and reliant on people’s words*”. The grounded theory (GT) approach is based on the early work of sociologists Glaser and Strauss (1967), who became the original founders of grounded theory when they promoted the concept of qualitative approach to research and the subsequent works of Glaser (1978 & 1998). In grounded theory, Glaser (1979) had a strong qualitative background and Strauss (1990), brought the perspective of symbolic interactionism (a sense of self through interaction with others and through shared experiences and creative meanings that influence collective behaviour) (Strauss & Corbin, 1990). They (Glaser and Strauss, 1967) maintained that the systematic collection and analysis of data could lead to robust generation of theory which was ‘grounded’ in data (Cooney, 2010), thus making it more applicable to reality. However, Glaser and Strauss later parted ways and developed two opposing views of GT.

Research revealed (Glaser, 1992; Strauss & Corbin, 1998) conflicting views on Glaser and Strauss' development of grounded theory where after Strauss formed a new allegiance with Corbin, whilst Glaser continued to protect the original grounded theory tenets maintaining that Strauss was 'forcing the data' and was no longer true to grounded theory. According to Kelle (2005), Glaser argued researchers could form a grounded theory using emerging ad hoc themes. Kelle (2005) further stated that Corbin and Strauss then introduced a coding paradigm to help researchers organize the data from which Glaser argued that Corbin and Strauss' approach "forced" themes to emerge. However, contemporary versions of grounded theory began to emerge, most prominently that of Charmaz (1983 and 2006), which suggests that flexibility in using different approaches to grounded theory is enormously beneficial (Birks & Mills, 2011). This flexibility enabled me as the researcher to consider all approaches by exploring underlying principles, processes and analytical methods of grounded theory and it led to determining which would be the most applicable for my study.

3.2.2 *Constructivist grounded theory*

Charmaz (2002) defines grounded theory "*as a qualitative method of which the purpose is to generate theory that advances the understanding of people's behaviour in terms of underlying meaning and change in varying circumstances and over time*". According to Charmaz (2002), grounded theory by its method and intent is to generate theory directly related to the data from which it has been developed. According to Hall, Griffiths and McKenna (2013), constructivist grounded theory (CGT) makes provision for the possibility to consider multiple meanings and understandings of reality which is influenced by many contextual factors and constantly redefined through interaction with others (Fisher & O'Connor, 2012). It embraces an emic (insider) stance, which merges with the researcher's personal understanding and input, as well as providing an interactive approach to data collection and analysis (Charmaz, 2006). This suggests that the researcher is a 'co-producer' of the research which can add depth and meaning to the process (Mills *et al.*, 2006a & 2006b). It proposes that the researcher needs to be able to enter the participants' world and discover how they interpret their perceptions and experiences, thus focussing on their lived experiences (Jeon, 2004).

Constructivist grounded theory will thus be the most applicable approach for this study, because, as the researcher, I will embrace an emic stance in being “*the primary instrument of data collection and analysis*” (Merriam, 2009: 29), on social workers’ perceptions of their role in providing palliative care to patients with life-limiting illnesses. The study “*assumes an inductive (as opposed to a deductive) stance and strives to derive meaning from the data*” (Merriam, 2009: 29), that is generated and ‘co-produced’ by me as the researcher. Social work and grounded theory focus on the interactions of individual and society. I was hoping that using the constructivist approach could provide a constructivist grounded theory about how social workers navigate their role in palliative care, and that it can be test in social work practice. Developing such a theory can be used to guide social work practitioners.

3.2.3 Rationale for choosing constructivist grounded theory

In this study, I chose to apply the constructivist approach to grounded theory. This allowed me situate myself within the research and form a part of the understanding from my own perceptions and experiences, which would create meaning between me, as the researcher and the participants. My study is in line with Charmaz’ (2006), discoveries which is concerned with beginning the research journey by identifying the ‘constructs’ which make up the meaning, (as opposed to ‘facts’) and building on these as the data collection progresses (Charmaz, 2006). The reality of palliative care social work practice, education and training mean that constructivist grounded theory and its tenets suit the main research question, its subsequent questions, the research design and permits self-disclosure, contrary to a detachment that may cause the participants to avoid open conversations (Wilde, 1992). This study was concerned with examining social workers’ perceptions of their role in providing palliative care to patients with life-limiting illnesses and it was able to explain and interpret the participants’ perceptions and experiences as opposed to merely describing them (Baker *et al.*, 1992). The aim was to develop a deeper understanding and insight of those experiences and then inductively create a theory, which can be utilising to optimise the role of the social worker. This led to constructivist grounded theory being the choice for this study.

3.3 THE CHOSEN RESEARCH DESIGN

This study adopts a qualitative research design because the nature of the research problem and the stated objectives demand an idiographic, case-based approach (Denzin & Lincoln, 2003: 28). My ontological stance in this study is constructivist, thus agreeing there can be various interpretations and not just one reality, all of which are influenced by context, in this case the participants' perceptions and experiences (Charmaz, 2009) of their roles in providing palliative care to patients with life-limiting illnesses. It is imperative that understanding of the social workers' perceived roles in providing palliative care is considered by forging strong links with the data and context and that the honesty of participants' perspectives, opinions and experiences are respected and presumed valid. My study sits within my worldview of a naturalistic and constructivist paradigm, where research is undertaken in natural settings and human experience is examined and meaning extracted (Mills *et al.*, 2006a & 2006b). A constructivist paradigm assumes that "*theories grounded in data are interpretative explorations (lived experiences) of the area explored, but do not provide a precise and accurate picture*" (Charmaz, 2006: 10). This paradigm would enable me as the researcher to gain a better understanding of social workers' perceptions and lived experiences of their roles because it seeks to build on theory, explore this phenomenon and yield in-depth meaningful information. At the time of this study, there was a lack of knowledge and research in the area of social work practice within the Namibian context. In particular, examining how social workers perceive their roles, conditions that hinder or strengthen their abilities to deliver palliative care and how social work education and training influence their competencies to deliver care.

The study did not begin with a hypothesis about the phenomenon to be studied (as in quantitative, theory testing research), but applied an inductive approach or theory-building research method. The study was exploratory in nature and was guided by loose and broad research questions with no limiting hypothesis. It instead remained open to emerging theory (through the induction process) from the generated data (Glaser & Strauss, 1967 and Straus & Corbin, 1990). In this study, I hold a subjective, interpretivist stance, where knowledge is not 'discovered', but constructed and then interpreted through many lenses (Hall *et al.*, 2013) and my active involvement in this

process is inevitable and necessary (Mills *et al.*, 2006a & 2006b). I was aware of the fact that I had some existing knowledge on palliative care and life-limiting illnesses and therefore felt it important not to disconnect that from the process of learning through research. It was important for me to acknowledge and embrace what I am bringing to the research and how I might influence it (Licqurish & Seibold, 2011). It felt inappropriate to attempt to “bracket off” my knowledge, thoughts and experience. I instead in following research protocol, openly acknowledged my experiences in the research process and considered how it would enhance what was learn from the participants. This lends itself well to the grounded theory approach. My experiences in practicing and teaching social work led to the initial notion that palliative care social work can be a beneficial intervention for both the patient and the family. Therefore, a study with the aim to examine the perspectives of social workers’ roles in providing palliative care to patients with life-limiting illnesses thought to be an appropriate avenue of exploration. The study happened in the following six social work offices; namely Katutura and Windhoek Central hospitals, the Oshakati social work office, Gobabis; Swakopmund and Keetmanshoop social work offices, respectively. The research methodology was guide by the aims and objectives of the study.

3.4 METHODOLOGICAL FRAMEWORK

I utilized grounded theory as a qualitative research approach in order to gain an in-depth understanding of how twenty (20) social workers perceived their roles in providing palliative care to patients with life-limiting illnesses. According to Lietz *et al.*, (2006: 445) qualitative research design offers the opportunity to seek an in-depth understanding of complex experiences. Denzin and Lincoln (2003) note that because qualitative researchers seek answers to questions that stress how social experiences create and given meaning, this type of research is value-laden. In order to obtain detailed, varied and extensive data in this study, I kept the interview conversation open and let the participants lead (Glaser, 1998). This accomplish by using in-depth, face-to-face and open-ended interviews. The intention was also to reveal conditions that hinder or strengthen social workers’ abilities to provide palliative care. The in-depth, face-to-face interviews used to examine the ways in which social work education and training in palliative care contributes to social workers’ competencies in providing this care.

The insights from this would form a backdrop to further uncovering aspects of social work education and training within this specialised care. Data-gathering used a narrative approach in which a sample of twenty (20) social workers who volunteered were asked to narrate their experiences and, hence, describe their perceptions of their roles of providing palliative care. The study intended to investigate how social workers perceive their roles and the specialised treatment of providing palliative care to patients with life-limiting illnesses. Interviews were tape recorded with prior consent from the participants. The narrative nature of the interviews made accurate transcription very important. I preferred to transcribe each of the tape-recorded interviews manually to gain a richness of detail as it emerged from the collected data.

During and after the interviews, I kept memoranda by recording field notes about the reactions, and observations of both the participants and the interviewer. The memos assisted me in analysing the field notes line by line to identify key issues applying traditional grounded theory coding techniques, as outlined by Strauss (1987) and Strauss and Corbin (1990), which identify human action and behaviours. An interpretative field of inquiry locates me as the researcher in the world I am exploring (Denzin & Lincoln, 2000), and lends itself well to generating theory, thus following inductive reasoning (Bryman, 2008).

Inductive reasoning: Observation Pattern Tentative / Emerging Theory

This qualitative study is concerned with service providers' view on health care delivery and services, which informed policy at local and national levels. My study sits within the qualitative methodology and it aims to examine and interpret social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses and encourages theory development. I was actively involved in the entire research process (i.e. data collection, analysis, interpretation and theory generation). In addition, embracing an interactive relationship was vital in producing a transparent understanding and account of the perceptions, experience and emerging theory (Carr, 1994).

3.5 ACCESS, NEGOTIATION AND SAMPLING TECHNIQUES

The actual processes of preparation, negotiation, permission and access to conduct research with twenty social workers based at six primary care hospitals in Namibia are discussed below:

3.5.1 Preparation and negotiation to conduct the study

Preparation and negotiation for fieldwork (data collection) took place over five months from January to May 2016. Hospital-based social workers were invited via the regional chief social workers in Namibia, in the Karas region (Keetmanshoop); the Omaheke region (Gobabis) the Khomas region (Windhoek) the Erongo region and the Oshana region (Oshakati) to voluntarily partake in the interviews. Information about the research and the implementation process was included in an electronic letter accompanied by a broad set of questions e-mailed to prospective participants. Individual follow-up telephone calls allowed the social workers to express whether they were interested in taking part in the research. A participant information sheet was use (Appendix 2). I received twenty forms. The overall selection was on geographical location and a mix of work settings in an endeavour to ensure that the sampling population was as diverse as possible to add to the meaningfulness of perceptions in the Namibian context. Appointments were made for the first round of interviews, based on geographical proximity and twenty interviews were held between May and July 2016.

3.5.2 Permission to conduct the research

Permission was obtain from the following institutions and persons in order to conduct research with the respective social workers; the University of South Africa (UNISA), Department of Sociology Ethics Committee, the Research Ethics Committee of the Ministry of Health and Social Services in Namibia, and the regional Chief Social Workers in Namibia.

3.5.3 Sampling

Purposive non-probability sampling was used which resulted in twenty in-depth, face-to-face interviews. For the purpose of this explorative study, volunteer social workers were accepted based on their geographical location to participate (i.e. all of who was approach). The sample exhibited the following characteristics: 1) aged between 25 and 50+ years old, 2) full time employed as social workers and 3) each had a minimum of 2 years of work experience as social workers. The inclusion criteria included qualified social workers who had two plus years of work experience. During the recruitment process, social workers younger than 25 years did not meet the inclusion criteria of two years of work experience. The study could have benefitted from interviewing social work educators at the University of Namibia under objective five of this study, however the primary aim at the outset of the study was to explore social workers' perspectives of their roles in providing palliative care and to investigate how social work education and training contribute to their competencies in delivering palliative care from the perspectives and views of the social workers, and not from social work educators. The study therefore did not include the social work educators. In addition, the study deliberately also did not interview key informants on the multi-disciplinary team, such as nurses and doctors, because it primarily focussed on the social workers' perceptions of their role in providing palliative care from their view. The inclusion of both the social work educators as well as key informants might have altered the construction of the emergent, grounded theory.

The sample based on their geographical location provided diverse social workers in order to add depth and variation to the meaning of the phenomenon of palliative care provision to patients with life-limiting illnesses. As opposed to random or convenience sampling Wengraf (2001) suggests purposeful sampling of selecting participants which is for interpretive research studies. The participants interviewed represent diverse ethnic backgrounds and geographical locations in Namibia including Katutura and Windhoek Central Hospital (central Namibia), Oshakati (northern Namibia) social work office, Gobabis (eastern Namibia) social work office, Swakopmund (western Namibia) social work office and the Keetmanshoop (southern Namibia) social work office. Each of the participants was treating with anonymity and each given a pseudonym.

3.6 DATA COLLECTION AND ANALYSIS

In grounded theory, data collection and analysis are conducted interchangeably, but in tandem and this process is referred to as theoretical sampling. The theoretical sampling process was applied throughout this study. Theoretical sampling according to Strauss and Corbin (1998: 202) “*is a process of searching for concepts relating to ‘incidents, events or happenings’ which appear frequently and which influence outcomes*”. This can happen over a period of time whilst building codes. In this study I began creating codes and later refined those codes to contribute towards theory building. In order to ensure the codes were an appropriate fit for my data, I sent the transcripts and the codes to the participants of the study whereby I requested their input as to the validity of the codes and to comment on the codes. Finally, after receiving input from the research participants, the coding was also conducted with NVIVO 10 software.

3.6.1 Data Collection Procedures

The primary data collection method used in this study was in-depth, face-to-face interviews (see Appendix 3 for Interview Guide on broad research questions). Yin (2014: 110) reiterates “... interviews will resemble guided conversations rather than structured queries”. In addition, in-depth interviews cater for privacy between the researcher and the research participant.

3.6.1.1 In-depth face-to-face qualitative interviews

Twenty qualitative interviews were conducted with participants (social workers). According to Warren and Karner (2010:2) qualitative interviewing involves present-time, face-to-face interaction. I used face-to-face interviews as a primary data collection technique for this study. It followed an unstructured format. Interviews were allowed to flow naturally based on information obtained from the participants. The in-depth interviews were conducted on a dyad basis (one interviewer and one respondent), ascribed by Warren and Karner (2010: 2). This enabled me to focus entirely on one participant at a time. I kept the interview conversation open and guided by the participant as suggested by Glaser (1967). The participants were given complete freedom to build a narrative from their experiences (Patton, 1990 & Riessman, 1993).

Hospital based social workers have hectic work schedules, making it difficult for them to leave their offices for extended periods. All interviews therefore were conducted in their offices at their requests and in English. Before and during the first interview, I gave each participant the informed consent form to read in an English translation (see Appendix 2). I guided them through the informed consent agreement until all the important issues were explored. After the participants reviewed it, I asked them to sign the informed consent agreement in duplicate form. Upon signing, each participant received a copy of the agreement and I kept a copy. The first interview included demographic background information and lasted between twenty (20) to thirty (30) minutes. Given the fact that the hospital-based social workers were also involved in another national survey on suicide in Namibia, they requested both the first and second interviews to happen on the same day. Agreeing to their request, both interviews were conducted on the same day with a five-minute break between the first and second interviews. To be able to provide descriptive illustrations of concepts that would arise, I in agreement with the participants tape-recorded the second interview. During the second interview, I asked the participants to provide pseudonyms for themselves and significant others. The pseudonyms were used in all communications and documents related to the study. I conducted, transcribed and reviewed all interviews myself. Upon completion of both interviews, email and telephone consultations took place where I applied member checks in order to verify with the participants and to allow them to comment. The participants did not give any comments.

3.6.2 Data Analysis and Interpretation

The study used the grounded theory approach of constant comparative analysis. According to Strauss and Corbin (1990), constant comparative analysis requires the researcher to move in and out of the data collection and the analysis process. I began the constant comparative process with the main research question exploring social workers' perceptions of their roles in the provision of palliative care to patients with life-limiting illnesses. The main research question was supported by a series of related sub-questions originating from the conversations and designed to lead to the development or generation of a theory. These questions examined social workers' understanding of palliative care.

It investigated conditions that might hinder or strengthen social workers' abilities to deliver palliative care to patients with life-limiting illnesses. It also explored how social work education and training contribute to social worker's competencies in the provision of palliative care. The intention is not to discover the theory, but a theory that leads to the understanding of the area under investigation (Heath and Cowley, 2004). Analysis was a repetitive process, which swung backwards and forwards through the data. I continued with thematic analysis on the data, which focuses on identifiable themes and patterns. It was a continuous movement, back and forward between the emerging codes and the process of making comparisons with the data (Charmaz, 2006). This provided further verification that the developing categories were truly grounded in the data (Bryant & Charmaz, 2007), which allowed me to make sense of, and analyse the new ideas (Charmaz, 2006). The repetitive process revealed the full complexity of the data and was not consider complete until all themes had been determined and the final theory made explicit.

I developed themes that emerged from the data collected (e.g. narratives, verbatim quotes and descriptions) to develop questions for the next round of data collection. The development of these themes produced concepts as explained in the grounded theory approach (Corbin & Strauss, 2008). This study applied the comparative process of open, axial and selective coding. I coded the interviews into themes and sub-themes, using inductive coding which relied on "*themes emerging from participants' conversations*" (Fereday & Muir-Cochrane, 2006), and then finally connected the data to the existing literature to support the argument for those themes. I integrated all concepts and connections in the process of developing a narrative of the grounded theory. The data was analysed and interpreted by applying a generalised inductive approach for qualitative data analysis. This was done until no new themes emerged and the research reached saturation (Corbin & Strauss, 2008). Thematic analysis afforded me the opportunity to connect the themes in current social work practices of palliative care in Namibia to the literature, discovering what methods of practice are not being utilized in the field and why.

3.7 ISSUES OF TRANSFERABILITY

Krefting (1991) and Lincoln and Guba (1985), define transferability in qualitative research as parallel to external validity in quantitative research. Transferability of this study was achieved through the preparation of detailed descriptions that will allow the persons evaluating or using this study to make judgements (Krefting, 1991; Lincoln & Guba, 1985). In order to enhance the transferability of the findings, I provided background information of the participants as well as the context of the study, Namibia, for future researchers (Krefting, 1991). The transferability of the data is evaluated in terms of the meaningfulness of the findings. Rolfe (2006) declares:

“quality judgements entail a subjective ‘reading’ of the research text and the responsibility for appraising research lies with the reader rather than with the writer of the report, with the consumer of the research rather than with the researchers themselves. This does not preclude the researchers from appraising the quality of their own work, but rather suggests that the readings of the researchers carry no more authority than those of the consumers of that research” (Rolfe, 2006: 309).

3.8 REFLECTION ON THE ROLE AND POSITION OF THE RESEARCHER

My roles as a social worker and social work educator were influential in determining my interest. My position as an academic in social work education and being the instrument in this qualitative study resulted in new ways of thinking and an exciting challenge of teaching in palliative care, which requires different skill sets. Teaching palliative care in the social work curriculum where my passion lies, is dependent on better understanding the roles of the social worker in the provision of palliative care to patients with life-limiting illnesses, the conditions that hinder or strengthen their abilities to provide this care and how social work education and training on palliative care influence their competencies to provide this care.

The holistic approach to care is fundamental in palliative care and this sits well within a constructivist, relativist approach to this study. According to Neuman (2007: 120), “*qualitative researchers are more interested in authenticity than validity. Authenticity means giving a fair, honest and balanced account of social life from the viewpoint of someone who lives it every day*”. Hammersley and Atkinson (1995: 24) state, “*research design should be a reflexive process which operates throughout every stage of a project*”. Qualitative research particularly requires a high level of reflexivity about the phenomenon under study (Darlington & Scott, 2002: 18) due to the “*immersion of the researcher in the research*”. It was crucial for me as the researcher to maintain an open and transparent position during this study. The term 'reflectivity' which refers to the ‘capacity to reflect upon one’s actions and values’ (Arber, 2006), and emerged from the professional practitioner and educational discourse - the process of reflecting upon practice, ensures confidence, scrutiny and credibility in the researcher. 'Reflexivity' comes more from social science researcher discourse, from qualitative and ethnographic researchers. It has, according to Finlay and Gough (2003: ix), 'exploded' into academic consciousness. Reflexivity is an opportunity to reflect systematically on my part as the researcher in the process and the events that are occurring, alongside how that might fit into the bigger research picture. It is seen as developing insight into my work as the researcher and applying a critically analytical approach (Birks & Mills, 2011).

As a social worker and a social work educator, I found it imperative to be reflexive in understanding the perception of the participants from their point of view, not my own. However, the analysis will be my own reflections and analysis. Being reflexive appears to be more complicated than being reflective: not merely searching for implicit theory, but searching for an understanding of the many ways in which one’s own presence and perspective influences the knowledge and actions created around it. In order to eliminate or limit any such biases or subjectivity, reflexive analysis is applied where member checks and thorough detailed descriptions of the participants are provided. Birch (1998), sees research as a journey, particularly in terms of reflexivity and divides the research journey into three phases: “*going there; being there; and, being here*” (Birch, 1998: 162). The ‘*going there*’ phase refers to what is happening before the field of study: preparing for undertaking the research, defining what to study, and gaining access into the field, which I described in this chapter (chapter 3).

The '*being there*' phase relates to being in the field: the actual taking part in the research through data collection. This includes the participation, the involvement, relationships made and presenting the findings. The '*being there*' phase will be address in the next chapter (chapter 4) in presenting the data. The *being here* phase is the last phase in the creation of the text: this is the final stage of data analysis and writing up the thesis, which will be cover in chapter 5. In this context, I use these three phases to share my experiences of my inner dialogue during the research process.

3.8.1 *Going there: Undertaking the research*

I embarked on this research journey after 21 years of a career in social work, together with practical experience in medical social work and five years as a social work educator at tertiary level. I was excited about this new undertaking in my life, determined to do well, but also anxious about proving my capabilities, not only to the academic world, but also to myself. In addition, I had to cope with a role reversal, now I was the student. The first supervision sessions felt strange, but the strangeness soon disappeared and the sessions felt supportive and challenging. Undertaking the initial literature review was done with enthusiasm. As my experience of conducting research was limited, I also read widely about the various methods of conducting qualitative research. At times, all this seemed rather bewildering as I grappled with some of the methodologies, philosophies and concepts, but gradually an understanding emerged.

I was delighted when the regional Chief Social Workers (CSWs) gave me permission to contact the district hospital based social workers who volunteered to participate in the study. However, I felt that I had to prove my capabilities to the social workers since they were granting me the privilege to enter into 'their world'. Being a qualified social worker, I hoped it would be an asset in conducting this research; there could be a shared understanding about the values of social work. Yet, I recognised it might also be a hindrance as it might lead me to make assumptions and introduce bias, and this was something I constantly needed to take into account in my contacts and later during the analysis. From the beginning, I documented my research journey by keeping a personal diary of events and thoughts (Moch, 2000). Memo writing (field notes) assisted me in the formulation, revision and refining of theory generation.

The writing of short notes served as a means to capture my ideas, thoughts and feelings as they occurred (Birks & Mills, 2011). They also aided my reflection and made any assumptions explicit and it stimulated me to challenge the interpretation of the data, which provided a balanced view and assisted in making meaningful linkages between the data and the theory that emerged (Hunter *et al.*, 2011a). This was not only in order to keep an audit trail (Huberman & Miles, 1998) but also to remember and understand the decisions made along the way that might otherwise be lost in memory as other events took over. I saw this as a positive tool (Payne & Payne, 2004). Sometimes, there were no entries for days or weeks on end. However, when a particular difficulty occurred (for example, me being diagnosed with a cancerous tumour in June 2015, the passing away of my mother in July 2015) and momentous events (for example, the approval of my research proposal; gaining approval from the UNISA Ethics Committee to conduct field research and receiving permission from the Ministry of Health and Social Services Research Committee), I took the opportunity to reflect back over the time since the last entry. Events that happened in my personal life (for example the numerous hospitalizations and surgical procedures during June 2015 – February 2017) were also noted and it was interesting to look back and see how these impact on my 'research based self' (Reinharz, 1997). Memo writing and keeping a diary were utilised from the beginning of the study and during the data collection and analysis, which enabled me as the researcher to be reflexive. Keeping a diary was in particular useful for recording the theory generation process, which felt arduous at times.

3.9 ETHICAL CONSIDERATIONS

In the section to follow, ethical principles of confidentiality, care and respect were identify as being vital when interviewing the participants and when processing, analysing and reporting on subsequent data collected. This option fostered a significant level of freedom within the interviews by allowing the participants to share their perceptions and experiences with minimum disruption, and permitted the interviewer to move with the participants throughout the telling of their life stories. I obtained ethical clearance from the Ethical Clearance Committee of University of South (UNISA), as well as approval to conduct the study from the Namibian Ministry of Health and Social Services Research Ethics Committee.

In this research, the ethical principles of confidentiality, voluntary participation, informed consent, avoidance of harm, protection of privacy, and respect as stipulated in UNISA's (2007) *Policy on research ethics* (UNISA, 2007: 21) were especially relevant in the research field of palliative care, due to the traumatic and sensitive nature of the subject material (Heise & Ellsberg, 2005). I pledged to protect the human rights of the participants prior to, during and after the interviews, as enshrined in the Universal Declaration of Human Rights (2004). Article 12 of the Declaration of Human Rights of 2004 is of particular interest to the research as it states that, "*No one shall be subjected to arbitrary interference with his or her privacy, family or home, nor attacks upon his honour and reputation.* In the following subsections, I describe how I protected the human rights of the participants in the study.

3.9.1 Confidentiality and Anonymity

I made every effort to keep the information the participants revealed during the study strictly confidential and anonymous as required by law. I discussed the study with the participants and provided them with a consent document. Any documents the participants signed, where they can be identifying by name, are kept in a locked drawer in my home office. These documents will be kept confidential. Only I had access to the information gathered for the study. The file created for each participant did not contain their names, only pseudonyms were used. All interviews were audio recorded with prior permission of the participants. The recordings had their names removed to ensure that information remained confidential and anonymous. Only I had access to the information with the names and pseudonyms of the participants. All information reviewed by the thesis committee was de-identified and only had a pseudonym attached. In order to protect the privacy of the participants, I ensured that interviews took place at a venue away from the public eye with little chance of disruption. All data (both electronic and hard) will be retained in at my home office for at least 5 years after the conclusion of the study, following which they will be verifiably destroyed.

3.9.2 Voluntary participation and Informed consent

I considered issues of voluntary participation which entailed that participation in the study would be voluntary and that failure to participate in the study or changing one's mind mid-way through would not result in any penalty or harm to the participant (UNISA, 2007: 21). All prospective participants were provided with informed consent forms after an explanation of what they could expect in the study. Each participant was given full explanations on the purpose of the study and that their information would be for the purpose of academic research only. Neuman (2000: 96) points out that a researcher must never coerce anyone into participating, and participation *must* be voluntary (emphasis in original). Every participant has the right to choose whether to participate in a research study and no coercion is to be in use. In this regard, I ensured voluntary participation by all participants by seeing to it that they signed a statement of 'informed consent' (See Appendix 2: Information Letter and Informed Consent Form, attached). The participants were reminded that their participation is voluntary and they may withdraw at any time that they wished, without any threat to their families and themselves. They signed two consent forms and one was for me and the other one for the participant. A guarantee of confidentiality of records and the protection of the identity of the participant were also included in the written informed consent statement. This helped the participants to build trust and confidence amongst themselves including me.

3.10 SUMMARY

This chapter outlined the research methodology that was used in the study, namely, the qualitative research design, sampling techniques, data collection methods, data analysis and issues of transferability, followed by ethical considerations and a reflection on the position and role of the researcher. The study was conducted using constructivist grounded theory methodology. This allowed me as the researcher to be interactive with the data. The participants were selected from six hospitals in Namibia. The study used a non-probability sampling technique and twenty social workers were interviewed as participants on a voluntary basis. They were able to talk about their perceptions and experiences.

The study was undertaken via appropriate ethical and research committees and supervision techniques to ensure a robust approach to research. Reflective approaches ensure the emotional safety of researchers and foster opportunities for emancipatory consciousness among research team members (Malacrida, 2007). The researcher conducted ethical research, by protecting the human rights of the participants as enshrined in the Universal Declaration of Human Rights (2004) and the UNISA (2007) *Policy on research ethics* available at: www.unisa.ac.za. In this study, the generation of grounded theory will be the outcome of an inductive procedure and concurrent data collection and analysis. Social work has an important role in the expansion of public health approaches to palliative care due to its philosophical value base, training and practice experience, improving the quality of life for those who receive care.

CHAPTER 4: PRESENTATION OF THE FINDINGS AND ANALYSIS

“In many aspects analysing data have similarities with social work practice. In both roles, you are face with rich and complex accounts and your task is to make sense of them. This involves seeing patterns and meaning in the accounts of the research participants and it is inevitable that this involves you exercising your judgement”
(Whittaker, 2009: 89).

4.1 INTRODUCTION

HOW DO SOCIAL WORKERS IN PRIMARY CARE SETTINGS IN NAMIBIA PERCEIVE THEIR ROLE IN PROVIDING PALLIATIVE CARE TO PATIENTS WITH LIFE-LIMITING ILLNESSES?

In this chapter, I present the findings of the study and the analysis of the narratives from twenty practicing social workers in Namibia. The findings are group according to the themes and sub-themes that emerged from the data analysis. In a large part, the sequencing of the data analysis was influence by the objectives of the study; that is the order of the data-generation steps and the structure of the data as revealed in the analysis of the transcribed interviews and field notes. This grounded theory study applied theoretical sampling throughout, where data collection and analysis were conducted interchangeably (Strauss & Corbin, 1998). Theoretical sampling happened over a period in time whilst I was building codes. The application of the constant comparative method benefitted the study shifting the analysis from the empirical to the theoretical level (Glaser, 1978; Charmaz, 2006). The study applied constant comparative analysis of the data a step explained in chapter 3 (3.6.2) from grounded theory experts, Charmaz (2006) and Strauss and Corbin (1990) produced themes relevant to the objectives and in answer to the main research question - *how do social workers in primary care settings in Namibia perceive their role in providing palliative care to patients with life-limiting illnesses?*

Themes were group into categories and a conceptual framework developed. During the data analysis process, I began creating codes and later refined those codes to contribute towards theory building. This thematic induction was use to sort and analyse the data as demonstrated in this chapter. I followed an interpretive process, which required me as the researcher to communicate with myself through memos, field notes, noting worthy events and initial analytic thoughts and reflections following the completion of each interview (Blumer, 1969). The disaggregation and analysis of data was accomplish through initial and focused coding. During this phase, a critical lens was applied to explore implicit meanings and actions and to identify directions to pursue. In order to ensure that the codes were an appropriate fit for my data, I sent the transcripts and the codes to the participants of the study, whereby I requested their input as to the validity of the codes and to comment on the codes that explored social workers' perceptions of their role in providing palliative care. The data was analysed through a structured thorough reading of the transcribed raw data from the field interviews, which yielded themes that I systematically categorized according to their relevance with the research question on social workers' perceptions of their roles in providing palliative care. My intention of data analysis was not to discover the theory, but a theory (by creating a constructivist grounded theory) that lead to the understanding of the area (of social workers' roles in providing palliative care) under investigation (Heath and Cowley, 2004).

I first examined how social workers perceive their role through explicated actions, interactions and meanings, compared data with data, and identified gaps in the data (Charmaz, 2006). Analysis of the action taken by the research participants in this study, in their roles as social workers providing palliative care, shed light on their perceived roles as social workers providing palliative care. It shed light on their understanding of palliative care, on the conditions that hindered or strengthened their abilities to provided palliative care as well insight into how social worker education and training influenced their competencies in providing palliative care. The application of symbolic interactionism in this study allowed me as the researcher the opportunity to draw out meaning from the verbal conversations and actions taken between the actors as they occupied their roles.

The first section of this chapter comprises of a discussion of an analytic story on my journey as a researcher collecting the data; presenting and analysing the findings. The chapter continues to present an interpretation of my reflective story as a researcher, being in the field, collecting data and nearing the end of my PhD thesis by presenting the findings and analysing the data. The findings of major themes and sub-themes in the individual narratives of the participants are present and analyse. The multi-dimensional roles of the social workers in providing palliative care are present and analyse, which in turn included identities of advocate, assessor, broker, counsellor, educator, facilitator, patient liaison, mediator, discharge planner and manager of in-country referrals. According to Spencer, Ritchie and O'Connor (2003: 199), "*data analysis is a challenging and exciting stage of the qualitative research process. It requires a mix of creativity and systematic searching, a blend of inspiration and diligent detection*" (Spencer *et al.*, 2003: 199). While writing this chapter, a realization became clear that there is still a long way to go, analysing these findings in completion of the study and even for future research because this specialist type of care is constantly developing, changing and evolving. Namibia, for example, will find newer ways to treat illness, conditions of pain and death. During the data collection, I experienced that the participants were very welcoming and positive about the research with regard to its relevance. I started each interview by repeating points in the participant information sheet (Appendix 2), in particular, that I am a qualified social worker and social work educator at the University of Namibia. I wanted participants to know that I had a thorough understanding of social work issues. I was fully aware that my role was to be a researcher in this context and not a social worker and certainly not a social work educator. These related roles did not hamper my requirement as a professional researcher for the task ahead. There were naturally times as the interview unfolded when follow-up or explanatory questions were need, but I checked myself, on many occasions to ensure that these follow-up questions were ask for the right reasons namely, that they were relevant for the purpose of the research study. Most participants did not appear to have any difficulty in telling their stories and sharing their experiences. The first few individual interviews were both exciting and daunting. Exciting, because I felt that I was at last beginning the research journey and daunting because of the long distances I had to travel in four different directions (north, south, east and west) of the country.

I wanted to ensure that the time was spent productively, not only for me, but also for the hospital-based social workers who had taken the time to participate. In the end, the interviews, which resembled stimulating conversations, went well, and afterwards the participants spent time informally talking about their experiences and interest in the research itself. The field notes assisted me in keeping detailed track of the methodology and in the analysis interesting information became known. In presenting and analysing the findings in this chapter, I am the insider (researcher) telling the story of the outsiders (the participants) without imposing my own conceptual frameworks on them and with the hope that these findings of my research may assist the readers to better understand social workers' perceptions and experiences of their roles in providing palliative care. I believe the data presents a vivid picture of the participants' perceptions and experiences.

This chapter seeks to answer the central research question:

“How do social workers in primary care settings in Namibia perceive their role in providing palliative care to patients with life-limiting illnesses?”

The following related sub-questions are report below:

- How do social workers understand palliative care?
- What conditions hinder social workers' abilities to provide palliative care to patients with life-limiting illnesses?
- What conditions strengthen social workers' abilities to deliver palliative care to patients with life-limiting illnesses?
- How do social work education and training in palliative care influence social workers' competencies in the provision of palliative care?

In the next section, the findings of the study and data analysis are present.

4.2 PRESENTATION OF THE FINDINGS AND DATA ANALYSIS

In presenting the findings of the study and analysing the data, I have used direct quotations from the participants as the organizing principle for presenting the narratives from the interviews conducted that gave rise to themes. The goal of the study was to examine the social workers' perceptions of their roles in providing palliative care to patients with life-limiting illnesses in primary care settings, applying a symbolic interactionist framework. I used the theory of symbolic interactionism, particularly of Dewey, Blumer, and Mead (Blumer, 1969) to organize the findings of twenty in-depth interviews. This theoretical framework lends constructive insights into my part as the researcher and the participants' part in the study, which proceeds from the foundational tenets of a traditional grounded theory approach. When social workers engage with patients with life-limiting illnesses and their families in providing palliative care and when they interact with the multi-disciplinary team in primary care settings, meaning making approaches are a key focus. This approach of "meaning" making in the lives of patients offers a focus that is compatible with the tenets of the symbolic interactionism and social work. Speck, Higginson and Addington-Hall (2004: 124, as quoted in Altilio & Otis-Green, 2011) relate meaning "*to how a person makes sense of life situations and derives purpose from existence*". In their definition Speck *et.al.*, (2004: 124, as quoted in Altilio & Otis-Green, 2011) recognize that both cognitive and existential facets of meaning are similarly fundamental in understanding the impact of a situation on a person's life and the strength he or she brings to that situation. The symbolic interactionist perspective requires the social worker to put him or herself in the shoes of the patient and to view the experience of a life-limiting illness from his or her perspective and to understand how he or she makes sense of and finds meaning in living. Meaning-making approaches support the co-existence of meaning, purposeful interaction and positive interpretation of suffering in patients' experience of a life-limiting illness.

This section begins with the presentation of the findings. It continues with an analysis of how social workers perceived their roles in providing palliative care and their understandings of palliative care.

The chapter presents data on the social workers' perceived experiences and interactions with the patient, the family and the multi-disciplinary team in the provision of palliative care. The chapter reports on conditions, which hindered or strengthened social workers' abilities to provide palliative care. Additional data is present on how social work education and training in palliative care influenced social workers' competencies to deliver palliative care. The chapter concludes with a summary on how to improve the practice of palliative care social work practice, and advocates for the appreciation of the multi-dimensional roles of social workers in providing palliative care.

The themes that follow are placed in this particular sequence for purpose of examining the social workers' perceptions of their roles. This is to draw a relationship between the data and the research questions. As the chapter proceeds, different themes and sub-themes are, discussed in relation to the data analysed, the research questions and the topic of focus. Analysis of the tape-recorded interviews and their narratives led to the following six emerging themes:

1. Social workers' perceived roles in providing palliative care
2. Social workers' understanding of palliative care
3. Social workers' perceptions and experiences in providing palliative care
4. Conditions that hinder social workers' abilities to deliver palliative care
5. Conditions that strengthen social workers' abilities to deliver palliative care
6. Social work education and training in palliative care

In the following section, I present the themes that were used for the analysis and discussion of the research findings.

Each of these emerging themes is further explored individually under sub-themes below and the excerpts from the interviews will demonstrate the relationship between the data and the emerging categories through inductive analysis.

4.3 SOCIAL WORKERS' PERCEIVED ROLES IN THE PROVISION OF PALLIATIVE CARE

Social workers are uniquely trained and qualified to provide palliative care as members of a multi-disciplinary team in the primary care setting of hospitals. Social work as a profession plays a critical role in the provision of palliative care because of its unique perspectives and skills. Several key elements are fundamental in providing palliative care. These include social workers' experiences and knowledge in the support, education and interactions with patients and their families; invaluable contributions to the multi-disciplinary team and social workers' commitment to promote social justice and alleviate health disparities. Social workers can have an enormous influence in patient-centred care and treatment and play several roles. They help patients adhere to the recommended treatment plan; they serve as a liaison between the patient and the multi-disciplinary team; they help to facilitate a family conference; they serve as an educator to the patient and family and advocate on behalf of the patients and the family for additional resources. In this study, the participants' different perceptions and experiences of their roles in providing palliative care became the main theme emerging from the data, which is in line with the primary research objective of the study.

Throughout the literature various roles and skills have been identified for social workers in hospitals (Altilio, 2011; Bartlett, 1975; Bomba, Morrissey & Leven, 2010; Dubus, 2010; Encyclopedia of Social Work, 2012; Forrest & Derrick, 2010; Goldsmith, Wittenberg-Lyles, Rodriguez & Sanchez-Reilly, 2010; Harper, 2011; Hartman-Shea, Hahn, Kraus, Cordts & Sevransky, 2011; Higgins, 2011; McCormick, 2011; McCormick, 2010; Morrissey, 2005; Nadicksbernd, Thornberry & von Guten, 2011; O'Mahoney, McHenry, Blank, Snow, Karakas, Santoro, Selwyn & Kvetan, 2010; and

Palos, 2011). In this ethnographic study, it is important to understand how each social worker perceives his or her role in providing palliative care and to gain insights on the conditions that influence his or her abilities to practice palliative care. The participants in this study were asked to describe how they perceive their roles and responsibilities as a social worker in the hospital. The data revealed that social workers' roles encompass a wide range of functions in addition to direct practice with patients and families. These include multi-dimensional roles, for example, providing counselling, facilitating education for patients, families, communities and other disciplines, advocacy for patients at all levels, assessing the psycho-social needs of the patients, linking patients with the necessary resources and planning the discharge of the patients.

The following sub-themes emerged from the participants' perceptions of their roles as a social worker:

- Role as Counsellor
- Role as Educator
- Role as Facilitator/ Liaison
- Role as Advocate
- Assessment role
- Role as Broker
- Conducting Referrals
- Role as Discharge Planner
- Role as Mediator /Intermediary

The participants perceived their roles as social workers as imperative in providing palliative care to patients with life-limiting illnesses. Below, a clear example from Gift summarizes the multi-dimensional roles of the social worker in the provision of palliative care:

According to Gift, *“we provide services such as counselling due to the social problems that they are going through and it depends to what situation it is we also link patients to*

resource; we do family therapy so that we help the patient, depending on the problem situation. First, we assess them to find out what is really the problem and it is from that, that we draw conclusions on what to do. We see that we have to include the family, then we take it from that point, where we also help mothers with provision of milk, because you will find situations whereby a mother has baby twins or triplets and she does not have enough milk, and if the babies are not satisfied with the milk the mother is breastfeeding they are referred to us to help so that they can be provided with formula milk, however not on a regular basis, it is only temporary. From there they can also help themselves they find ways how to survive. We are also providing entrepreneurship skills training that they can make use of to be able to get milk for the babies. We are also involved in clubfoot treatment. We assess and we educate the mothers who have babies with a clubfoot condition and they receive treatment here. We motivate them not to give up on bringing the babies to come for follow-ups and we educate them so that they complete the whole treatment so that their babies heal from the condition of clubfoot. We also provide bereavement counselling to people with life-limiting illnesses and for example, mothers who give birth to severely macerated babies. If a mother delivers such a baby who is not alive, that mother is affect emotionally and she needs help. She needs to see this from a positive perspective and not as a punishment. We help them through bereavement counselling to normalize their feelings towards what happened to them. We also assist when it comes to issues of poverty. For example, if a patient is on treatment, a patient needs food and if there is no food at home, it means that a patient is not going to cope because some medicines require a person to eat, not to just to take them on an empty stomach as the side effects might bring up some comfortability within them. Therefore, we link them to other service providers, such as constituency counsellors for provision of food and at the same time we also incorporate entrepreneurship skills well for them, because some of the people have inborn skills that a person is capable of doing a, b, c, to bring up some income for themselves”

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The following section outlines the sub-themes that emerged from the data analysis of the various individual transcriptions.

4.3.1 *Role as counsellor*

Social workers have much to contribute to the psychosocial well-being of patients with life-limiting illnesses and their families. Social workers are critical to patients' access to quality health care. They are trained to provide counselling and psychosocial support and to promote human dignity and social justice. The role of the social worker on the multi-disciplinary team as a counsellor is to provide humane, compassionate and competent counselling to the patient and the family and to help the family access resources available to them in the society. The predominant role of the social worker identified by all of the participants was that of counsellor in the provision of counselling and psychosocial support to patients and their families. The participants introduced themselves to the patients or the families in the hospital, and identify themselves as counsellors and support persons while they are in the hospital. Counselling and psychosocial support provision are viewed as important parts of the social workers' role in listening to and bearing witness to the stories of those in the hospital. The following excerpts from Catherine, Selma and Abel highlight the social workers' role as counsellor:

Catherine narrated that, *"we basically give counselling, counselling...and interventions when need be and if there is a need for outside family interventions. In the counselling some of the areas that I focus on is acceptance, forgiveness ... we also focus on self-worth and how to try and think otherwise ... positive thinking. I perceive my role as a support person ... I make sure that I am the support system, I am also going to the people who the person lives with and letting this patient understand how important it is for them to have people that support them, around them."*

Selma states that, *"I focus on individual counselling, which is either one session that I usually have with patients and it depends on how each individual patient understands their situation, it can be longer than five sessions or six sessions, whereby every week I give counselling session one, and after the 1st session, then after two weeks and then I have to change it to after two weeks that's when I do counselling with them. Through*

this I really helped them to make sure that they move on to the new life or new world. And whereby it's not only those ones, I do for those ones who return to work. ...”.

Abel said, “I am providing counselling and I am also doing adherence counselling so that they cannot default their treatment or medication and explain to them about their sickness, to accept it and give their cooperation so that they can recover as soon as possible”.

They perceived the support they provide as an empowering tool to help the patients to look at their illness from a different perspective and feel that there are actually people that care. The social workers used counselling to support the patients to cope with their diagnoses. For example:

Faith described, “... another very important role is to counsel patients in order to help them cope with the cancer diagnosis, to help them see that they are not the first ones to get cancer, other patients have also been diagnosed with cancer and also can share with each of them coping mechanisms. As a member of the multi-disciplinary team, I am also utilizing group work to help patients with similar struggles or similar diagnosis just to support each other to cope. For them just to realize that they can still enjoy life, ‘there can still be life after a cancer diagnosis’ it doesn’t mean that their life has to end the day that they are diagnosed with cancer”.

Alice explained, “I see my role in providing palliative care as very much important and vital in service-delivery, because I feel that in my involvement with a patient and with the patient’s family, the little information and just the general support of being there for the patient and telling the patient that you are there in this time is a big relief for the patients themselves. It is also an empowering tool to help the patients to look at it in a different perspective and feel that there are actually people that care and that show the

importance of their family member or their relative. So, I see it as a very important and a vital role in service delivery”.

Kay perceived the role of the social worker as *“a very important role I would say, a very important role, because if I can give an example, today during our ward round one of the doctors said to me, ‘I think you need to talk to these patients, because it is like we are telling them this is the condition, this is what they have to do but they do not seem to understand’. So, you realize the way we social workers communicate to our patients is different. If you sit down with the same patients, giving the same message, it is much easier for them to understand and get to a point where they see things clearly. So, the role we are playing is great I would say, is very important for our patients. I would say it is very important and necessary”.*

It is evident from the data that the participants perceived their role as a support person. They will sit with the patients and the family upon receiving a diagnosis of a life-limiting illness, and sometimes they will even have to prepare the patient and the family before breaking the bad news of their diagnosis. Social workers in this study perceived their role as helping the patients and the family to process the information that is given and once the diagnosis is complete. The social worker helps them to understand the meaning behind their diagnosis, and how the patient may react to it. Although the physical pain of patients with life-limiting illnesses is control and manage by medical doctors, the participants perceived their role as addressing total pain through spiritual counselling, emotional and psycho-social support. This finding is consistent with what Hartman-Shea *et al.* (2011) found that psycho-social counselling and support was one of the most frequent social work activities most linked to family satisfaction and the reduction of anxiety. For example:

Si’s narration revealed that, *“actually when you are working in a hospital there is one thing that you must expect, that patients are getting sick and they are dying and most of them need support.*

When a person enters this hospital, you do not actually know what to expect and when it comes to life-limiting sicknesses it is very difficult for the client to accept the situation wherein he is. Sometimes he does not understand what to expect from the sickness he is having. You would also find that sometimes the doctors are not straightforward about the patients' diagnoses they do not want to tell the person, because maybe they are afraid the person will break down emotionally. The doctor himself will not be able to handle the situation. That is why most of the doctors maybe on the medical team are a little bit scared about maybe disclosing the situation the client is finding himself in. So, the cases which I have been dealing with mostly are cancer related and when the cancer is at the final stage it is very uncomfortable for the medical staff and also for the family, because there is a lot of, how can I say, stench, flies ... flying around and with all those things, it is very difficult for the patient to be around them. As a family member when you come to your beloved one, you do not expect the person to die and they do not actually talk about dying. Those are the issues, which social workers must deal with; the social worker must be able to prepare the person. We do not expect the person to die, but the reality of the fact is, that you have to bring it close to the person that 'this can be, maybe one of the things, you must understand that this person is very sick and when a person is sick there are certain things to expect'. So, those are the things we are dealing with. If you have to prepare a person, there are many things you have to deal with, you have to think about, maybe the life afterwards, so you have to give him spiritual counselling. The person is also going through too much pain, it can be an emotional pain it can be physical pain, so you have to help the person to deal with the pain. Dealing with pain, there are many ways. The doctor can make sure that he gets his painkillers and also there is the emotional pain, the person has to talk about maybe how he is feeling. Currently, I was working with one of the patients and mostly what patients are experiencing is that they are not getting enough attention from the staff. I do not know how far it is true, but some of them believe that they do not get enough. They feel that 'these medical staff just want to get rid of me and they do not meet my needs actually'. So, one has to look at all those aspects. As a social worker you have to comfort the person, kind of, telling him that the solution of his problem will be able to come".

Nanna indicated that, *“I am the link between the family, the patient and the medical team. I bring them in together, if there’s a need ... obviously there’s always a need for them to be brought together for the family to be aware of what goes around, so the role of the social worker is very important for the patient to be assisted psychosocially to be able to come to terms with their condition if they are about to die, to be prepared for descent time for the family also to be prepared and supported”*.

Linda explained, *“apart from the counselling, we do mostly a deep therapy where we apply all the other social work methods of therapy because, most patients, every patient, might look as if things are okay, but it’s not, it’s not okay because of the long terms illness, it need to be attended to every time. So, we do a lot of educational talk and a lot of support and also provide services in terms of food and referral and where necessary also a grant, because some of them are unable to work. And because of HIV, there can be other illnesses that can make it impossible for people to function. So you end up going beyond what you were supposed to just offer”*.

Gift perceived her role as a social worker providing palliative care *“as a very important role and responsibility, because in my role as a social worker in palliative care, I am doing things that I am trained to do and the doctor is not the one who has to do that. That is why we need a multi-disciplinary team. I need to provide counselling to the patient who is grieving due to that loss of health and I also need to provide counselling to the family members as they are grieving their loved one who lost health”*.

4.3.2 Role as facilitator / liaison

The role of facilitator or liaison in the hospital was identified as another key role of the social worker. This role encompasses facilitating the communication between patients, families and the multi-disciplinary team to help the hospital team understand the patient and the family’s experiences, needs and perspectives, and vice versa. As the multi-disciplinary team works together, the social worker facilitates the communication and helps with everyone’s understanding through reflections, asking clarifying questions,

and assessing reactions to information. A key to the success of palliative care provision is good communication. This can take place between the social worker and the patients on a micro level or on meso level between the social worker, the family or the multi-disciplinary team members, as many participants discussed taking an active role in liaising with doctors, nurses and other staff to facilitate patients' assistance needed. For example:

Faith confirmed, *“when some of the patients are classified disabled because of cancer, I liaise with the doctor. I also do my assessment to make sure that the patient got all the supporting documents that are needed for the application, because its’ of no use like having a doctor fill in a disability grant application form, but at the end of the day realize that the patient doesn't have even an ID, you know. So I make my thorough assessment first of all to see that the patient has got a birth certificate, the patient is a Namibian citizen and the patient has got an ID. Sometimes you also have to break, breakdown the medical jargon used by the doctors and explain in more simple terms what the doctor is trying to say, but in all this I work in consultation with the doctor, I don't work independent of the doctor. We work as interdependent team members and I also point out to the doctors where patients need clarification because, sometimes you know, a patient says to me they were never told that they've got cancer. So that is one of my roles within the palliative care setting”*.

Ashley said, *“I feel that the social worker's role is very important in palliative care as the social worker is a go-between the patient and the doctors. The doctors are just there to disseminate information to the patient, but as a social worker, I am there to be able to talk to the patient in a calm environment whereby there is confidentiality and also in simple terms. As a social worker, I am able to help the patient understand their disease better. For example, like a case whereby a patient is diagnose with advanced cancer, the doctor is just there to say, 'you have cancer and you are going to die'. You know, it is just a shock, the doctor did not even prepare the patient, but as the social worker you are there to gradually talk about the topic and make the patient understand that 'this is*

how it has come to be' and this is what you are expected to do in order for them to also prepare them".

Si perceived, *"the role of the social worker as actually to make sure that there is good communication between the medical staff, good communication between the family, between the spiritual staff, like the pastors and all those people and to prepare the person in the process of dealing with the pain. My role actually as a palliative care member, since I am a social worker, is to facilitate and to make sure that there is good communication between the patient and his family outside there and if the patient is coming out from a community, it is to link him together with the doctors and then also that we come together and you start with your role definition, goals of treatment and all those things".*

Edward explained, *"I prepare them to understand or to accept their condition, to the patients as well as their families. Sometimes I do some home visits to meet them in their own settings and to meet their families there. Sometimes I hold and facilitate what I call family conferences, particularly when the patient is nearing towards the end of life, in order to explain and to help the family what to expect".*

4.3.3 Role as educator

One of the major roles that the participants identified is that of an educator. The social worker provides health education to the patients and dispels myths around life-limiting illnesses. They may also educate the hospital staff on the dynamics and beliefs of the patient and family, or they may inform the patient and the family about the resources that are available and describe the different options for available care. Social workers may also educate the hospital staff and the communities on their different roles and responsibilities and the services they deliver. They are also conducting therapeutic educational group sessions with patients providing them with health information and counselling. The following narrations explain the social workers' role as educators:

Faith described, *“as a social worker, I play an important role of educating the patients on cancer, trying to dispel the myths, you know, give them the facts about cancer. Some will say ‘no I was bewitched, you know that's why I am having cancer’, you know ... and so many myths that they might have, but I try to give them the facts that cancer is a disease that has to be treated by radiotherapy, surgery or chemotherapy. So I help to put some of their fears at rest”*.

Nanna explained that, *“... the other thing also that we basically do is also to inform the doctors, to educate the doctors on, the role of the social worker and the importance. When there is meetings with the doctors we also emphasize on the importance of involving the social worker from the point of diagnosis, especially with HIV as well as the TB patients, because it is very a difficult point to only involve the social worker when the person has defaulted or where the person is bedridden, because that's the only point the social workers are called. So we always try and emphasize and also involve and inform the churches of the type of services that we provide. When we go out to communities, we have presentations with the communities where we share, ‘this is what the social workers do, this is where their offices are, this is the contact details where you can reach out for this particular type of social issues’ and we also had a meeting with the pastors to also share ‘this is what we go through, this is how we need to support each other’, because as a pastor, the spiritual aspect is necessary for the patient as well as the clients in general. Also how can we work together as pastors, as social workers to assist a particular patient so, this is how we try and inform the people in the communities”*.

Selma experienced her role as *“doing group therapeutic sessions and conducting educational talks with the patients in the spinal cord injury and rehabilitation units. I usually use the sessions with them every week, whereby I have a session or educational talks with them. The group sessions educate them on what they are you going to experience from now onwards, to, ‘in your future or in your life and when you go back you reintegrate back in the community’; what they might experience or see in the*

community, so that when they go back there, it is not a surprise that might come to them”.

Gift explained that, “I also need to educate the family members on home-based care, because sometimes a patient can be discharged home. The people need to be educated on how to take care of the patient at home and to help the patient come for follow-ups. I need to make sure that there is somebody with that responsibility in the family, who is bringing the patient to come for follow-ups. That is why I perceive it as a very important role and I perceive it as very necessary that social workers are involved to perform such a big role”.

4.3.4 Role as broker

Faith described her role as a broker. She said, “I play an important role in acquiring toiletries and donations on second hand clothing for the patients. What happens is that cancer patients are sent or initially they are diagnosing from outside Windhoek. So when it’s detected that a patient has got cancer they are sometimes just put on a bus without any preparation as to how long they are going to stay in Windhoek and, told that, you are going to Windhoek. So when they come here, they will be shocked to learn from the doctors that they have to stay for about eight weeks, getting radio therapy, or about three to six months to undergo chemotherapy, without them going home. So, now, the patient’s first reaction will be shock, and then ah later on they will start stressing. One, they, didn't come with enough clothing, maybe they just came with one extra set of clothing. Or they didn't come with enough toiletries they only brought maybe, one small bar of soap. They don't have family in Windhoek, to them Windhoek is actually a strange place and for them they have never been in Windhoek they are not employed, so they stress a lot. And some of them can even or want to default on treatment, because of that, because of toiletries they don’t have. You know, they want to maintain their dignity by keeping themselves hygienic and smelling good, but if that is missing, they will choose to default on treatment and go back home instead of continuing with the treatment.

So as the broker, I look for donation of clothing and toiletries from families and other well-wishers. And by families I mean close friends, churches and other well-wishers. I also play an important role in linking the patients, those qualifying patients with disability grants”.

Selma described, “in the spinal cord injury and rehabilitation ward we have quadriplegics, where you find patients who are either complete or incomplete. Some of their sides, as if left side could be working then the right side could not be working. So in this case now, when it comes there, what I do to assist them, is I make sure that I help them. I assist them immediately when they come in, during their in-patient time because, they are admitting for plus/minus over 8 weeks up to 12 weeks. During that period I make sure that they for those who does not have IDs, birth certificates, they do apply for those ones. I direct them, myself like by linking patients whereby, I take them or escort them to the Ministry of Home Affairs to acquire their IDs, because there’s no way they can apply for a disability grant if they don’t have, any if those ones”.

Charlotte described social workers as multi-functional, indicating “we check what people need for example, if the person is deaf then we will see that the person gets hearing aids, if there’s a problem with eyes, we see that the problem is solved, that the person gets an eye test and glasses and when it’s a limb problem you see that he gets either a wheelchair, or this, if he can still use the frames to walk with. I see we should provide the training, facilitate training process and then we should facilitate the physical care taking. And we can maybe be involving ourselves with the psychotherapy if there’s any need as social workers and we can mobilize resources”.

4.3.5 Role of assessment of patients

A key aspect to social work practice is performing comprehensive assessments. Social workers are trained to assess the person in totality (physically, mentally, emotionally and spiritually) be it a patient or client.

The application of screening, assessment and interventions of social workers are critical to explain clearly how patients and family members are responding to diagnoses of life-limiting illnesses and the prospect of end-of-life. In the interviews with the participants, assessment of patients emerged in various forms. Social workers in primary care settings (e.g. hospitals) assess patients' social circumstances prior to discharge and potential needs for post- discharge. For discharge planning, the social worker assesses the family dynamics to understand the family's beliefs around palliative care and potential conflict that may arise, as well as assessing the various stressors affecting the patient and family. Some examples of assessments from the participants are describe below.

Nanna reported, “... *when we see the patient, we assess the person's state of mind. Is this person is the state of mind normal to be able to go through a counselling session. We assess the reasons why this person has been referred to the social worker. We assess the support system of this particular patient*”.

Gift explained that, “*as a social worker I need to do a proper assessment to find out what is really the needs of the client. I need also to assess that when a patient is in the ward in what state they are and whether they perhaps need a disability grant to use that money to buy soap or lotion, because they need to wash, they need to apply lotion and sometimes a person is unemployed. Also sometimes the person is not really from a good background where people are supportive, so I need to find out all those*”.

4.3.6 Role as advocate

This study found that the participants serve as an advocate in their role of providing palliative care. During the interviews, five of the participants recognized their role as an advocate, but in this chapter, only two narrations are included.

The social worker advocates for the patient and family to ensure their needs are being listened to and met.

For example, Ashley described her role as, *“mainly advocating for the patients. For example, if a patient is not getting better treatment or the family members are complaining that the patient is being neglected, I can go and talk to the nurses and find out how best the patient can be cared for and half of the time you find that the nurses are also complaining that the patient is in that state, because they are short-staffed. But you always have to find a way whereby you can really ask them and talk to them and then they will be able to take good care of the patient. There are also maybe incidences whereby a doctor would want to discharge the patient, because the patient no longer needs the services per se, because the patient to them is dying and there is nothing else they can do, so you can also like negotiate with the doctors to say, ‘why can’t you give the family time, maybe the family don’t have enough space at the house or they need extra help to be able to care for the patient’, so you are there to talk to the doctors and other multi-disciplinary team”*.

Nanna said, *“my role as a social worker in the multi-disciplinary team is firstly, to advocate for the rights of the patient. To make sure that this patient is getting the treatment in a correct way and not only in a correct way, but whether the patient is taken care of in this particular facility, whether the patient is made comfortable. If the patient has any complaints, I have to make it known to the nurse in charge or the medical doctor. If the person needs information on his or her condition, I need to make contact with the doctors as well as the nurses that are there, also to have the involvement of the family as well. So the role of the social worker in this multi-disciplinary team is also to make the doctors and the nurses or the other multi-disciplinary team members aware of the systems that this particular patient is having. If it works, how this is influence and how the other multi-disciplinary team members can assist this person in other systems that he or she is also having. So I advocate on behalf of the patient, especially if I feel that the doctors are not listening to, the patient, or the patient is lacking a well-deserved service. So I have to advocate for the patient”*.

4.3.7 Managing in-country and international referrals

As part of the emergent themes based on the grounded theory analysis, this study found that social workers in the primary care settings in Namibia manage in-country as well as international referrals. This finding is unique to the context being explored. For example,

Tayawa described, “you’ll find that there are situations where you will refer someone for a disability grant to the Ministry of Labour, which is the only kind of financial assistance which is there from the government side, but it takes two, three months for someone to start getting that money and in the meantime the people are suffering. We have those home based forum members that I’ve mentioned about. Some of them they just refer to those home-based care forums or to the home-based care organizations and then they usually help them, but the ones who they feel ‘this one needs the attention of the social worker’, they do refer, so I think they recognize the role of the social worker”.

Abel reported, “working with Angolan patients who are coming from Angola, and referred to the TB ward. So I am helping them with renewal of their passports, medical visas ... The medical visas are for the patient, the TB patients who are admitted in the Windhoek TB ward for two years and for the patients, who are admitted in Namibia. The medical visas are only given for three months for the patients and then after that, it expires and then it must be renewed. My role is to deal with the referrals from the doctors and if there is a problem, I am investigating and then I report to the doctors. I also deal with cases referred by the Woman and Child Protection Unit. They send clients to us, but we refer them to the district social workers and from the hospital itself, they are also referring some cases here to us if there is no social worker on their other side”.

Gift explained, “this hospital is a referral hospital and it accommodates patients coming from various regions, even from abroad patients are coming for treatment here.

...

For example, a patient can be from Zimbabwe or Angola and according to my experience, it is on ART, the treatment for HIV and AIDS and that patient only came to Namibia to visit a family member in Namibia and since he is a patient on ART, he happens to finish the medication while he is here. Therefore, we assist those patients here. We are the ones who do the assessment and refer to the top offices for them to get permission to be provide with the ART that they need to take, because with those medicines you do not need to stop them, every day you have to take it and if they do not have it, it is a challenge. A patient can also be from Angola and he came here through referral and he will be admitted here in Oshakati, they are also treated here”.

4.3.8 Role as discharge planner

One of the roles identified by one of the participants was discharge planning. The finding in this study revealed that social workers have a critical role to perform as a discharge planner in the hospital. Discharge planning by the social workers range from sending patients to a rehabilitation facility, arranging and coordinating home-based care, arranging hospice care, or referring to bereavement resources once a patient has passed away. Coordination and optimization of discharge planning by social workers is often necessary and calls for an inclusive approach with the patients, the families and the caregivers. The findings revealed that there is a need for decision making over the course of the illness, and social workers are often essential facilitators of discharge planning, communication and a process that supports informed decision-making. The responsibilities of coordinating home-based care consist of sending a patient home with coordinating the transfer of a dying patient to an inpatient hospice centre. For example:

Si shared that, “it is very important to establish the goals actually why you as a social worker are there. Sometimes you have to prepare the person the go home. How do you prepare the person to go home? You have to go to the house, you have to prepare the family, you have to tell the family such and such things are going to happen with this patient, they have to consider the sickness of the patient and they also have to deal with certain things and the patient is sick.

The person is lying helpless there and needs support at all the levels. They cannot go to the toilet, so you have to be prepared to deal with all those aspects. Si narrated his role in the discharge planning as “I had a case of a cancer patient who was just lying there. What I have discovered is that the person was actually working some time ago at TransNamib, public transport company, so the person got sick and it has come to a stage that he cannot help himself anymore. He was just lying there in the bed he was actually in the final stage of his sickness. Then it looked like he did not have good family support, so I had to trace all the family members. I found some of them, but the person who was supportive was the neighbour and he was really a useful source for me. I got all the details of the family, the relatives, brought them all together and we were planning now what is going to happen to this man when he is discharged, since he was sleeping alone in his house there was nobody to take care of him ...So I had to bring the family together and discuss what is going to happen from there. At the end of the day one of the family members came up and said that they will be able to take care of the patient and initially the patient was discharged and moved from the house where he was staying alone and then he was with the sister the last days. Some of the issues mainly which came out is just the physical care of the person, who is going to take care of this person and then also talk about the possessions, he had many things, what is going to happen to those things...”

4.3.9 Role as mediator /intermediary

Faith expressed, “I feel that the social worker works as an intermediary, between the patient and the doctors. Sometimes the patient they don’t have the confidence or the courage to ask the doctors certain information regarding their condition or regarding their family members, because doctors are perceived as having a higher social status and the patients are perceived as having a lower social status. Nevertheless, the patients they feel more comfortable to come to the social worker. They feel that the social worker listens more to their problems, as, compared to the doctors who they think doctors will be extremely busy and they don’t really have time to listen to the patients’ concerns so sometimes they, the patients come to the social worker to get information regarding their families, or their family member or their own medical

condition My role as a mediator within the oncology setting is very important and as an educator, to educate the patients on cancer. What does it mean to, to live with cancer, you know”?

Nanna said, “in this hospital, I see it as a very important role because, as a social worker I am in the middle of the medical team, the patient and the family. So uh-mm, my role is very important because I am the link between the patients and the family”.

Anna explained, “when you look at enhancing the quality of every person’s life, does not matter whether it is a life-limiting illness or any other patient with a medical condition, I feel my role as a social worker is very important to make this person feel humane, loved, cared for and to help this person to cope. Like I said previously, mediate between family and other programs within the community or institutions where this person can get assistance, just to improve their quality of life even though they have a life-limiting illness”.

4.4 SOCIAL WORKERS’ UNDERSTANDING OF PALLIATIVE CARE

The participants’ perceptions in defining palliative care became one of the central themes emerging from the data, which is in line with the second research objective. Findings on the social workers’ understanding of palliative care, the World Health Organization’s (2002) definition of palliative care and the gaps in knowledge on palliative care are present in the section below.

4.4.1 Social workers’ definition of palliative care

When the participants were asked to provide their understanding of the definition of palliative care nine (9) of the participants were able to share their view of the definition of palliative care.

In addition, while of those who did, only a few were able to elaborate on the different dimensions of the World Health Organizations' (2002) palliative care definition. The following transcript extracts explain the participants' perceived understanding of palliative care:

Faith defined palliative care as *“a multidisciplinary approach that is meant to improve the quality of life of patients and their families. Particularly, patients diagnosed with a life-limiting illnesses such as cancer or HIV whereby there is no cure for these diseases. So the aim of palliative care is to alleviate pain and needless suffering. We want the patient's life's quality to be enhanced, so that they can enjoy life. Yes, palliative care is not there to sort of prolong their life or hasten their death, but just to make sure that each and every day is enjoyable and is pain free”*.

Edward perceived palliative care *“as the care that is given to a patient who is facing a life-threatening illness. That care is holistic and it is about not only physical things, but it is also concerns spiritual, religious and other care that provides for the improvement of the patient's life before they eventually pass on. In other words, the way I understand is that if we cannot put days in their lives, then we put life in their days. When Edward was ask to elaborate about what he meant by ‘we put life in their days’, he explained “by putting life in their days, we are saying we want to provide as much quality in the life that they are enjoying, so we are making them very comfortable so that even though they have a life-limiting illness, they are at least enjoying their life”*.

Si explained palliative care as *“giving care at all the levels to human beings, who are spirit and body, so you have to address all those needs and consider the fact that in actual fact this person is dying and this person who is lying down here is in pain and is experiencing pain. It is not the normal pain it needs a lot of painkilling medication. I do not know the doctors are using some other words there ... yes, pain management. So, according to my view palliative care has to do with, as I have already said, is that you have to make sure that this person's needs are addressed when it comes to pain and*

also social aspects. This person is concerned about ‘what is going to happen with my position, what is going to happen with my family’ ... and all those things are things which you need to take into consideration when it comes to palliative care. So also the aspect of spiritual counselling is very important for the person, because before you die, you do not even know what is going to happen with your soul....”

Aardvark reported “... what I understand is that it is similar to providing care for patients with life-limiting illnesses, care such as holistic psycho-social approach whereby the emotions of a person is care for, the physical needs of the person is taken care of, the mental needs of the person is taken care of and then also the spiritual needs of the person is taken care of. This is what I understand”.

Importantly, for the rest of the participants, eleven (11) referred to palliative care in simple terms, in particular: end-of-life care; helping the patients to die in peace; or referred to it as ‘that thing’; specialist care for people on death beds; psychosocial care for the terminally ill; preparing patients for a painless journey; helping and teaching patients to cope with life-limiting illnesses and provide support to sick, bedridden patients admitted in hospital. The following excerpts explain their understandings of palliative care:

Nanna said, “what I understand with palliative care is helping this patient to die in peace. Or to better ... make the dying process more easier, easier if it comes to the point that the person is going to that point ... and also to support the family in understanding the condition and also to support the family in, in preparing for this person’s death if it comes to the point that there’s not much that can be done”.

Selma referred to palliative care as “‘that thing’ saying my understanding with palliative care, we know ‘these things’ of like illnesses that are limiting patients, or people, from, being doing their daily life activities, they might start thinking that ‘okay,

am maybe ... this is the end of my life, I'm not going to do anything anymore'. So now, when those people are with us as social workers, my role, or the way I understand 'that thing', it's like I'm here to assist them to know that they should know that this is not the end of the world, they should continue, live like before, even though there are things they cannot be able to do in their life, but you know, things when they come to us when they attack us it's something that we didn't expect to happen to us, but it's something that just came unexpectedly and when it comes unexpectedly. Meaning we should take it the way it is till the end of our life instead of us like saying 'okay, even though I'm going through this situation where I cannot do anything for myself, I start thinking okay this is the end of life'".

Taywa said, *"my understanding is it's where you give specialist care to a patient, who is probably on their deathbed for example. And uh, usually the doctors have not much that they can do to the patient"*.

Lucky expressed her understanding of palliative care, as *"I would say palliative care is a psychosocial care for terminally ill patients with life-limiting illnesses and their families. With this maybe I will provide examples, like HIV and AIDS, cancer, heart failure, kidney failure, just to mention a few"*.

Alice in response said, *"my general understanding of palliative care is preparing the patient for end of the life journey, a painless journey. This is making the time the patient has worthwhile, memorable, offering support to the family and also preparing the patient to face fears and understand issues around death and dying"*.

Abel explained his understanding of palliative care as *"the way the patient is admitted and he is sick and is bedridden, he needs support from the family, from the social worker, from nurses and from the doctor"*.

4.4.2 The definition of palliative care according to the World Health Organization

As already explained in chapter one, the term palliative care is most commonly used by health professionals in primary healthcare settings and in hospices. Namibia adopted and uses the World Health Organization's (WHO, 2002) definition of palliative care, which defines palliative care as "*an approach which improves the quality of life of patients and their families facing life-threatening illness through the prevention and relief of suffering by early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems*". Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- ;2Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;

The comprehensive definition of palliative care by WHO (2002), adopted in Namibia, clearly highlights that a life-limiting illness is not simply a biological or physiological condition, but also a process of living that contains a broad range of emotional, psychosocial and spiritual issues. Social workers, as trained and skilful healthcare professionals, have a critical role to perform in attending to the impact of a life-limiting illness, beginning with diagnosis and continuing through phases of treatment and subsequent transition to off-treatment survivorship or end-of-life.

4.4.3 Gap in knowledge according to participants' understanding of palliative care

It is evident from the definitions provided by the participants and their understanding of palliative care that a gap exists in knowledge of palliative care. The majority of the participants (11) could not provide a clear definition on palliative care. This study identified a gap in knowledge on palliative care and therefore recommends awareness and education for healthcare professionals and the public at large in primary care settings in addressing this identified gap, which will be further analysed and discussed in chapter 5.

4.5 SOCIAL WORKERS' PERCEPTIONS AND EXPERIENCES IN PROVIDING PALLIATIVE CARE

The participants were asked to talk about their perceptions and experiences in providing palliative care. They were asked to talk about what proportion of their work focused around palliative care social work. In the case of Namibia, there is no scientific information about social workers' work focusing around palliative care, specifically from the social workers' point of view. This broad research question was therefore included as the core of the study, which is in line with the first research objective of the study. The question intended to identify the participants' experiences in palliative care. Furthermore, the study intended to gain a grounded approach to understanding social workers' perceptions and experiences of their role in providing palliative care to patients with life-limiting illnesses. As mentioned in chapter one, the intention is to capture the essence of that role as perceived by those carrying it out, rather than simply to approach it as a series of tasks.

In the next section, I present and analyse data on the following seven sub-themes:

- participants' perceptions and experiences of the proportion of their work that focuses on palliative care;
- perceptions and satisfaction with the management of palliative care services; perceived confidence in the provision of palliative care;

- perceptions and satisfaction with the provision of palliative care services;
- perceptions and satisfaction with the role of the social worker in the provision of palliative care;
- perceptions about interactions with patients and family; and
- perceptions about interactions with the multi-disciplinary team

4.5.1 Perceptions of the proportion of social work focusing on palliative care

This section discussed the social workers' perceptions and experiences on interactions with patients and family. In addition, perceptions and experiences about their interactions with the multi-disciplinary team and skills needed as palliative care social workers are presented. The findings indicated that despite the fact that more than half (14) of the participants in the study received undergraduate training in palliative care, the majority of the participants' work did not have a focus on palliative care provision only. This is due to the shortage of social workers in Namibia, the lack of opportunities for specialization as palliative care social workers, the lack of in-service training and continuous education and training on palliative care and the fact that social workers worked both as generalists and hospital based social workers. However, a few of the participants had experiences as medical or palliative care social workers. The excerpts below demonstrate some of the findings.

Nanna responded saying, "in terms of palliative care I wouldn't say it is a lot, because with this Hospital most of the things are referred to Windhoek. If it comes to a point when our doctors here cannot manage then most of the cases are referred to Windhoek, but then if it comes to Windhoek and there's not much that can be done then, if they're referred back, as I have mentioned, you just get involved at the last stage of life".

Faith described, *“I work as an oncology medical social worker, at the Windhoek Central Hospital. Windhoek Central Hospital is a National referral hospital in Namibia, where...all the specialized services are rendered to patients in terms of oncology, cardiac services, dermatology all the spectrum, specialist areas that you can think of...So I work within a medical team, multidisciplinary team set up. In this team, my duty is to provide psychosocial support to patients and their families. I also offer counselling, group work, community work. Basically we practice all the social work methods”*.

Taywa explained, *“I would want to say for half, but let me say quarter. It has, it’s mostly referrals from the hospital, the doctors from the hospital, where referral, this patient needs the services of a social worker and they refer the patients to us. We also have home-based care forum that we organized as a region. Where, colleagues and I are also members of that home-based care forum, in terms of giving our technical support to the existing community based organizations. We also do home visits, to visit some of the patients in the, in the community and as well as support whilst they are in the hospital. So in the palliative care that is what we do and we usually also help, there are some patients who probably, because of their illnesses which they have, they’re need support in terms of food materials, financial materials and so forth. Uh so we refer to, especially for the grant, if there are instances where somebody might not be disabled as such physically, but they’re incapacitated to an extent that they cannot defend for themselves. Then we write a background report for them to get the, the grant from Ministry of Labour, we also do home visits like I said, just to go and support them in the community to see the type of care that they are receiving from the family and try to organize extra support when there’s needed. Even spiritual support, spiritual counselling from the pastors around and to make sure their life is as much comfortable as possible. Life-limiting illnesses such as diabetes all types of illnesses which you know which is life-limiting including HIV and TB”*.

Shaka reported, *“there is no specific you know the component of my work that focuses or deals with palliative care. I think the reason is that palliative care is not being*

institutionalized within our ministry, it has not been, you know, emphasize to district social workers, you know although there is personal attempts. Or mechanisms to attempt to clients or patients with life limiting illnesses, for example HIV, TB or even you know cancer, but there's no coordinated palliative care or home based care program, which is there to respond to the needs of people, with life limiting illnesses. So my work of cause I do come into contact with people with life limiting illnesses on a case work basis. You know somebody has been referred perhaps a cancer patient who uh you know contemplating on ending a life I have had one. So that is how we only attend to, to issues of palliative care”.

Gift shared her experience in palliative care as, “my experiences regarding palliative care, I can say that since I have only worked for two years, I can say that I was not involved much, I was just involved a little bit”.

Alice responded, “It is my day-to-day part of working, but my encounter with patients with life-limiting illnesses, especially regarding palliative care, is when I worked closely with the students, the Faculty students, when they came for their palliative care programme. That is when I had my encounter with them mostly. The referrals regarding care are going quite slowly. I cannot blame the doctors for not referring patients that require palliative care it is just a matter of sensitizing and bringing about awareness to the nurses and the doctors that we also cover palliative care”.

For Anna reported, “it really depends, because we work with a variety, with different types of medical conditions, so it really depends. For me personally, I would not say I had that much in terms of dealing with palliative care, but I had a few cases of palliative care, five at the most that I have dealt with”.

Ashley rated herself on a scale: “1/10, basically there isn't much of this palliative care. I think most of these cases might be in the medical wards, because I am dealing mainly

with outpatients, patients who are coming in from home and are being seen by the doctor on a one-day basis and then they go back home”.

4.5.2 Perceptions, experiences and satisfaction with the management of palliative care services

In response to the questions to describe how palliative care is managed and whether the participants are satisfied with how palliative care is managed in their respective hospitals, five participants responded as not being satisfied with how palliative care is managed. For example:

Lucky responded, “it is not really well managed, because like I mentioned in the beginning, some of these cases just come as maybe the doctor picks that, maybe this patient is suffering from stress, but then the root cause of the stress is not known and then when you intervene as a social worker, it is when you find that it is something which was needed from the beginning. In this case I would say, by saying it is not well-managed, because it is not picked from the beginning whereby this person, maybe at the diagnosis one was supposed to already see that this person is in need of palliative care and it is picked from the beginning”.

Shane said, “what I have seen in our hospital, probably because of the lack of doctors, because of the lack of staff like maybe social workers and nurses and because of the lack of accommodation, we do not have enough place to keep such people, so in most cases we find the doctors referring those patients to us, so we have to go and attend to those patients so that we can trace their relatives, for the relatives to come and get their patient. Sometimes you can really see that ‘this person, can he or she really go home, how she is going to make it?’ For example, the day that they are transporting that patient home, on the day of arrival, who knows that this patient will just not come back because of like the way they are transporting that patient again.

So at time we might find this patient needs to be in the hospital, but because the whole lot of things that I have mentioned, it is unfortunate that the person has to go home for the families to take care of their relative. At least as I have been thinking, can't we, like maybe the government of our country at least just provide a special ward for those people with life-limiting illnesses, for them at least just to be there and the doctor will just go to them any time, because those people, you expect anything to happen to those people anytime and even family members will be tired of bringing the patient to the hospital each and every day because it is a life-limiting illness, life-threatening illness. So, you expect anything to happen to that person anytime, at least for them just to have a department or a ward, just in the hospital for them, even for the doctor just to make a ward round even once a day or once in two days. It will just be enough for them because the doctor can run to the ward for emergency because they can go into emergency any time. At least it will be a better place. And another thing, as I have mentioned that we have a shortage of staff, at least a nurse, at least a social worker to be allocated to that ward because especially a social worker is very much needed because family members are also traumatized because their patient is going through that stage...”.

Charlotte described, “I am not satisfied at all, because very little attention is given in the psychological aspect of the person and it's just as I said by chance that they refer some of them to us, but most of the time they don't. So they just give the physical support on treating the person and that's it. So it's something that we still have to take up with the medical profession”.

Alice said, “it is not something that is of major importance, should I say, it is not brought like an emergency case, because generally it is just that the doctors announce that they cannot do anything anymore for this patient, so this patient is being discharged in the care of the family and then the family are not really aware about from here onwards, what will happen to the patient. Sometimes you will find a family that is hopeful that this patient will recover, but then to their surprise the patient actually did not come out of it.

So, the management of palliative care basically is a very slow progress, it requires attention as well, because I feel that it should be one of the most important aspects that we have to work with in the hospital and that we are currently under-involving ourselves in it. Actually, I am not fully satisfied with it that is why they are also thinking of maybe having an awareness campaign, sensitizing on the importance of it, maybe just entailing what aspects it involves. But so far, because of the UNAM social work students involved in coming there and just focusing on palliative care, I could see that the past few months I had a reasonable amount of palliative care referrals from the doctors, because we were able to go and see the doctors directly and were able to consult them, 'if you have any palliative care cases, you can refer them to us'. So, that has improved slightly. But I believe that more sensitizing and more referrals need to be done”.

Ashley reported, “I am not really satisfied. I thought that things can really improve, there would be better settings for these patients, because normally what happens if a person is at that stage whereby the doctors cannot do anything for them, the doctors just say the patient should be discharged and go home and in those cases I saw the family is not in that position to bear that burden. It is somehow a sort of a burden to them, because they do not really know how they are going to handle this patient and maybe if there was a department where they are just taking care of those patients, they have better knowledge and better information and also training to the families so that they can be able to take care of their own relatives when it comes to that stage”.

Three participants however were satisfied with how palliative care is managed in their respective hospitals. For example:

Faith responded, “I'm very much satisfied. Um ... one, we have specialists in palliative care we have doctors who were trained in palliative care. They know the principles of palliate, palliative care, so they try to implement those principles. I'll give for instance with regards to morphine a doctor trained in palliative care should know that he cannot just prescribe morphine.

He has to provide morphine, plus a laxative, because morphine causes constipation. Our doctors are very knowledgeable and they are trying to adhering palliative care principles. And as a social worker I have a specialist diploma in palliative care. Ja, so I'm quite knowledgeable in terms of what is palliative care and how we should support patients suffering from life limiting illnesses and their families. And on what should be avoided when dealing with a patient who's dying in terms of medication, in terms of even communication. Yah, so I can say I'm extremely satisfied, even, because we have like the medication available for cancer patients and other patients suffering from life limiting illnesses, because palliative care says 'if a patient's physical pain is not well managed or well controlled by a certain drug, for example Panadol, you should step up the medication to give a stronger medication such as codeine. If codeine doesn't work, go to morphine'. So our hospital has the facilities, they have got the medication available, they've got the staff. In terms of quality, the quality of services that are rendering to palliative care patients, I am very much satisfied. Also our patients, they get free assistive devices, such as wheelchairs, ah-m leg prostheses, breast prostheses even the food, all the food that they want, the nutritional dietary requirements that they require within the hospital they get free of charge. And some time the hospital, they actually go to an extra extent of providing, buying expensive nutritional ah supplements such as ah ensure and these are small tins that are very, very expensive, but the hospital they buy it and give it free of charge to the patients requiring it".

Kay articulated, "in the unit where I am I would say I am satisfied. I am satisfied, because the way it is done gives patients room of not feeling like giving up easily and it is not making them lose hope totally, we do not give them hope but we also do not make them lose hope. It is as if they are just somewhere in the middle where they get to a point where they feel a bit comfortable to talk about it, because sometimes those fears are not cleared.

In most cases what I have noticed, when they are told 'you have a heart condition', because they know the heart is a vital organ in the body, they start panicking that anytime my heart could stop, but if you sit down with them and talk to them, you explain to them what the doctors are saying, then they get to a point they will say, 'okay, so that

is what is happening', so that fear is not really there of 'I am going to die, I can collapse any time from now'. They manage to rise up and still see life there, although they know 'this is my condition'".

Anna narrated, "we work hand- in- hand. There is always a connection. When it comes to the doctors, sometimes they are not comfortable to tell the patient 'this is what is happening to you' and this is where the social worker comes in or the nurses. The caring of the patient is done very well and the communication between the multi-disciplinary team is very well. I haven't gone through a situation where I found there is no cooperation between the different professionals within the setting, so there is care and support and it comes from different professions at the same time". However, on her level of satisfaction on how palliative care is manage in her primary care setting, she responded that, "it can be challenging at times when it comes to rotation especially because of the doctors. It can be challenging, because sometimes you cannot really get hold of the doctor that initially admitted the patient or diagnosed the patient with a life-limiting illness. That makes it a bit challenging".

4.5.3 Perceived confidence in the provision of palliative care

Faith said, "I am very, very confident in providing palliative care, because the training that I got, it was very, very, thorough and it was also accompanied by a lot of case studies and a lot of practical. So, and the curriculum was quite comprehensive, it covered ethical issues in palliative care, communication skills, team work in palliative care, it talked about grief and bereavement, palliative care with children, it also talked about pain, management, it also talks, talked about doing research in palliative care. So the training was really comprehensive and I, the institution where I did my course, an internationally renowned is one of the best palliative care training institution in Africa, if not in the whole world. So I really am, extremely confident in the knowledge and skills that I have".

Edward expressed, *“I am very confident. Why I say I am very confident, I have been working with palliative patients in a non-governmental organization first. I started as a social worker who was visiting people with cancer and HIV only and then as a training officer later on to train social workers and nurses and community groups, as well as other professionals ... on palliative care and home-based care. So I am quite confident”*.

Shaka perceived his confidence in providing palliative care as, *“I am quite comfortable, but the challenge, not the challenge, but I don't have much knowledge regarding palliative care which I can be confident to engage with a patient you know, effectively, I don't have that then when, for instance, a case is been referred to you”*.

Lucky said, *“I am confident enough, because I know what it entails for me to provide palliative care despite maybe the challenges that one will face when you are providing palliative care”*.

Aardvark responded, *“I do not know, first I would really need to sit down and define palliative care before I can respond confidently to whatever is happening around palliative word. It is a Greek word it is a strange word to me”*.

Alice expressed, *“I would say I am confident, because I have the knowledge and the skills that are required during the time when the person has come to that stage of the end-of-life. I am able to talk to them earlier so that they can be able to control their lives in order for them to be able to live their lives as they wish and how they would want to be buried, because when you talk about death, mostly in our African culture it is a taboo. So as a social worker you are able to talk to the patient and be able to inform them, they can be able to accept that this is the way it is and they will not feel like offended by you talking to them about it”*.

4.5.4 Perceptions and satisfaction with the provision of palliative care services

Faith expressed, *“I'm very much satisfied. Um ... one, we have specialists in palliative care we have doctors who were trained in palliative care. They know the principles of palliative care, so they try to implement those principles. I'll give for instance, with regards to morphine you know a doctor trained in palliative care should know that he cannot just prescribe morphine. He has to provide morphine plus a laxative because, morphine causes constipation. So our doctors are very knowledgeable and they try to adhere to the palliative care principles. In addition, I as a social worker I have a specialist diploma in palliative care. So I'm quite knowledgeable in term of what is palliative care. How should we support patients suffering from life-limiting illnesses and their families and also you know, ...what should be avoided, ... when dealing with a patient, who's dying in terms of medication, in terms of even communication. Yah, so I can say I'm extremely satisfied, even..., because we have like the medication is available for cancer patients and other patients suffering from life-limiting illnesses, because palliative care says that if a patient's physical pain is not well managed or well controlled by a certain drug, for example, Panadol, you should step up the medication to give a stronger medication such as codeine. If codeine does not work, go to morphine. So our hospital has the facilities, they have the medication that are available. They have the staff, although limited staff ...but otherwise in terms of quality the quality of services that are rendered to palliative care patients, I am very much satisfied. Also our patients they get free assistive devices, such as wheelchairs, prostheses, breast prostheses even the food, all the food that they want, the nutritional dietary requirements that they require within the hospital they get free of charge. And sometimes the hospital, they actually go to an extra extent of providing, buying expensive nutritional supplements such as ensure and these are small tins that are very, very expensive, but the hospital they buy it and give it free of charge to, to the patients requiring it”*.

Gift said, *“I am not hundred percent satisfied here, because really we are not involved that much with palliative care. That is why I was also talking about that idea that, if we could have may be have a certain ward, whereby those patients are accommodated,*

that way it will be easy for us to be fully involved, because I have to deal with this patient over and over until everything is final”.

Lucky expressed, “I would say I am not really satisfied. As I said, I think more still needs to be done so that at the very beginning when the person is diagnosed with any of the terminal illnesses, then such a person should be referred for palliative care to the social worker, so already the social worker can start with psycho-social counselling or now palliative care, because I believe this is the reason why you will find problems such as adherence problems, maybe people not adhering to appointments and so on, because some of these things where you pick up that maybe this person was supposed to be adhering, but because there is a component that the person did not understand from the beginning, then they tend to become like hesitant to care or maybe sometimes it is not that they are hesitant, but maybe there are other social needs that were not catered for”.

Shane indicated, “I am not really well satisfied, I am sorry to say, I am not really well satisfied. In most cases, the doctors refer cases to us to trace the relatives. You can even see that the relatives just do not want to stay with their family members. For example, even though you provide the counselling to them today, if you happen to come back from that house, let me say you happen to come to the office, not going there in a month or so because of the cases also that we are experiencing, imagine how that person will be treated by the family members. That is why I am saying I am not really well satisfied by the doctors just sending the patient to go home, just to stay home, I am not satisfied. There are a lot of things involved though, as I have mentioned”.

4.5.5 Perceptions and satisfaction with the role of the social worker in the provision of palliative care

Shaka said, *“I think social workers are being, under-utilized, but what they are doing is less than what they can do. If they, you know, the playing field is improved or if they are equipped, I think social workers can do a lot, if they have the passion and desire and commitment as well”*.

Gift reported, *“we can do education to relatives of the patient, because seriously Madam, sometimes a patient needs to be washed and if that patient is having sores, you cannot just wash the patient like that with your hand like that because, you never know, maybe you are also having some sores, some openings, and you might get germs. They need education on how to do it. They need to be taught that when you are providing these services such as cleaning, maybe you are cutting off the nails of the patient, you are cutting their hair, please use only the things that are only for the patient, do not share those with any other and take care of yourself as well. Maybe you need gloves when you are touching the patient if he has sores. That education we as social workers need to do and we need to educate on the diet. We need to empower the family to ask the doctor that, ‘Doctor, which food is suitable for this patient?’ Sometimes they need a specific diet, not just anything that comes, because the person is already on the worse side, they need something good for their systems, not anything, and the doctor can pinpoint that since the dietician is no longer here. We used to have a dietician, so it is my role as a social worker also to refer the patient to a dietician or the family of the patient to a dietician, to be taught on what foods are suitable to be eaten by the patient with that specific life-limiting illness”*.

Aardvark explained, *“the Ministry of Health social workers do everything in the community. They do not only palliative care in hospitals, but then here in Swakopmund we are all in one, Jack-of-all-trades, master of none. There is nothing we cannot say we won’t do it, there is nothing I can complain about, it is something that has to be done and we are here for the needs of the patients”*.

4.5.6 Perceptions and experiences about interactions with patients and family

Each individual patient and family system has its own unique history, culture and values. How, when and who we interact and communicate with should be respectful of the patients' culture and the patients' needs. Families are an essential part of people's lives. They are the immediate social system that outlines who people are and the lives they lead. The significance of family becomes expanded at times of serious illnesses when people must cope not only with the illness itself, but also with facing end-of-life. During times of an illness and certainly in the context of palliative care, families often become significant sources of support and practical assistance. They need to be engaged in the process that provides a supportive and safe environment as they integrate the diagnosis and prognosis and participate in the care planning process. Family conferences are one of the effective methods to be used in the hospital in the interaction with patients and families in order to deliver palliative care information in a supportive way. This is an opportunity for social workers to facilitate conversations that are open and honest, as well as to support the patients and families as they learn of the prognosis and options for care. For example,

Lucky perceived her interactions with the patients and the family as “a very important role because family in the first place is the only people we have. Like for instance at home, maybe these are the people who will be providing all the care for you and sometimes you find that if these people do not understand your illness, if they were not involved, then sometimes they are likely to drag you back into your stress level or whatever problem you are going through if they were not part of the team when you were diagnosed. So, their involvement is very important and sometimes these are the people that will provide you with resources. As I said, sometimes resources are also a challenge, but you will find that maybe if you involve the family they will be able to assist where they can and they are the ones who are going to take care of this person throughout their lives since maybe sometimes they cannot even help themselves.

Deepening the relationship between the family members and the clinicians is vital to develop therapeutic rapport and trust that may enhance the relationship with palliative care clinicians. For example:

Lucky said, “Another important component, because these people sometimes, the way a patient him or herself understands the sickness and the way you made the patient understand, these are sometimes even the people who will influence the patient not even to adhere to medication when they come in with cultural issues and traditions, because if they are not made to understand the conditions, they are the ones who might even think that this is a curse or something and then they are likely to take this person for traditional healing and so on and then you find that the medication or whatever you are trying to do will not work out because of that. So, if you involve them and then they are at the same level of understanding, then your challenges will also be less from your team as a medical team and also their side as a family”.

When an individual is diagnosing with a life-limiting illness, the entire family system is impacted. Each member of the family is in a different state of well-being, with some more than others able to endure, grow and adapt positively to the new situation. Core communication and intervention skills for interaction and working with patients and families are essential cornerstones of every good medical encounter and within the framework of treatment of a life-limiting illness.

Key components of social workers’ interactions with patients and families include assessing the patients’ needs and the families’ social circumstances building trust and therapeutic alliances; providing continuous psychotherapy and offering practical support. For example:

Alice perceived the social workers’ interaction with the patient and the family as “one of our major roles, involving the family members, because we believe that the family members are the key point, the foundation of successful interventions.

So it is very important communicating with the patient and communicating with the family, a very significant point, as very significant interaction, because you get to know that in the family's encounter or in the patient's encounter that the patient is actually going through a major change and that is only if you get involved with them that you see this. Sometimes some patients feel that 'if my brother is there, if my mom is there I open up'. So it also helps opening up those doors to the patients, whereby the patients can openly, freely express themselves seeing that they have the support of the family members or they have the support of the social worker”.

However according to Shane's experiences, some of the family members were not willing to cooperate. He said, *“Some of the family members are very welcoming, because they really care about their patient, but there are some of the family members who are not welcoming you because of the patient that you are bringing at their houses. They will look at the patient as a threat and they will no longer look only at the patient, because you are the one who brought the patient they will also look at you like, so why are they coming at our house, she came to do what now?’ So there are some family members who are very welcoming and there are some who are not. On top of that, even though they are not welcoming, you just have to provide them with information. At least some of them in the middle of your session will at least understand the reason why you brought the patient, the reason why the patient has to be home, the reason why you need a social worker to be involved in those cases and they will accept their patient. Some patients whose family members, I did not bring this one in, but our brothers who are suffering from mental illnesses, there are some of them just do not have relatives. You know we are near the Angolan border and we are not even allowed to go in there, so the patient will mention some family members in Namibia but in your investigation you would just find out that those people are nowhere to be found. So, we have those patients in Ward 16, I think they even stayed for more than ten years, we have them”.*

4.5.7 Perceptions and experiences about interactions with the multi-disciplinary team

Palliative care by definition, through the multi-disciplinary team approach, attempts to improve the quality of care for patients with advanced life-limiting illnesses and their families. It takes a multi-disciplinary team of highly specialized professionals to care for a single patient with a life-limiting illness. Providing palliative care for several patients with life-limiting illnesses is a daunting task. Such care requires a multi-disciplinary team approach and the social worker is an essential member of this team. Collaboration with the multi-disciplinary team is a vital cornerstone of palliative care. The social worker's interaction with the multi-disciplinary team is important because many identified needs of the patient and the family require specific social work skills to provide better preparation and education, clarify the goals of care, enhances communication, helping with transition between care settings and connection to resources. In addition, this teamwork ensures the best provision of palliative care for the patient and the family whose needs are at the centre of the team's purpose and function. Lucky, Shane and Alice emphasize the importance of a strong team.

Lucky perceived her interactions with the multi-disciplinary team as “very important, because the multi-disciplinary team members are in most cases, like I said, the patients in the first place are diagnosed by the doctors and when they are diagnosed you would find that even with the doctor finding that this patient is one of your patients that they need to refer, but then again you will find that even if you are to provide this palliative care, you have a long list of needs as well from the medical point of view. Like maybe you still need occupational therapists who will also provide some assistance on what a patient can do and what they cannot do and sometimes you would see that this person may also be in need of exercise maybe, whereby we involve physiotherapist and others and also nurses who care for patients on a daily basis, they also need to be made aware or as part of the disciplinary team. My experience is quite good as long as you work together, then each one makes the others aware of what they are doing, and then they know why you are doing it.

Like I mentioned in the beginning, the particular role that the social worker has to do, first is for you to make other members of the multi-disciplinary team understand your role and this role is you have to provide that psycho-social counselling whereby now you intervene and see what you can do for a particular patient, because each patient is unique and each one will have their own needs according to their uniqueness. So it is not one size fits all”.

Shane said, “the interaction, when it comes to life-limiting illnesses, one thing that I have seen especially with motor vehicle accidents, when the case is very serious, like life-threatening, life-limiting, the social worker from MVA organizes a meeting. He or she will contact the doctor, the nurse, and the physiotherapist and the social worker involved in the case. In the meeting we have to gather, that case will be presented, and all the roles of the social workers, doctors, nurses and physiotherapist will be highlighted. So at least in that case when it comes to the motor vehicle accidents, the communication or the interaction among the team is good. Another one for the multi-disciplinary team again is for the clubfoot that I have just mentioned. So, the interaction is very good because what I have observed, I am the one who had been responsible for that thing, so 2014 July when it was introduced, they just dis-allocated me there like not even a month ago, but the interaction is really good, they cannot even make the decision without one person, so meaning that they value every person in that. When the mother is coming, the first person to see the patient is the social worker to assess the patient. In the assessment of the patient it is actually like, information about who are some of the family members who can be of support to this patient and to provide education, because that treatment is for four years. So, we give that information on the importance, for them to be committed to come for follow-ups each and every time. Once we are done with that, then we refer to some other nurses, doctors and some other technicians, like the casting, to release the tendons because the tendons used to be very tight, that is preventing the feet to move. So, without one the multi-disciplinary team will not be working”.

Alice described, *“my experience is actually very big, it is very encouraging and it is motivating, because you see that the doctors are working for the best interest and the well-being of the patient, the nurses the same and it is just amazing to see how things get done faster if you work in a team rather than working alone, because you get there and then you are stuck on a medical term and you go to the doctor and you ask the doctor to elaborate and they do it freely and it also helps with your plan of action at the end of the day to know what you are going to do with the patient. So the experience for me has just been amazing. What usually happens in the hospital setting, there is a multi-disciplinary team whereby the doctors and the medical social workers work together with the nurses, which means once the patient is admitted within the hospital and the patient is diagnosed with a life-limiting illness and the doctors find that according to the prognoses there is not actually much that can be done for the patient besides treatment, then the social worker is informed or referral is given to the social worker in order to prepare the patient with the family and the role of the social worker will then be to prepare the patient, explain to the patient, explain to the family about the condition or the life-limiting illness and also in terms of linking the patient with any other home-based care, depending on how far or how the doctors see the patient’s illness, the life-limiting illness.”*

Some of the participants shared some negative team experiences. For some of the participants who were able and not able to attend multi-disciplinary team meetings or ward rounds, they shared different experiences on the multi-disciplinary team. For example:

Aardvark perceived the social workers’ interaction with the multi-disciplinary team in her setting as, *“challenging, because social workers are seen as not so important and if you talk, sort of advocacy talk and trying to make demands and put your foot down, you are seen as this trouble-maker or always-fighting person, like, ‘oh, social workers like fighting’, that kind of thing, but I think it is not only here, I think it is a ministerial thing whereby it is saying Ministry of Health, so the health that is an emergency is always put first and social services come in lastly.*

I think also with that most of the staff members, especially nurses and doctors, but the doctors we do not really have that much of a challenge with them, because immediately if there is something we can refer, but then the nurses and most of the other staff members, like the community counsellors and so on, they do not really see what we do, they just feel like it is a profession for losers”.

Shaka described his interactions with the multi-disciplinary team as, “*not strong or non-existent in the hospital. Of course they are here and there are referrals that I’ve been dealing with but, I think it’s also important not only to train social workers, but also the doctors and the nurses they are the professionals who give the clinical input so that they when they provide care, because they are the first point of contact when a client comes to them, they be able to have the knowledge and say ‘okay, this is a patient in a life-limiting illness, let’s refer him to a social worker, let’s work together as a team’ ... but here it is not strong, may be it is, because of the shortage of the healthcare professional. The doctors do not have time that we have to sit and say ‘so what is the problem with the patient ...’. Or the doctor just writes the referral ‘it is a HIV defaulter’ see social work. So this is how it is done, so there’s no feedback between the professionals”.*

4.6 CONDITIONS THAT HINDER SOCIAL WORKERS’ ABILITIES TO PROVIDE PALLIATIVE CARE

The third objective of the study, to analyse possible conditions that hinder social workers’ abilities to provide palliative to patients, became one of the central themes emerging from the data. In addition to the sub-theme of feeling that their role as social workers is not well understood, minimized and underappreciated, many other sub-themes emerged as conditions that hinder the social workers’ abilities to provide palliative care. These include the roles of the social workers not understood by other health care professionals; lack of palliative care training; lack of in-service and continuous education and research on palliative care for social workers; communication barriers; referrals from doctors and nurses to social workers not mainstreamed; medical jargon used by doctors and shortage of specialized palliative care social workers.

It include heavy workloads; the well-being of social workers; the lack of supervision and debriefing opportunities; lack of support from management; lack of appreciation for the role of the social worker; lack of bed space in the hospital and additional factors were identified as hindrances in social workers' abilities to provide palliative care.

4.6.1 Roles of the social workers not understood by other health care professionals

Role clarity is essential within the palliative care team and between team members and it is equally important in collaborating with the primary team members. Social workers' ability to articulate their role is vital if professional team members are to learn about palliative care social work. Theoretically, the notion of insufficient multi-disciplinary understanding was presented as a possible barrier to effective social work health care professional relationships in the multi-disciplinary team, since health care professionals may be unsure about the job description of their social work colleagues. Too often, the role of the social worker, when one is included in the multi-disciplinary team, may be misunderstood and underutilized.

Referrals are often done for practical assistance such as assisting with housing, school fees, nutritional support, linking resources and families, community networking and income-generating projects. Social workers are seldom recognized as allied health professionals because their training is strongly focused on welfare and development issues. In most cases, the counselling role of the social worker in treatment is unacknowledged. Role definition and boundaries issues emerged for two of the participants.

Catherine explained, *“sometimes it is really not clear, I think to the other members, to the nursing staff. Sometimes it is not clear what type of cases to refer to the social workers, so anything that they do not understand, sometimes I think like they neglect what they are supposed to do.*

In addition, they just refer to the social worker like if a patient come in with a headache or with a neck pain or you know something that is just giving a stress symptom then it is refer to social worker. So sometimes I feel there is a lack, ... they can neglect with regards to what they're supposed to do, their intervention, first intervention and they will just refer the patient to the social workers, because whatever sign sounds like it can be stress... Yes, many times cases for social workers are linked with depression, stress you know that type of thing and not the long term support that the social worker can surely give someone in order to live a positive life, yes, with regards to whatever illness they have been diagnosed with...sometimes you find that the patients themselves will just be angry about this and then they go home”.

Lobbying for an equal place on the multi-disciplinary team remains a challenge for social workers, however, it remains the responsibility of the palliative care social worker to raise awareness about the potential and benefits of palliative care social work.

Edward narrated that, *“with the professionals we are working with, there are others who do not understand our role and again sometimes it is not the problem of the professional, perhaps it is ours as social workers, because we have not been able to explain ourselves before them. However, basically, because there are other professionals who do not understand what social workers do, they would just think we are there to facilitate the provision of food or the provision of other services in the community that is their perception. I am saying it depends on the individual, others understand that this one is not my job as a nurse, this person needs counselling the right person to do that is the social worker”.*

Aardvark reported. *“... over the years social work has only be seen for children's problems and when HIV started, now counselling is only for HIV people and then also the fact that the social work professionals themselves do not really advocate much or market their profession, so the lack of understanding due to this can also be a contributing factor”.*

4.6.2 Lack of palliative care training; in-service training; continuous education and research on palliative care in the Namibian context

All participants noted the lack of training, lack of in-service training and lack of continuous professional development on palliative care as barriers that hinder the social workers' abilities to provide palliative care. For example:

Faith described, *“the lack of training on palliative care as a condition that hinders social workers' abilities to provide palliative care. At my particular department ...some social workers are afraid, to work in a palliative care setting. They rather work in a ward, whereby they are no palliative care cases. They are afraid, you know of death and dying. Yes and some of the factors that may hinder social workers at my institution from offering, good palliative care services are a lack of refresher courses on palliative care. Moreover, we do not sit as a department to discuss best practices, to share cases, you know, to discuss, like, even case studies, to share our experiences. We do not have time for that. Therefore, it is like the experience that I have, you know, in, as a palliative care social worker, we do not make time to share, you know. Others, social workers are not learning from me, because each one is just busy in their own departments. We do not really have time, you know, for continuous professional development for professional growth. The time that we have, it has just to attend to the needs of the clients that are all, but you know, if you do not sit and share best practices I believe that we are actually doing a disservice to the profession, yes. Another challenge that I see is lack of support, like in terms of debriefing, you don't have professional support, just to support you as a, counsellor in a palliative care setting, So, that one is also a very big, challenge”.*

Catherine explained, the *“lack of training in palliative hinders the work of the multi-disciplinary team. Due to the lack of information, the lack of knowledge that the multi-disciplinary team does not have, does not acquire, they do not refer cases to the social worker. I am also challenged to provide bereavement care because I did not receive any training in palliative. I am not confident with bereavement counselling”.*

Shaka reported, *“the lack of training and continuous education as number one and the lack of the institutionalization of palliative care component within the ministry or within our care setting as the two major hindrances that I have encountered”*.

Aardvark expressed, the *“lack of knowledge is perishing. Knowledge brings wisdom and then more better understanding of things”*. Her responses to whether she received any undergraduate social work training in palliative care or attended any continuous education in palliative care were all *“no”*.

Faith further expressed, *“we don’t have local information on palliative care. What we normally utilize is western-based. There is not so much research, even like if we are to look in the Namibian scenario, we do not have local information on palliative care. We do not have research on palliative care we do not have research on the social workers’ role in a palliative care setting. We do not have case studies, social case studies on palliative care. There is so much information that is missing in terms of palliative care in the Namibian context. So that one is a very big limitation, which limits social workers’ abilities to render palliative care like culturally specific and context specific palliative care services”*.

4.6.3 Communication barriers

Communication barriers, for example, lack of referrals from the doctors and nurses to the social workers result in patients not accessing palliative care, and some even dying without being referred to the social worker. Theoretically, communication breakdowns between social workers and the other health care professionals occur for many reasons, as presented below:

Alice explained one of the factors that hinder her ability to deliver palliative care. She said, *“sometimes you will have patients that are just lying there without palliative care and at the end of the day they just pass away. You just pass by the ward, for example, and you see a dead body and then you maybe try and encounter, asking questions to the nurses, ‘now what has happened with this patient’ and then you are told that this patient has been suffering from this and this, which actually is a reflection to yourself by thinking like, ‘but this patient could have been for palliative care, family could have been involved, but that was not done’. So, sometimes I just feel, especially with the discharge and sometimes with the dying of patients it is not brought forth to the social worker, you just go hear after that”*.

Edward’s experience highlighted the gap in proper referrals from the doctors or nurses to the social workers. He described, *“sometimes you learn from clients, like for example, how is your mother, ‘oh, she died a long time ago’. Where did she die? ‘She died there at the hospital’. Then you as the social worker ask the family member, ‘so what happened?’ So yes, my friend, there are many things I do not have time to explain to you. There is a gap and that is how we identify certain clients”*.

Anna said, *“sometimes it can also be communication between the nurse and social worker that can also be a challenge, a misunderstanding, because sometimes why I say that is, it is a process for the social worker especially when family members move or they are transferred from another health institution to the hospital and it is difficult to get hold of the family members. It takes time and that also brings a little bit of friction”*.

Participants identified heavy caseloads that were overwhelming due to shortage of staff, lack of specialized or medical social workers as well as their given realities of operating as both generalist- and hospital based social workers.

Alice explained, *“in terms of communication, I think the lack of it comes from both ways. It can be sometimes that we get too busy given our workloads, which we do not get back to the patient maybe, which at the end of the day is a strain to our work as well. Maybe it is relooking at how we do in the ward rounds. Does it mean getting involved more in the ward rounds to pick up the cases as well, because sometimes the doctors will not pick it up at that day, but maybe the next day as they are communicating with the patient, but our side is getting involved maybe more”*.

4.6.4 Referrals from doctors and nurses to social workers not mainstreamed

In the section below, the subtheme on referrals from the doctors to the social workers not been mainstreamed are discussed. Catherine shares her experience.

She indicated that, *“no referrals from the doctors and the nurses hinder my ability in providing palliative care. Yes, I think that is the main thing that would hinder. It is standing in the way, the fact that people just leave the hospital are just discharged from the hospital without ... been seen by a social worker. I think it would be more effective if we could probably get the doctors to really refer cases that they think need further support, because many times the person is just diagnosed here and then the person is at home, until such a time that a person would be in a depressive mode or depressive state and comes back to the hospital then it's diagnosed as depression and referred to social worker”*.

Nanna's excerpt highlighted, *“if the person is terminally ill, because most of the time if a person is diagnosed with a life-limiting illness, social workers are not involved or rarely involved, or referred to the social worker. With my two years' experience, most of the cases that I have handled are at the last point where the person is bedridden or if it is cancer ... when there is nothing more that the doctors can do, that is the point where the social worker is called in. Or where patients with HIV and AIDS have defaulted and at that point where the person is not capable to take care of himself that most types of the referrals are made.*

When the person is diagnose with cancer or HIV and AIDS or any other life-limiting illness, many a times we are not involved. In the two years when a patient was diagnosed with cancer a doctor informing me that ‘this person has been diagnosed with cancer and needs counselling’, I have not experienced such a thing. With my experience, I had two cases where people were terminally ill to a point where this person cannot talk. That is the point where I was called in and I was questioning now, how long has this person had this condition. Why was the social worker not involved from the beginning? So many times, it is at the last point with HIV and AIDS. There are here and there cases where or only when the person does not want to accept their condition, that is the only time most of the times they are referred. But then when it comes to Windhoek and there is not much that can be done for the patients and they are referred back ...you just get involved at the last stage of life”.

Nanna further explained that, “firstly what I would say ...factors that could hinder me as a social worker from providing this particular palliative care services is, if I’m not involved, I won’t be able to reach out to this patient. If I am not involved from the beginning, or if I am not aware, it’s very challenging at this hospital setup. It has not specialized as to say, there are particular doctors that handles particular cases. Or this particular ward is for these particular cases, it’s not specialized to such an extent where I will be aware if there’s a patient that is recently diagnosed with a life-limiting illness, in order to attend to the patient. So this is what would hinder my ability, if I’m not involved at the beginning. So, making the doctor aware of the importance of involving the social worker from the beginning is there, but then that involvement from the beginning could be a hindrance if the patient is just discharged without referring the case to the social worker and then this person just comes back and dies in the hospital, nobody was informed”.

Aardvark emphasized, “I think two weeks ago it is the first time that it was brought under my attention by a medical social worker from Windhoek that cardiac patients also need this intervention and so on and many a times most of these patients who have life-limiting illnesses or who need palliative care, they just end up in the hospital and discharged from there without being referred to the social workers...”

I think lack of knowledge of what social workers are also supposed to do as well as lack of knowledge for me especially as a senior social worker when it comes to palliative care, what is it that I am supposed to do, how am I supposed to approach this, because in the end I am able to educate the medical officers on the importance of referring this and this type of patient to the social workers for psycho-social support. I only get involved when HIV patients default and then they are in the hospital. I will mostly say it is when they are about to die, this is how I got to see them. The moment we see them they are almost just like bone and skin. So, the reason why we get involved, the purpose for the medical staff to call us in is just to explain to this person what will happen to him if he is not taking the medication, but then we do more than that, we try to understand why the patient is doing this, then we try to help the patient and find solutions to the challenges that they are facing. With the TB ones we actually only get involved when the patient is referred to the TB Hospital in Walvis Bay, then they have to go through a social worker. Sometimes they can even just tell us the same morning that patient is going, not even when they are diagnosed with multiple drug-resistance TB, just that same day, then you have to now quickly, quickly run around and try and inform and then you find out from the patient the nurses have already told him all these things, is there anything that needs to be done before you go and so on. Sometimes we tell them this patient still cannot go, because he is having this challenge, but then you will just realize 'no', the nurses will tell you the doctor send the patient even though they gave you such a short period of time”.

Charlotte said, “they maybe have to refer some of this more, they are not referring enough. Rarely will we get palliative care issue here. I know there is one woman who was lying here in the hospital for three months, who was never referred to us. It is only that I know her that go to her sometimes, but she is in a coma, but her family is with her. So you could have worked with the family if there was a proper referral, but now she has just seen as, she is just captive and this family really needs support. As if now the family has asked to be given a hospital bed and things and so on, a hospital bed and gas cylinders for oxygen and so but people refuse, because they said it is the hospital property that the hospital refused to give it so the family cannot afford it. Nevertheless, they are willing to take care of her she is still in a lot of pain.

The hospital personnel feel the person cannot stay in the hospital, because she's in a coma for three months and now to send her out to the family, she needs some equipment to keep her alive, but the hospital is not able to provide the equipment”.

Alice explained, *“normally the doctors pick it up, but then the referral is very slow. They have ward rounds Mondays and Wednesdays, so if they see that this patient requires a social worker's intervention, you will find that the referral of that the patient will be brought to your office or the nurses will bring the referral which has been made by the doctor on Monday, only on Friday for me to the patient. I do not know if there is communication problem with the nurses and the doctors about referrals that are made, but it is very slow”.*

4.6.5 Explaining Medical jargon used by doctors

Medical jargon used by doctors is one barrier contributing to lack of communication towards ensuring effective patient health-care and treatment adherence. In addition, a lack of education (in relation to the ability to read, write and understand in a language) is another dimension that affects patients' understanding of treatment adherence. The manner in which doctors inform patients and the terminologies they use describing the diagnoses of a life-limiting illness often has implications in the patient's understanding of their experience with this illness. Cassileth and Ackerman (2000: 229 as quoted in Altilio and Otis-Green, 2011) allude that *“during the initial conversation the patient may not have heard what was said, concentrating instead on the word ‘cancer’”*. In such cases, it is evident that the social worker has a vital role in communication with the patients and the medical team in breaking down and simplifying the medical jargon used by doctors. Social workers help the patient to identify important issues regarding their understanding, experiences and treatment goals and prognosis. During the communication and interactions with the patients, social workers can identify gaps in patients' understanding that they themselves may not have recognized and then support them.

As an essential member of the multi-disciplinary team, the social worker is well positioned to verify and clear health information with the medical service providers and convey information to the team when needed. The data from this study revealed that medical jargon and a lack of understanding from the patients are some barriers identified to effective communication between patients and the medical service providers. For example:

Faith reported, *“I have seen that the doctors they use medical jargon that the patients don't understand. The doctor can just say ‘no your cancer has metastasized, your cancer is terminal’, but the patient does not know or understand what that is. So sometimes after speaking to the doctor, the patient comes to the social worker and says ‘the doctor told me that my cancer is terminal, can you please explain more’. So, yes sometimes you have to breakdown that jargon and explain in more simple terms what the doctor is trying to say. However, in all this, I work in consultation with the doctor I do not work independently from the doctor. We are we work as interdependent team members. Yes, and I point out to the doctors where patients need clarification...because, sometimes you know, a patient says to me, they were never told that they have cancer. Then I explain to the doctor that the patient says they were never told that they have cancer. But due to communication breakdown the doctor might have said ‘ah no you’ve got osteosarcoma’, but do not really explain it in explicit terms that ‘you know you’ve got this and it is called cancer’”*.

The communication dynamics between staff members are identified. For example,

Aardvark reported, *“we have a very good communication, even though I said they have the attitude that if social workers stand up and go say ‘sorry, we are human rights officers, we are here to fight for these patients, we do not want to cause problems ... in the end we are also here to make sure that our ministry has a good image’, that way they at least listen and then they do not really give us that much of an attitude.*

If there is something we put it down in the patient file and then we are also called to inform them that it there is this and that, but it is also in the patient file and then the medical officer we inform him and if we cannot trace him, we at least let the nurse know, 'please make sure the medical officer sees the note that we have put in there'. With that we have actually made sure that if we put our point down, 'sorry, you do not come and overrun it' and then we try to stand up for the patients the little chance that we get to stand up for the patients”.

The issues of communication breakdowns are discussed in the literature. Nanna also experienced this.

She described, “the lack of communication can be a hindrance and providing feedback if this person was under investigation for a particular life-limiting illness and it was confirmed, then no communication was given to the rest of the multi-disciplinary team, this person was just put on treatment, because the person can still cope with the condition, but then if that feedback was given in the beginning this person was under investigation for this particular life-limiting illness, these are the results, it is confirmed, this person is put on this particular treatment, then, that can be a help, but then the feedback that is not provided can be a hindrance, the lack of communication can be a hindrance, the lack of, of proper history taking can be also a, a hindrance as well as the lack of working together as a, as a team can also be a hindrance”.

Kay emphasized that, *“sometimes it gets to be a challenge when it comes to language, to talk with these patients and probably the person that should come and help is also busy and the patients cannot wait, so how do I render that service if we do not understand each other? I might understand, but for me to give them the information, we do not understand each other. At the end of the day maybe that patient was just coming from the clinic for follow-up and that is the time I am supposed to see this person, then I will not be able to do it. Sometimes I make an appointment with the patient for the next follow-up and then I arrange for the interpreter to be on standby that time”.*

4.6.6. Shortage of specialized palliative care social workers and social workers' workloads

Faith indicated, *“the only challenge is that the staff is few, they're short staffed and they're quite limited so they may not be able to render the services at an expected place to the expected extent, because they are short staffed. The problem with some team members is that they are short staffed. Moreover, like the OTs, we only have, let me talk about the physiotherapists. We have three physiotherapists for the whole hospital, and those physiotherapists are supposed to work with each department in the hospital. I think that within the hospital we have more than ten departments, so it is impossible for them even to attend ward rounds on the wards. In addition, at any one point in time, there could be five ward rounds taking place at the same time in the hospital, and the physiotherapists are supposed to be on, in all of them. So, because of that you won't see them coming, because, they don't have the capacity and at the same time they should be attending to patients within their department”*.

Tawya reported, *“now we are three, our chief resigned, we are only three, and we are covering the whole region. The region, which is having seven constituencies, and some of our patients are not only in Gobabis. They are outside Gobabis, and when it comes to support, supporting them you really need to visit them, once or twice, or once a forth night. Or once a week, but it's not possible, because we are overwhelmed. Therefore, there is need to, while you look at the staff establishment you also to look at the material support and financial support for such patients. If I could have it my way, I could probably change the policy to say, “whoever has been diagnosed with a life-limiting illness should automatically qualify for the financial support from the government, because they are going through a lot”*. Tawya further explains conditions that hinder his ability, as a social worker *“is the amount of cases that we deal with. That one is or can be a great hindrance and uh...”*.

Edward explained, “one thing that we have to understand here is that this is not primarily a palliative care setting, and as a result social workers have certain duties which are considered critical to their functions at the hospital. Therefore, I would say that social workers are doing a lot in terms of the mandate given to them by the government, but when it comes to palliative care, that is where I am saying palliative care is one among many other functions that have to be fulfilled by social workers. They are doing well, because they have a mandate to fulfil. Palliative care is very important, but it does not get the attention that it deserves, because it is one among many other competing functions that social workers have to undertake”.

Richard reported, “I think the roles I play in this department, as I am doing palliative care, I am doing research or I might be assigned especially from my chief to do something else. Like other commitments, for example, I would be going for survey for a whole month, which is not a bad thing, but I have to make a plan for follow-up for my patients. So, I am not saying it is a bad thing to be doing other things, but looking from the point of view of the patient, I think I am not giving them as much attention as they require”.

Shaka indicated, “a huge workload is one problem, because we do everything, for example, if you want to plan for an event, let’s just say a TB day, when you start, for example, you are the one who do everything from getting quotations, preparing the program content, going to the venue to get chairs, you are the one who carry them, put it in the car, go to the place, so it’s a huge workload. So for me then to think and worry about palliative care, ah, it will be difficult”.

Aardvark said, “the first thing would be to advocate for a medical social worker to be appointed for that specifically, just like at Windhoek Central Hospital and so on, because it was amazing to hear that at Windhoek Central Hospital each ward has got their own social worker dealing with that specific illness of a patient. I think that will be the most important thing, which is already in the pipeline though.

Then for the operational social workers, if the patients are discharged back to the community, maybe link them with home-based care and then let the home-based care know that if they feel that they are being challenged to this point, then they can refer back to the social workers. I think that is what can be done because palliative care will not be an operational or developmental social focus area, but if we are in the community, just to educate the community to know about that and link them to the resources that are there to give those services". Aardvark further reported that, "the fact that we are not medical social workers. It is frustrating to be out in the community and people expect you to be sitting inside the offices and then the social workers also get frustrated to be in the offices most of the time, sitting and waiting for when counselling is arriving or walking around in the wards, trying to ask, there is nothing. So as I said, I think there is a need for medical social workers to just come in and do their part so that we can focus on what we are able to do inside the community. I think that would be something important for me and then besides that, what I have realized around is that there is so much demand coming with this on the social workers. Forgetting that social workers currently in the Ministry of Health and Social Services are not specialized and they are not specialized in one thing only. It is a great challenge when every directorate or department, let me say, every division, as human trafficking comes and make their demand ... suicide comes and makes their demand. Then here comes psycho-social support and makes their demand. I think it is a lot on one social worker and it can cause havoc rather than giving quality services to a patient. Even though we are in the hospital, we are actually district social workers who also serve as medical social workers and I think it becomes too much, because later on what you do is you try to plan something whereby you can see how you can integrate this, but then if palliative care was maybe singled out and addressed separately, which means you will have to neglect all the other social problems in order to focus on this for at least maybe one quarter, but then you are expected to report on all of them on an a quarterly basis".

Alice explained, *“because of the shortage of social workers it is impossible to join the doctors with the ward rounds, so we do not join them in the ward rounds we just do our own ward rounds. There is a certain time we put aside and then we go into the wards and we go and find out what cases were referred.*

Time and heavy caseloads were some of the other contributory conditions hindering social workers’ abilities to render palliative care. For example:

Alice said, *“time, in the sense of, let me start with the medical ward, in the medical ward there is a very heavy caseload, because the patients require a lot of in-depth interventions and a lot of in-depth assessments. Sometimes you just do not get to that point whereby you go and see the patient or you sit with the family and you talk with them, because of the limited time you have trying to deal with other cases and neglecting this case. I think also the lack of awareness by the other health professions regarding palliative care can be also one of the major factors in hindering my service and people’s ignorance”.*

4.6.7 Well-being of social workers

Some participants noted feeling overwhelmed and overstretched, resulting in feeling inadequate around the quality of care he or she is able to provide. They noted that the well-being of the social workers is compromised due to lack of supervision, lack of debriefing opportunities and lack of staff wellness programs. For example,

Faith’s experiences guarantee further investigation into the well-being of social workers. She said, *“the only issue is that I sometimes feel I feel overwhelmed. So much work needs to be done. There are so many things that I desire, so many initiatives that I do desire to do. You know as a social worker, but I am limited, I am not able to do it because, I am all alone.*

Therefore, yes, that is the only issue that sometimes I feel overwhelmed. There are no resources that are availed even, for such services in terms of caring for the professionals. The staff must take care of their own welfare. There is no one to take care of the staff. Even our supervisors, it is as they are only concerned about patients' wellness and not staff wellness. Yes, it is quite unfortunate and then people get burnout. People get burnout, yes, sometimes people are booked off sick because, they are overwhelmed with work they are burnout. In addition, we do not have a wellness program in place just to even to do those debriefing sessions, just to relax to go outside the hospital environment, you know, and socialize. We don't make such provisions, yes...so there is a great, great need for, you know, caring for the carers”.

4.6.8 Lack of Supervision; Debriefing and Support from management

On the issue of whether there is any support structures in place to alleviate feelings of being overwhelmed, Faith reported that there are minimal, if any opportunities for supervision, peer support and debriefing.

She responded, “unfortunately, there is not any debriefing or supervision provided. It’s, like within the hospital setting, everybody is just busy attending to the patient's needs, that we forget, you know to care for the carers”. It is as if we are here fulltime for the patients. And sometimes because, the staff is so short staffed, people can make medical errors, you know, especially the medical doctors in terms of prescribing, or the nurses in terms of dispensing the medication or the pharmacist as well. There is no supervision. I am somebody who can function independently, however, for somebody new to the oncology department, the person may struggle if they are just put in an oncology department and you do not get supervision from anybody, but you are just alone, and expected to work. Somebody can find or experience a lot of challenges, so there is a need for supervision and also there is a need for appreciation”.

4.6.9 Lack of appreciation for the role of the social worker in providing palliative care

Faith described, “you know, for you to feel that you are being appreciated by your employer in as far as the work that you are doing, there should also be incentives for people to pursue palliative care training. And also for efforts to be acknowledged, even when, like I went, to get that postgraduate diploma in palliative care, I took unpaid leave, I... went at my own expense, I stayed for a month and I obtained my qualification after the course ended, but my hospital did not even acknowledge it. Although the qualification is benefitting the hospital and I was one of the first two social workers to enrol for that palliative care course in Uganda. Nevertheless, my, my employer didn't seem to really even, see it as a big achievement [laughs]. So it can be very, very discouraging that you know, I, I go an extra mile giving it all my best, but my efforts are not acknowledged. They were not appreciated, so I think that is an important role, there is an important gap that is there in terms of lack of appreciating palliative care staff... Cause it takes, you know a big heart, you know, it takes dedication, it takes commitment, it takes patience you know to work in a palliative care setting but, I feel that our hospital does not appreciate such effort ...”.

Edward indicated, “what has been lacking is support from management and as I have said, it comes back to what I said earlier, they have to be given further training or I do not know whether we can call it further training. I think it should start from their training at university for them to appreciate the role that palliative care social worker has to play here in the hospital”.

4.6.10 Lack of bed space in the hospital

Selma reported bed space in the hospital as another challenge. She described, “because I will still feel I still need to continue talking to this person, but when it comes to bed space in the hospital (accommodation), we have a lot of patients that are coming in on the waiting list to come and they receive active treatment, then the team will decide, ‘no but we cannot keep this person here, because we need space we need a bed to keep this

person in, to bring the other person. If we keep this person alone for this period of time, meaning we will be having a lot of patients waiting and we will not even meet our target'. So, it's really disturbing when it comes to that part... And they get discharge they go home at the same time they find social problems going on there and then at the end of the day they come back again. It's like there's a lot of relapse there. Yes, um, because of space that is short in the hospital”.

4.6.11 Limited resources

Social workers in the primary care settings in Namibia operate within insufficient resources and palliative care social work in particular needs to attend to the psychosocial impact of life-limiting illnesses in the health and well-being of the patients and their families. In this study, the majority of the participants mentioned lack or limited resources affiliated with the hospital, such as limited budget allocations, lack of transport, breakdown in telecommunication such as computers and telephone lines as hindrances in their abilities to provide palliative care. Although palliative care in Namibia is still a growing trend, social workers in primary care settings are often face with a hospital that has limited resources for palliative care provision. Si, Taywa, Edward and Ashley describe their challenges.

Si reported, “factors that are hindering... are when there is no transport, it can hinder. Then here and there a communication breakdown, because of telephone lines which are not working. You also find that when your computer has broken down there are no way you can give nice feedback when it comes to statistics and all those aspects. Currently what we are experiencing, we do not have computers. Some of the computers have broken down which are maybe the things that can be address from the management’s side. When it comes to abilities of the social worker itself, for palliative care, people need to be informed they need to be taught about this topic”.

Taywa in response said, *“I don’t know how many times we have sat now as a region, as to cut on the budget. So already, you can tell that our operations may be hinder.*

We were supposed to start with our monthly outreach visits. Where we have an opportunity to visit our clients, who are outside, but we have not done that from April and now we are in May, we have not done that, because of budget issues and transport issues. So those are some of the challenges that we meet on a daily basis for us to do our work, ja”.

Edward reported, “the most important one is as I have said the competing targets that we have to accomplish and as such we operate under limited resources. That is the main major problem, resources. If I have to follow up to meet patients and their families, I need transport and sometimes the budget does not allow and sometimes the budget is there, but the patient has not been identified for follow-up. You only learn about certain clients by default when community members come to tell you this is what is happening”.

Ashley explained, “we have limited resources in terms of manpower, in terms of office space, in terms of hospices. I feel if we are able to have hospices, they can also be very helpful in the provision of palliative care”.

One of the participants identified a gap in palliative care service delivery. She highlighted the fact that palliative care does not feature in the national work plans of social work and that is another condition that hinders social workers’ abilities to deliver palliative care.

Charlotte explained, “one of our biggest problems is the fact that palliative care was not featuring anywhere in our plan. I brought it in. So it is also still new for some of them, they do not really think it is their work. So they feel, if you say do this, you have to try and every time repeat it, ‘no I didn’t get time, I didn’t get time’, but in the meantime the patient there needs it urgently. So that is the type of things it is kind of, I don’t know how we will, how, in what short sentence I can say it, it’s a little bit stuck to a plan which is. They feel they, it is not in their job descriptions, not their work. It’s supposed to be health extension workers who should do those things ...”

4.7 CONDITIONS THAT STRENGTHEN SOCIAL WORKERS' ABILITIES TO DELIVER PALLIATIVE CARE

Conditions that strengthened social workers' abilities to deliver palliative care became one of the central themes emerging from the data, which is in line with the fourth research objective of the study.

The following sub-themes emerged as key conditions that strengthen social workers' abilities to provide palliative care: palliative care social work education; training; research on palliative care in a Namibian context; a national palliative care policy; collaboration with the multi-disciplinary team; acknowledging the important roles of the social worker in the provision of palliative care; mainstreaming of referrals of palliative care patients to social workers; designated palliative care social worker and networking with other stakeholders. Participants also highlighted some of the skills social workers used in order to strengthen their abilities to provide palliative care.

4.7.1 Palliative care social work education; in-service training; continuous education; research and a national palliative care policy

All participants identified core components, which influenced the social workers' abilities and competencies in the provision of palliative care to patients with life-limiting illnesses. These included undergraduate social work education and training on palliative care; in-service training and continuous palliative care training; research and a national palliative care policy.

Faith, for example, indicated, *“looking at the conditions that maybe promote the social worker to provide better palliative care services is training, training is very, very important. We need to get training on what is palliative care. The principles of palliative care, the ethics, communication, how do you communicate with a dying patient. How do you deal with a patient diagnosed with a life-limiting illness, so we need training in terms of workshops, and extra curriculum course, however, I'm glad that UNAM introduced a palliative care module in their social work training for the*

third year social worker students. That will go, a long way in giving social workers the competencies that are needed in working in a palliative care setting. What is needed within the Namibian setting is for us to have a centre of excellence for palliative care, where various professionals from various parts of the country can come and learn, you know, best practices on how palliative care should be done. Social work education on palliative care helps to boost the confidence of social workers in terms of providing palliative care services. It also helps that you know your duties and what is expected of you in a palliative care setting. Education helps to equip social workers the information that they need to know on palliative care and working with patients, who dying, working with grief and bereavement issues. So social work education in palliative care plays a very, very big role in training and is a yielding, competent for social workers who are very, knowledgeable, of, about the principles of palliative care and who are able to apply, especially if the education is paired with practice, field placements of clinical placements. Clinical placements are indispensable to palliative care, because theory on its own, it's not enough. So there is need for theory and also the patients, the students.....the social work students, to be placed on clinical placements, for them to see first-hand experience...what goes in, on in palliative care settings. We also need research on social work interventions within a palliative care setting. We need to learn best practice models. We need more clinical placements sites, you know. Palliative care clinical placement sites could have been ideal if students could get more time, you know, if we could spent more time within a palliative care setting. However, it is not possible. Yah, because even the supervisors they are few, and they're... overwhelmed with their own workload, so taking students is like an extra, an extra, workload you know, on an already burnt out, overloaded staff. And also I've talked about research”.

Taywa said, *“more in-service training in palliative care will further strengthen our relationship with our community based organizations to make sure that they are there when we are not there”.*

Edward emphasized training. He said, *“I think the most important one is the training. Training is very important, but social workers themselves should make time to meet with other professionals at the hospital to discuss about palliative care patients so that they can identify gaps where they need to improve or where they need to learn new things. But I also think there is also scope for us as social workers to join other professional organizations or journals, for example, not specifically to palliative care, to learn, but let us say on the internet or on journals, but because of our setting it is not always possible to get access to those journals or sometimes there is no Internet, things like that. The one way to improve palliative care is continuous research in the area of palliative care and I think that is very important. I think that should be the starting point. And second, I think within the curriculum of social workers it should be a very important area that should be examined and I also think that students should be given an opportunity to specialize in one of these areas, if it was possible”*.

Catherine in response said that, *“the training on palliative care for the multi-disciplinary team and regular team meetings once a month with regards to palliative care cases only” will strengthen her ability to deliver palliative care. In that way she will be able to “have it on record or the palliative care cases will come to the social worker’s attention, even in cases where the patient is discharged, then we can attend to it, as a home visit...”*.

Richard said, *“I think if we could have continuous education and training. In my two years of practice, the only training I had was back at university. So, if we could have more training on palliative care, that is in-service training for the social worker, continuous professional development, I think that would improve our services as well”*.

Gift indicated, *“for us to do much we need things such as training in palliative care, we need workshops on palliative care, we need to be trained on home-based care, because at times the things are not easy due to the shortage of staff.*

Really, we could do much, but just because of that, also our role as a department on what we provide to people with life-limiting illnesses, we see it as a very important aspect because it is our social responsibility as well”.

Lucky explained, *“we are social workers, we also need more information on palliative care, because when I studied, I think I only received palliative care as a module, I mean as a chapter. It was not a module. Therefore, I think we still need more, either in-service training or workshops on palliative care and even the nurses themselves and the doctors, because the nurses are the ones that are working with those people each day. Sometimes they are not discharged, so at least they need to learn how to react to those people. At least it will really improve also their condition because sometimes although the person is suffering from life-limiting illnesses, it will be worsened by the way you are treating your patient”.*

Kay explained that, *“we do need to be trained in lines of our unit. I think it would give us a strong background. So far, we have the practical part, but I cannot say I am really sure this is what we are supposed to be doing... It still goes back to that training, because by then you would be sure this is the right thing, this is what I was trained, but now the social work that we did was the general one, we did not major in medical social work, but we call ourselves medical social workers. We do not have a qualification of saying you are a medical social worker. But anyway, we feel we are doing a great job, but probably if we could have maybe a certificate or a diploma in medical social work we would do more”.*

Ashley’s excerpt highlighted the necessity to have a national palliative care policy. She said, *“I think a policy should be put in place regarding palliative care as I feel that there isn’t one at the moment. Maybe a palliative care policy should be put in place for better services”.*

4.7.2 Collaborating with the multi-disciplinary team

The participants who identified working on a collaborative team identified the other health care providers, such as the physicians, as a great resource as well as the hospital nurses and other staff. The multi-disciplinary rounds can take place one-on-one as many participants discussed taking an active role in seeking out the physicians, nurses and other staff to gain updates on the patients, as well as in the formal setting of ward rounds. For those participants who identified being on a collaborative multi-disciplinary team, rounds is a part of their week. Si described, *“they can regularly meet as a multi-disciplinary staff, meet and discuss some of the difficult issues so that they can also get some support from the multi-disciplinary team”*.

Alice indicated, *“teamwork as getting more involved together with the multi-disciplinary team, sitting with them in meetings and just having a case conference regarding maybe the divisions or the patients that need more in-depth interventions. I can only think of that one now. One of the things also is maybe being educated, getting more training on palliative care, getting comfortable with palliative care. Right now we just have the knowledge from the university training and we try to use it to the best of our abilities where we can, but that is one of the things that can strengthen”*.

Anna highlighted, *“more intense working with the multi-disciplinary team, also on a regular basis and it would be awesome if you can specialize. If you are specialized then you will be more focused on the patient and the condition, the life-limiting illness. Specialization I think that will also be something very good”*.

4.7.3 The role of the social worker in palliative care provision

Healthcare providers (HCPs) need to educate themselves and others on the core duties that each professional performs in the primary care setting in order to avoid misunderstandings in teamwork. The different roles of the HCPs need to be acknowledged in order for conflict to be avoided in teamwork.

One of the participants emphasized their role on the team, which is the social workers' visibility and availability on the multi-disciplinary team.

For example, Edward described, *“as I have said, sometimes it is us and I think, I insist that it is us, social workers who must take the initiative to step up and explain to them that this is what social work can bring to the institution, rather than for them to learn about social workers. It is not their job to learn about social workers, for them it is to learn about being a nurse, about being a doctor, not about being a social worker. So I think we should take the initiative ourselves to explain what we can do”*.

4.7.4 Mainstreaming of referrals of palliative care patients to social workers

Gift indicated, *“what hinders, is the fact that the referral sometimes is not that much and as I have emphasized previously, if we could have a certain ward that this is only having patients who need that, but currently, we do not have a ward that accommodates those ones who need palliative care. And also as I have said, if a specific patient who needs palliative care is at a certain ward and I am not the one responsible, because we rotate here, then it is the other one who will deal with that. We rotate after every three months we do it per quarter. You work with this ward and then in the next quarter you get a different ward”*.

4.7.5 Designated palliative care social worker

Tawya said, *“we need to come up with a, robust staff establishment, which would ensure that if we have two social workers attached the hospital, or three or, I don't know what number. ... then it means they can have more time to do palliative care, as contained to the current situation like I told you, we are doing both. Therefore, at end of the day, it compromises a lot on quality. I think the one can also be the availability of the social worker himself or attention to palliative care cases and also the time as a generalist, if I am not available due to commitments and other aspects, such as*

outreach to other clinics and (inaudible), I am going there once every month. So, I am not as available as I would want to be for follow-ups”.

Richard explained, *“to start with, we could increase the number of social workers who are available so that people can begin to specialize and they do not have to do both things, become Jack-of-all trades. So we could increase the number of social workers and I think as social workers we can train and specialize in particular fields. Say for example, if I am specialized in palliative care that should also enhance my service provision. But I think the major issue is the issue of the staff, we need a number of social workers with regards to the demands of social services”.*

4.7.6 Networking with other stakeholders

Catherine indicated, *“maybe to have pastors involved also, because I feel pastors are the next people, who works with people in big numbers and there are some things that are just answered at the pastor’s desk, and just been prayed for and that is it. So I think maybe to have pastors also trained in palliative care for them to have knowledge on palliative care and to know that they need to involve specifically trained people that would also help”.*

Selma reported that the social workers’ abilities to provide palliative care *“will be only strengthened, if we have an open relationship with the other line ministries. Yes, so that they can know that when social worker are really coming to advocate for patients or ask for assistance for patients, at least we need to get something. And the other thing is we need to have an organization really that can be, like when social worker needs some assistance for patients, or for whoseever clients ... these things can be available for us ... like for example let me give an example of Red Cross. If Red Cross can say ‘Ok whenever you need any assistance from us, you are welcome to ask, to request for that assistance’ and then you will get it”.*

Charlotte highlighted, *“look, I believe we have to work very closely with environmental medical officers because, the problem is that the patients that are seriously in need come from informal settlements, there are also people from other areas. And in that informal settlements there are no, no toilettes, there’s nothing, to have a patient in a small shack like this, it’s very low, very hot. Not everything is conducive for that patient to become healthy and you need a team of environmental people to come in to see how we can improve, because the toilets in those areas are non-existent. The water, taps are very far, so now you sit with a patient that is bedridden, all the (inaudible), poverty issues around them is influence the way that patient can be supported. You have to for example, have people have to pay people to get water for them. To go and get water for them and they have, they are sometimes alone right through the day. In the informal settlements, we have the issue of, of fire. We had serious issues with few huts burned down and people burn dead in that. It is mostly those who are bedridden, who are at biggest risk. So, we have to work very closely with the environmental people to help us through that, how we can map out a solution for these problems, because we had, I was thinking we should really go to the municipality and ask for, there is this big, there is mobile toilets, there is, especially for sick people. So those toilets can be, somewhere we should find a solution for the sanitation problem and hygiene problem of those old people”*.

Lucky said, *“in palliative care you also need to have knowledge of community work, because that is when you are going to know on the pool of resources in the community, on how to do, for instance, if you know different forms of community profile, you know who are the data-keepers, who is going to help me with this, for instance with referrals, referring to the councillors, regional councillors or I mean constituency councillors, regional councillors and so on and administration also had a subject called Administration in Social Work. You cannot do anything without that administration, because it teaches you how to file, how to do your process note and everything, so we also did groups in social work. You find sometimes you do not even need to go, for instance, as I mentioned that case of a child who has hydrocephalic condition, sometimes you find there are maybe three or four mothers. Once you have made an intervention with one parent and then you have seen there are maybe three or five of them, then you do a group counselling”*.

4.7.7. Strengthening the skills of palliative care social workers

Social workers utilize and value several of their skills in the hospital setting. Stemming from their work providing counselling and psychosocial support, assessments; liaison, mediating and advocating on behalf of the patients; most of the participants discussed needing strong clinical and relationship building skills. This includes understanding family dynamics, listening, empathizing with others and counselling skills. The ability to listen is a major component to strong clinical skills that will strengthen social workers' abilities to provide palliative care. The hospital social workers need to be open to and listen to the wishes and needs of the patients, their families, as well as the different members of the multi-disciplinary team. It is important that the social worker take the time to listen and understand the patients.

Edward for example, highlighted the ability to listen. He said, *“my role is to articulate the needs of the patient by listening to them. Sometimes our doctors and nurses do not have the patience to wait, to listen, because of the pressure that they have, which is quite understandable. Sometimes the doctors, because of the pressure, do not have time to listen or even to explain to the family and we must be realistic and say that as social workers do not have the medical background even to explain certain things to the family members who might want to know”*.

Due to the nature of the hospital environment, people are exposed to death and dying, human suffering, and crisis management. Palliative care social workers therefore need to be aware of their own personal beliefs and drives, and how this may affect their work in palliative care provision and methods to manage those potential influences. In strengthening the social workers' abilities to deliver palliative care, the palliative care social workers need to also be skilful in taking care of one's self to decrease the risk of compassion fatigue and burn-out.

Shane emphasizes this point. He said, *“we also need to take care of ourselves since we are also human beings, as we are social workers, because like every time people are just coming to us its problems, problems, problems, at least can the ministry look at us and maybe to organize just a week for a retreat, just for soul feeling, because it is very much needed. On top of the problems, people are telling you every time, you also have a heart. It does not mean since people are not related to you, you would not mind about what they are going through. You are minding about what they are going through and on top of that again, you have your family members who are also giving you some tough times. So, that is why you really need that retreat, at least for one week to be able to be refreshed and when we are coming to start, at least we are very energetic”*.

Social workers also have to know how to take care of themselves.

Kay narrated her experience working in the oncology ward as *“I would say when I started it was a bit tricky. I started with oncology and the tricky part with oncology was that it is most likely you are just told this condition is at this stage, there is nothing we can do. It became a bit, not too much for me, but uncomfortable to sit there and all you keep hearing is it is end stage, it is end stage until at some point I observed, I think it was during the ward rounds, twice, I think, I would say for the first time seeing a man panicking, because the son had never been sick in his life. It only happened once when he fell in the bath tub and then he started bleeding and he was rushed to the hospital, where the father was told ‘no, he has leukaemia’ and they did not know that. So, he only survived for maybe two weeks ... When they got here there was nothing to be done and then I was just a bit surprised to see the mother was at least there trying to be strong, but the way the father panicked, he was rushing like, ‘doctor, please save my son’ and all that. It is such experiences that I said ‘no, I do not think I can keep to this, I think I need to get someone’. So luckily one of our colleagues was to leave the country, she was the one who was covering cardiac, and then I thought I would try cardiac. I have been here at least these are things that are a bit manageable”*.

On the issue of whether the social workers are comfortable to talk to the patients and the families about death and dying issues,

Alice responded, “yes and no in initiating a conversation regarding dying. I feel it is a more personal aspect. If one is not comfortable with coming to terms with dying and knowing that all of us are going to die at some point, it is kind of very difficult, because this person comes in with hope and they feel that they know that they are not dying and just finding the right words to tell the person without making them feel bad or without de-motivating their spirit, that is the biggest challenges. Trying to be neutral to accommodate both sides, making the patient to explore, ‘but what if you die today, are you going to be happy with that or what if you find out today you are going to die, what does that mean to you?’. Just that balance, bringing in that balance is the uncomfortable”.

4.8 SOCIAL WORK EDUCATION AND TRAINING IN PALLIATIVE CARE

The last objective of the study was to present and analyse how social work education and training on palliative care influenced social workers’ competencies in rendering palliative care, which became one of the main themes emerging from the data. Altilio and Otis-Green (2011), state that palliative care social work is the conjunction between two distinct bodies of knowledge: 1) social work theory and practice and 2) the science and treatment of a life-limiting illness, such as cancer. Indicating that knowledge of the art through education, training, and the science of each are essential to practice and delivery of palliative care social work services. Social workers through their palliative care training are educated to start where the patient is, thoughtfully assessing the patient in the context of the disease and treatment and then tailor the interventions to meet the patients’ needs. These remain the core tenets of palliative care social work practice. The participants in this study were asked to share their respective experiences of the education and training in palliative care.

Some of them shared their experiences in the palliative care module in the Bachelors of Art Degree in social work at the University of Namibia; others shared their perceptions and experiences on the lack or limited palliative care module; internship experiences on palliative care; continuous education and training on palliative care. They also suggested training topics in palliative care. Suggestions concerning the improvement of palliative care social work in Namibia are presented with a view to recommend a way forward to enhance practice and to optimize the invaluable and multi-dimensional roles of social workers in providing palliative care.

4.8.1 Experiences on undergraduate social work education and training in the palliative care module

Since 2012, the Social Work Department at the University of Namibia has offered a six-month-module in palliative care. In addition, since 2014, supervised palliative care clinical placement experiences are provided on inpatients at the national referral hospitals at the Windhoek Central and Katutura Intermediary hospital. The third year undergraduate social work students participate in the three days clinical training. This experience includes palliative care team rounds, case discussions, family conferences, case work, counselling patient group health education sessions, educational sessions on the roles of the social worker, multi-disciplinary team meetings and departmental planning meetings. The findings of this study revealed that the participants had different experiences in education and training in their Bachelors of Arts (Hons.) degree in social work. For some their undergraduate training in social work and their internship in a primary care setting prepared them for the provision of palliative care. However, for a few others there were little to no opportunities to take the palliative care course and to experience an internship in a hospital setting. More than half (14) of the participants noted getting training in a semester module on palliative care in the Bachelors of Arts (Hon.) Degree in Social Work program at the University of Namibia. For example,

Nanna reported, *“the education that I have received was in detail. It prepared you for everything from a child to an adult, from the beginning to the end, it was in detail and it was practical where you would know your role as the social worker and also the training gave you an understanding of what each multi-disciplinary role player’s role is in, in providing palliative care, starting from the family, the spiritual leaders, the employers, all the relevant systems of the patient. It makes you understand all... this person is not an individual on his or her own, this person is not living in isolation, this person is a person that you need to see in a holistic way where you need to assess all the systems of this particular person so the training gave you a lot to work on and made you aware of each and everyone’s role that needs to be played in this particular patient and how this role needs to be played in, in this patient’s life. So the training was in depth and it was clear and you know you always referred back to this, one of the books that I always carry is that of the University study guide for the palliative care where, where you get stuck or where you feel I need to understand what I need to do. I always go back and see, and this is how I can go about, so the training was indeed helpful. It helped me very much to be able to assist patients that were diagnose with life-limiting illness in understanding that, this person also has systems that needs to be involved. Also to help this patient to understand how these systems are affected by this particular condition and how the systems can support this particular uh patient in this condition. So it really helped in that regard”*.

Gift narrated, *“I might say that it is because of the training that I got at the university that made me to know palliative care. I was not aware of palliative care really, and I did not know if I am coming to work in the hospital setting here, but already when I came here, even when the doctor told me, ‘this patient is in palliative care’, I did not have to ask the doctor, ‘Doctor, what is palliative care?’ I was already aware from university my lecturer taught me already most of the things. We were taught theory and a little bit of practice, but the theory was the one that I am now converting into practice and my experience that I got there at university, are the ones that I am incorporating in my cases here and I am also combining them with other techniques that I am taught in other modules, as I have mentioned of cognitive behaviour.*

I am also incorporating it in palliative care as well because I want the mind-set of my patients to change, to move from those negative thoughts to come to positive thoughts. Yes, the university training is the one that made me to know more. I was taught concepts, home-based care, I was taught from UNAM how to provide counselling, I am taught what counselling is and all those things, even physical care. I was taught there at UNAM about physical care and incorporate these things. You have to cut the hair of the patient to be short, however, with that you have to be sensitive about culture. Some people prefer to have their hair like that, especially men. A woman is fine, we like hair. In addition, the nails of the patients, they need to be cut short so that they do not trap germs. We are Africans we eat with our hands so if the nails are too long and the patient is in the hospital, you know that a person could swallow the germs. Really, university education about palliative care is number one, is the one, which made me to know more about palliative care. I do not have to ask the nurse about what is palliative care, not at all, not at all. Maybe about some other things, because I just came to work in a health setting and some of the things we were not aware of, but now most of the things we are getting to learn. Nevertheless, my training at the university, I am really counting it number one. I know what palliative care is and I can even reflect. I think we had a drama if I reflect I was also in that drama of palliative care and it was fun. The crowd had much fun about that drama, how you have to take care of a patient with terminal illness, portraying the message in a very format that is really making people to be interested because it is fun when they are looking at the people performing the drama, they are sharing some laughter, joy, it was really nice”.

Anna said, “I only got training on palliative care during my social work years at UNAM and that was in 2012. So it is a long time ago and as I said previously, it hampers the way you will go about helping and assisting the patients because from 2012 until now it differs, there is a big gap of four years. So I really think we need more training on that. I think there are many loopholes in terms of understanding and how to go about assisting the patients and also I think a lot of training is needed, as I previously said, for the professional also be trained, because when you hear about palliative care or life-limiting illness, automatically your brain goes to death and dying. I think the aspect of death and dying should be more intensely trained on.

Training should be given more intensely on death and dying so that you know the difference between them and how to go about to assist the patients or the client that has a life-limiting illness. This will also help you as the professional social worker to enhance the quality of life, make it easier for the patient to accept the condition of the life-limiting illness and also make informed decisions about their condition in terms of treatment, care, who they want to be with them and when they want to go for a second opinion, those types of things, so that you as a professional can also know how to direct the patient and the family”.

4.8.2 Lack or limited under-graduate palliative care curriculum

Seven of the participants, including Alice, Simon, Charlotte, Shaka, Abel, Lucky and Aardvark indicate that their undergraduate social work curriculum did not include training in palliative care. Alice in particular described, *“by the time the course palliative care was granted as a single module, I was not present, so most of my information I got was through personal reading and through the encounters I had with the students and my personal experience in case reviews whereby we shared with my fellow social workers about a case regarding palliative care and I was able to get their ideas. For me, I would have loved to go through the course Palliative Care as a module from start one, because I feel that the experience you get in the class is broader than you personally going out and reading on it and trying to figure out this is what it means and this is how you are going to do it. That is basically it if there is a training for that a workshop or something, but it is a key”.*

One participant said he only received training on palliative care through a brief chapter in a course. For example,

Shane indicated, *“we only had palliative care as a chapter, but some other people who came after me had it as a module or something.*

We are learning a lot from them and I can really tell that they have more information and even they were the only ones who were taught in class, they are also teaching us every day, because like every Monday we meet, we gather and we do briefings on what are the cases that we have been dealing with in the previous week and how did you deal with them. So we do provide feedback and where they can see that there is something missing that you were supposed to do and did not do, they can at least direct you. So we learn through that. It is a very good thing, because your fellow social worker will equip you. Even though you did not learn it as a module, they will equip you with a lot of information and at the end of the day you will end up being at the same level with them. Sometimes you might even be better, because practice makes perfect”.

Shaka discussed wanting a course on palliative care, expressing his desire and need for *“training and also my desire and motivation from a personal point of view as factors I think that can strengthen my ability to provide palliative care”.*

4.8.3 Internship experiences on palliative care in the Bachelors of Arts (Honours) in social work

When looking at the participants’ internship experiences in palliative care in the Bachelors of Arts (Hon.) degree in Social Work there were two common trends. Some participants had internship experiences in a hospital setting, which prepared them for the provision of palliative care to patients with life-limiting illnesses, while others did not have an internship experience in a primary care setting.

Faith, Shaka, Catherine and Nanna did not have any internship experiences in palliative care to prepare them for their current positions as hospital social workers providing palliative care. Faith explained, *“frankly speaking, throughout my four years training, I never made contact with a hospital. The first time that I was placed in the hospital setting was on my day of appointment, but during my four years training as a social worker, I never had any placements within a hospital setting.*

I had one course on mental health, but really, that course didn't even prepare me for medical social work, because it was not accompanied by field or clinical placements...and my internship was at the prison, I was working with inmates”.

Shaka in response said, *“not really, my internship did not prepare me for my current position. I think there is a need for post-graduate diplomas in Namibia at universities in Namibia, that's number one, and so that people can specialize in palliative care. I think that would be great and if the Ministry of Health can take a leading role in putting palliative care along its other strategic functions. You know in the ministry, I think that would be helpful because, there is emphasis on immunizations. So if it can be done also with palliative care that will be better”.*

Abel reported, *“we were the first social workers of that time, so our training was at Augustineum College. Mostly we were trained on how to work with the families, casework, community work and court work. Palliative care was not part of our training”.*

However, for those that did have internship experiences in primary care settings, their experiences were positive.

Richard narrated, *“I think it did me very well, because that is where I had my first bedridden patient in the Mariental hospital, is where I experienced the patient passing away during our helping process and that is where I managed to be familiarized with working in a hospital, going through the wards, seeing people who are sick, seeing people pass away. So, it prepared me very well. It wasn't a big shock when I came here at the hospital”.*

Gift based at the Oshakati intermediary hospital said, “Yes, at least for me, lucky me, I did it here, but thinking of somebody who just did it at Youth or maybe at Gender and was not exposed to patients like that. At least with me I got my internship here, I did it here at least I then already saw them. I have to talk about when I was doing internship, because I did my internship here. I was referred to see a client who was diagnosed with cervical cancer, stage 4. I was told she needs a social worker. I went to the ward, luckily enough she was communicating and I did an assessment and I found out that she is from far, she is from deep in the villages, very far away from town and she only has one child who was schooling at the hostel and she is not visited much. She told me it is because people do not have transport money to be coming here, travelling long distances to come to Oshakati, because it is those deep, deep villages and it requires one to have money to come here. I was also asking more about her feelings and perhaps to help her to just talk to the family, if at least they can sacrifice to just even send one person to come and visit the patient, because that patient also needed a helping hand she could not do things on her own, she needed a helping hand. She needed to be washed and also looking at the conditions surrounding the patient, when that person came I also had to talk to her to educate her on how to take care of herself because she cannot, for example, just touch the patient like that without gloves as there could be a possibility of germs because her safety is also needed as well. I helped the patient at least to be visited by the relative. I know the doctors were also doing their part, they were managing the pain and all that, but then they told me that there is not much that could be done for her to recover, it was like she was already in that line to just die. However, I also provided counselling to her to cope. I provided counselling because at the same time she was grieving for her health, that she lost health. Actually it was all that, but then since that time I was involved in that case, I was a student, so during that time we sometimes had to go back to classes and I could not get to do follow-up anymore because I went to classes and I had to stay there again, but I hoped if there was any other urgent need for a social worker, those who were in the office were still available. It is just that with that patient there were things to be done, those little things that we helped her with, but the doctor has also confirmed that she was on her end-of-life.

I also attended to patients with life-limiting illnesses such as HIV, however looking at HIV, you cannot compare it with cancer, for example, and with HIV patients are on HAART to control their CD4 counts to prolong their lives. So the patients that I have seen were not that worse, however I still played my role there that I can”.

Lucky expressed, “*yes, internship mostly gives you the real picture of what is in the field in the Oshakati district, not in the hospital, out in the community and it already starts preparing you for the real field and then you even come to learn how to deal with some of those things, like maybe burnout and so on, because even our fourth year training where we used to see patients at the same time when you are also having school work. So it was not easy, but then being there and able to do what was required of you also strengthened you that you can do it though sometimes you are burnout, but then you still find the courage to go on and finish what you had to finish”.*

Ashley reported the internship prepared her for her current position, saying “*yes it did because I was placed here at Katutura hospital therefore it was a smooth way, because I did my internship and then I managed to be able to fit in”.*

4.8.4 Continuous education and training on palliative care

Participants were asked to discuss their experiences with post-Bachelors of Arts Degree in social work in continuous education and training in palliative care. For almost all of the participants, continuing education and training on palliative care has been lacking thus far. This is because they have not come across a continuing education program that discussed palliative care in social work in the hospital. For example,

Selma narrated, “*so far I would say not really. We are really not receiving training on palliative care. Yah, it’s like we just grow on our own, because of seeing different patients every day”.*

Catherine in response said, “no, not that I can remember, specifically on palliative care, no not that I can think of, no”.

Only a few participants had a once-off training on continuing education on palliative care through their department, which was unfortunately not repeated. For example,

Faith reported, “I only attended once from the hospital side, from my employer's side it was only a once-off training that was organized in 2015 for all the oncology staff. Unfortunately, that training was not repeated, it was just once off”.

Si said, “not really, because maybe two years ago there was something on palliative care, that is where I heard a little bit about palliative care. It must really be done on a continuous basis so that we can be aware of that, because sometimes when you refer such cases to a social worker some of them need practical experience”.

Edward described, “on a personal level, yes, I have. As I told you earlier on that I worked in the palliative care setting for six to seven years and I was a training officer in that field and my training was practical. Also I used to subscribe during that time to certain journals, like *European Journal of Palliative Care*. There is also a journal called *Mortality*, which talks about death and bereavement and various other publications during that time, but my membership lapse, because I was not in that institution anymore”.

4.8.5 Continuing education and training topic suggestions

When participants were asked to discuss potential topics for continuing education, they listed several topics including: conducting comprehensive assessments; providing home-based care; bereavement; breaking bad news; dealing with issues of disclosure;

preparing and supporting patients and families on death and dying issues; gaining additional clinical information and skills on dealing with different diseases and disabilities and other mental health issues; sign language training and palliative care for patients.

For example, Catherine said, *“I am not confident providing bereavement counselling and I think it is an area that needs improvement. It is just that I feel it is an area that needs improvement within my skills”*.

Aardvark indicated, *“capacity building, equipping the social workers, including me, of what is palliative care and what is expected of a social worker, because you cannot do something you do not understand how and what to do really. We would maybe do the little bit that we are doing currently, but we would not really know how did palliative care, since the word is also sounding so special and so big, we do not really know what is inside that work of what is really expected of us or how should we perform with these patients and we might end up just giving the normal counselling and follow-ups and this, like ‘how are you’, that kind of thing, but not really as in what is it that palliative care is expecting of social workers. If we have that understanding I think that would really help”*.

Gift said, *“we need a workshop on palliative care, we need training once in a while. We need experts who know very well on home-based care to train us. We were even told there are some home-based care kits and I would really love to see what is involved in that kit and how to use everything. I want to know more about home-based care because really, if a patient is discharged that home-based care is needed for, because you have to look at different factors that can even make a patient worse, like alcohol, smoking, those things, a patient does not need to utilize those things at all and they need a balanced diet, their physical needs, need to be taken care of. They need also somebody from their side, a person who is always there.*

They do not need to be alone If then they are alone, at least with a radio by their side just to cheer them up, not to be thinking too much and get stressed and high blood pressure. I need to focus on home-based care, at home and what can I do. I worked for two years, but I know the attitude of relatives when it comes to patients who are in the hospital. Some, when the person is in the hospital, they feel relieved, they say, 'at least he is at the hospital'. But there is a time that the patient himself would ask, 'Doctor, can't I go home for a week and come back maybe'. A person just longs to go back to their natural environment and when a patient is in the hospital, some people feel like, 'at least he is in the hands of the nurses and doctors and the social workers are also there, at least we have a break'. We really need more knowledge on it".

Shane expressed, *"I wish I had palliative care as a module, it would be really good"*. He also expressed the need to be trained on how to conduct holistic assessments because *"sometimes you think you are making the person understand, but you are not, so I would really love to be equipped on how to make the person understand the situation that he or she finds herself in"*. When Shane was asked to explain what he would like to be strengthened, he responded saying *"the training should focus on holistic assessment skills, because you might think you know all of them, but you do not really know culture, language, environment all those types of things. So you really need to know how to assess a person holistically"*.

Another topic discussed was the desire to learn more about how to take precautionary measures and manage infections in the hospital and in the home-base care of a patient with a life-limiting illness. For example,

Gift indicated, *"I want to know how to control infections surrounding the whole situation of the patient, because the reason I am mentioning about infection control is, because a patient might have a life-limiting illness and also other diseases, like TB.... Yes, I cannot just go like that, I have to have that mask to protect myself. Precautionary measures, yes"*.

In the next section, a summary of the demographics of the participants are provided (see Appendix 8) and the biographical profiles are presented (see Appendix 7). The characteristics of the research participants are also described and presented (see Appendix 9). To protect the identities of the participants' pseudonyms were assigned to each person interviewed. Readers are thus introduced to Catherine, Nanna, Faith, Selma, Linda, Si, Taywa, Edward, Richard, Charlotte, Shaka, Gift, Lucky, Shane, Aardvark, Kay, Alice, Anna, Abel and Ashley. Moreover, the names of the significant others in the participant's profiles and narrations have also been removed to protect the identities of these individuals.

4.9 BIOGRAPHICAL DETAILS OF THE RESEARCH PARTICIPANTS

This section provides a demographic account, which presents a summary description of the participants (social workers in Namibian hospitals) and the research findings. See Appendix 8 on the summarizing the demographic features of the participants. A detailed discussion on each participant is provided in Appendix 7, but is summarized in table form (see Appendix 9) for the sake of clarity and brevity to avoid an overly extended chapter.

(Please see Appendix 7 for a detailed overview of each participant's biographical information, which was too extensive to include within this chapter.)

4.9.1 Sex and religious affiliation of participants

The majority of the participants were females (14) while six (6) were males. There was a wide range of religious beliefs (six religious affiliations, including Charismatic Christian, Catholic, Adventist, Lutheran, Methodist and Anglican); however, Charismatic Christian and Catholicism were the most predominant religious groups present in the sample. Catherine, Nanna, Faith, Si, Taywa, Richard, identified themselves as adherents of Christianity. Edward, Charlotte, Shane, Aardvark and Ashley were Roman Catholics. Selma, Linda, Kay and Anna reported that they followed the Seventh Day Adventist religion.

Gift, Lucky and Abel were Lutheran. Alice was a Methodist and Shaka an Anglican. Social workers' faith and spirituality are key cornerstones to self-care and survival in providing care to patients with life-limiting illnesses, given the reality that palliative care social workers are at risk of compassion fatigue, burnout and moral distress. The diversity of social workers' spirituality together with the principles of compassion, empathy, warmth and genuineness and active listening skills serve to provide a solid foundation for the creation of a safe environment for the exploration and relief of total pain and suffering (Otis-Green, 2008, as quoted in Altilio and Otis-Green, 2011). The provision of spiritual care in palliative care delivery requires social workers who are committed to reflective practice, who are thoughtful about their own motivation for care work and who consider existential questions about meaning, connectedness and purpose in life. Otis-Green (2011a, as quoted in Altilio and Otis-Green, 2011: 330) state those social workers' abilities to "offer one's authentic presence is a key social work skill that can be seen as a spiritual intervention". The experience of faith has been necessary to cope with the harsh realities on the job in what is seen, heard and revealed; in addition, faith serves as an interior solace to deal with these experiences.

4.9.2 The ages of the participants

When the researcher asked the participants for their age, they were not comfortable to offer this information. The ages of the participants are therefore presented in broad age categories. Fifteen (15) of the participants were in the broad age bracket of between 25 and 35 years old, while four (4) of the participants were in the age bracket of 50 years plus, and only one (1) participant was in the age bracket of between 36 to 44 years old. More than half (15) of the participants were in the 25 to 35 years' age bracket. The youngest participant was 25 years old and the oldest participant, 60 years old.

4.9.3 The ethnicities of the participants

The participants were from five different ethnic groups: namely Damara>Nama, Shona, Oshiwambo, Silosi and Coloureds (referring to the Namibian classification of people from mixed backgrounds).

The Damara / Nama (6) and Shona (6) speaking participants were the most predominant ethnic groups. The majority of the participants were Namibian women: Damara/Nama speaking women (4), followed by three (3) Silosi speaking and three (3) Oshiwambo speaking women, two (2) Coloured Afrikaans speaking women and two (2) Shona speaking Zimbabwean women. There were four (4) Shona speaking Zimbabwean men and two (2) Nama/Damara speaking Namibian men in the study. All of the participants were fluent in English but they were also fluent in their vernacular languages. The diversity of ethnicity is very important in providing culturally appropriate and sensitive care to the patients and their families who represent diverse groups.

4.9.4 Years of experience as a social worker

All of the participants were full time employed social workers with the Ministry of Health and Social Services in Namibia. Eight (8) of the participants worked at intermediary hospitals, five (5) worked at district hospitals and four (4) of the participants worked at a national referral hospital, while the other three (3) participants worked at a regional training hospital. Years of experience ranged from two to thirty-two years. The average time working in the hospital was 6.25 years.

4.9.5 Educational and training backgrounds

All of the participants held a Bachelors of Arts Degree in Social Work. The estimated amount of years with a Bachelors of Arts Degree in social work was between 2-32 years. Three of the participants held a postgraduate qualification in a Master of Arts Degree in Social Work. In addition, twelve (12) of the participants received a six-month palliative care training and a one- week palliative care clinical experience during their undergraduate training. The other eight participants did not receive any undergraduate palliative care training. The majority of the participants did not receive any in-service or professional continuous education in palliative care since their assumption of duty. One of the participants continued her post-graduate studies with a diploma in palliative care social work. All of these factors made this a unique study.

A detailed and extensive biographical introduction of each research participant can be found in Appendix 7. Placing this information in Appendix 7 serves as a simple reference point for the reader. Table 4.2 summarizes the main characteristics of the participants found in their profiles in Appendix 7.

This chapter concludes with a summary of the presented findings of the research.

4.10 SUMMARY

This chapter concludes with a summary of the findings presented. The chapter highlighted the themes of the social workers' perceptions and experiences of their roles in providing palliative care to patients with life limiting illnesses in the primary care settings in Namibia. The findings demonstrate that social workers perceived their roles as assessors, counsellors, brokers, educators, advocates, facilitators, liaisons and discharge planners providing physical patient care, conducting patient follow up, outreaches, home visits, family conferences, end-of-life care and managing in-country and international referrals. The major barriers, which hindered their abilities in providing palliative care, included the experiences that social workers' roles are not well understood by some of the multi-disciplinary team members. In addition, while some participants reported receiving basic training on palliative care in their undergraduate social work education and training, the study found an inconsistency in the undergraduate training curriculum at the University of Namibia prior to 2012. There is a lack of in-service training and a lack of continuing education and training on palliative care. In optimizing the roles of the social worker on the multi-disciplinary team in providing palliative care, many participants in this study, as a departure point suggested in-service -, continuing education and training in palliative care for the social workers in primary health care settings in Namibia. Training on bereavement, death and dying and on the roles and responsibilities of the multi-disciplinary team were also suggested. The findings advocate for a designated palliative care social worker in primary care settings in Namibia.

The well-being of social workers is a major concern with limited supervision and debriefing opportunities available and limited support from the multi-disciplinary team and management. The study adds to the limited existing knowledge about palliative care social work practice in Namibia. The study argues that there is a need for policy guidelines and further research on the roles of the social worker in providing palliative care to patients with life-limiting illnesses to identify ways to improve the field and science of palliative care social work.

CHAPTER 5: ~ ‘Being here’ - Creating a constructivist grounded theory of social workers’ multi-dimensional roles in providing palliative care

5.1 INTRODUCTION

This chapter in the field of sociology of healthcare provides analytical discussions and interpretations of the data provided by creating a constructivist grounded theory on the social workers’ multi-dimensional roles providing palliative care. This study applied the grounded theory as a qualitative method of which the purpose was to create a constructivist grounded theory directly related to the data from which it is developed. In this chapter, I reflect on the way in which the chosen research design enabled effective data generation. The findings (chapter 4), were organized and analyzed utilizing the symbolic interactionism perspective. This framework was helpful at guiding and informing the findings. In offering an understanding and operationalizing of the role of the social worker in the provision of palliative care and in shaping social services, this sociological study provides social workers’ perspectives for trying to understand their role of providing palliative care where *“each perspective gives us a different slant on social behavior and hereby adds to our knowledge of nature, structure and content of social relationships and patterns of social interaction”* (Clarke, 2001:7-8, 26). The social workers’ perspectives of their multi-dimensional roles in providing palliative care contributed by creating a constructivist grounded theory directly related to the data from which it has been develop. The generation of a constructivist grounded theory advances the understanding of the social workers’ multi-dimensional roles in providing palliative care in terms of underlying meaning and change in varying circumstances and over time (Charmaz, 2002).

In this study I embraced an emic stance in being the *“primary instrument of data collection and analysis”* (Merriam, 2009:29) by creating a constructivist grounded theory, which merged with my personal understanding and input, as well as providing an interactive approach to data interpretation (Charmaz, 2006).

The emic stance allowed me as a ‘co-producer’ of the research to add depth and meaning to the creation of a constructivist grounded theory on the multi-dimensional roles of social workers in providing palliative care. The constructivist approach to grounded theory allowed me to situate myself within the research and formed a part of the understandings from my own perceptions and experiences (as social worker, social work - and palliative care educator) which created meaning between the participants and me. This allowed me the possibility to consider multiple meanings by interpreting the multi-dimensional roles (for example, advocate, assessor, broker, counsellor, educator, facilitator, patient liaison, mediator, discharge planner and manager of in-country referrals) of social workers in providing palliative care. It offered insights into social workers’ understandings of palliative care. The constructivist grounded theory offered me understandings of reality, which was influenced by many contextual factors (e.g. conditions that hindered or strengthened the social workers’ abilities in their role to deliver palliative care) and constantly redefined through interaction with others (e.g. collaboration with the families, MDT and networking with other stakeholders) (Fisher & O’Connor, 2012).

This study is suggesting starting not with professional ideologies, which presume the patient to be a whole individual with a range of needs – which inevitably promotes holistic assessment in meeting them, but rather to start with seeing patient as persons embedded in and constituted by language, relationships and interactions with others “*on the basis of the meanings that those interactions have for them personally*” (Blumer, 1969). This study applied the symbolic interactionism “*where meaning is derived from, or arise out of social interaction, where meanings are modified through an interpretive process and therefore meaning is created through each new experience* (Blumer 1969). The importance of relationships and interactions in improving health and well-being has been captured in the symbolic interactionism of Mead (1934) and Blumer (1969) where “*the health of individuals is partly dependent on the characteristics of their relationships and the social structures in which people live*” (Social Science Med, 2001:52:1). This research drew on interpretive knowledge informed by symbolic interactionism of Mead (1934) and Blumer (1969).

The pragmatism of symbolic interactionism provided a broad orientation that gave focus to both the micro level of interpretation and the structural level within which the provision of palliative care social work was construct in the primary care settings in Namibia. Mead (1934) and Blumer's (1969) work focus on the dynamics of interaction that provided insight into the ways in which meanings were constructed.

The central research question of the study was how do social workers in primary care settings in Namibia perceive their role in providing palliative care to patients with life-limiting illnesses? I conclude this study by juxtaposing the set of research objectives with the findings. In extending this, the symbolic interactionism perspective was useful where the system represents technical scientific rationality and the lifeworld denotes the everyday world that humans share with others. Hence, these latter ideas extended the interpretation of analysis from human action at micro level to the systemic and macro levels.

This chapter begins with an analytical story of my experience as a researcher creating a constructivist grounded theory on social workers' multi-dimensional roles in providing palliative care. This chapter continues with discussions and interpretations of the findings on the social workers' perceptions of their multi-dimensional roles in providing palliative care to patients in primary care settings in Namibia. The chapter concludes with the sociological significance of social workers' role in providing palliative care. As indicated in chapter 4 on the perceptions of social workers in their role of providing palliative care, several themes (or major topics) and sub-themes (specific topics) emerged from the data. Themes were categorize according to the researcher's interpretation of the data in relation to the main research question and study objectives.

The purpose of this study was to examine social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses in the hospital setting in Namibia.

It aimed at examining social workers' understanding of palliative care and it investigated conditions that hindered or strengthened social workers' role in providing palliative care. It induces the status of palliative care education among social workers in hospital settings in relation to the WHO (2002) definition. My study is design to fill a gap in this area where there is insufficient research (and mandatory education) on social workers' perceptions in their role of providing palliative care to patients with life-limiting illnesses within the Namibian context.

In this section, I share an analytical story of my experience as a researcher creating a constructivist grounded theory of social workers' multi-dimensional roles in providing palliative care to patients. I refer to the '*being here*' phase' (Birch, 1998) in my research journey, which relates to the creation of this text through data interpretation directly related to the data from which it has been develop. The '*being here*' phase refers to the final stages of analysis and interpretation in the writing up of the findings (Birch, 1998). I am using the '*being here*' phase to share a story of aspects of my inner dialogue during the research process. When interpreting the data, I wondered whether themes would ever crystallize (Borkan, 1999). I wanted to ensure that my data analysis and interpretation "*involves seeing patterns and meaning in the accounts of the research participants and it is inevitable that this involves you exercising your judgement*" (Whittaker, 2009: 89). I realized that I could interpret the participants' words in many ways and I felt a strong sense of responsibility in what I was undertaking. I also recognized that there were occasions during the interviews when I failed to ask follow-up questions to clarify points, which meant I might be making assumptions. However, after trying various ways of looking at the data writing up my ideas and having discussions with my supervisor, a picture began to emerge that represented the findings in a meaningful way. I was reassured when I read the words of Mauthner and Doucet (1998: 122) regarding the early phases of data analysis and interpretation "*they can feel messy, confusing and uncertain, because we are at a stage where we simply do not know what to think yet*". During the various analysis stages, I wondered how necessary it was to go through all the steps with each transcript. How thorough did I have to be? Is there a right way to use a particular method? The words of Froggatt (2001: 434) were consoling, "*there is no one right way to work with the data and it is a process best learnt by doing*".

I felt a great responsibility when interpreting the data and writing up my findings. I was not only presenting it for academic scrutiny, but to the social work community of Namibia and beyond. I did not want to let myself down and particularly, not the social workers who had contributed their time along the way. As I proceeded, I kept on thinking whose voice (Hertz, 1997) was I selecting to put forward in the write-up? How would I choose which extracts to quote to illustrate my themes (Humphries & Martin, 2000)? I was also conscious of the fact that I could be judging the reality of others in relation to my own (O'Leary, 2004). I used thematic analysis induced from the data to sort and analyse the information. Emergent themes were group into categories relevant to the study's objectives and for the creation of the grounded theory approach that I developed. Supervision sessions and feedback on my writings were extremely constructive and helped me to take a fresh look at my findings. '*Being here*' was at times a lonely place, but was also a heartening and rewarding one.

This chapter aims to answer the central research question, namely:

How do social workers in primary care settings in Namibia perceive their role in providing palliative care to patients with life-limiting illnesses?

In order to address the main research question, the following related sub-questions were also answered in discussion and interpretation of the findings in chapter 4: 1) How do social workers understand palliative care? 2) What conditions hinder social workers' abilities to provide palliative care to patients with life-limiting illnesses? 3) What conditions strengthen social workers' abilities to deliver palliative care to patients with life-limiting illnesses? 4) How does social work education and training in palliative care influence social worker's competency in the provision of palliative care to patients with life-limiting illnesses?

The core focus of the study was to analyse and interpret social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses, to explore their understanding of palliative care, the conditions that hinder or strengthen social workers' ability to perform that role and insights into how social work education and training in palliative care influence palliative care social work practice.

Broad questions were asked of the participants to gain a deep understanding of their perceived role in providing palliative care. Further, questions were asked in order to examine potential opportunities to change and improve the social worker's education, training and field of palliative care social work. The findings were organized and analysed utilizing the grounded theory framework. This framework was helpful at guiding and informing the findings. As the chapter proceeds, different themes and sub-themes are discussed and interpreted in relation to the data analysed by creating a constructivist grounded theory on social workers' roles in providing palliative care.

5.2 MULTI-DIMENSIONAL ROLES OF THE SOCIAL WORKERS IN PROVIDING PALLIATIVE CARE

This section provides a discussion and interpretation of the findings of the study and relates the multi-dimensional roles constructed by social workers in providing palliative care. The constructivist grounded theory on the multi-dimensional roles of the social workers in providing palliative care was developed from the "*implications of the symbolic interactionist view of human behavior*" (Chenitz & Swanson, 1986:7). Chenitz and Swanson (1986) refer to symbolic interactionism as a sociological theory that explains that people interact with each other on the basis of the meaning (symbols) they attach to situations. My study applied this theory (symbolic interactionism), which is based on the premise that no object, situation or person has meaning of itself. The meaning is attached to the experience of that situation. From a symbolic interaction perspective, social development is a process of reflection and interaction. Individuals learn a sense of self and rationality through a process interacting with others, of seeing themselves reflected in their relationships with others, evident in my study. Mead (Strauss, 1962) described this process of developing a concept of self, unique to roles human beings perform, as leading to self-directed behavior and identities, evident in creating this constructivist grounded theory of social workers' multi-dimensional roles in providing palliative care. Blumer (1962) proposed that symbolic interaction also explains the ways that groups of people are able to function together because of their shared meanings in the phenomena around them. "*The individual as part of the collective, aligns his or her self-definition with those of others and acts according to shared meaning*" (Chenitz & Swanson, 1986:6).

In developing this constructivist grounded theory of social workers' multi-dimensional roles in providing palliative care, this study underpinned by symbolic interaction examined both the human behavior and the symbolic meaning attached to interaction and in forming identities. Therefore, field notes of a range of verbal and non-verbal interactions in the natural settings of the social workers occurred were essential. The application of grounded theory approach and symbolic interactionism enabled me as the researcher to experience the meaning of the interaction and therefore cannot remain a disinterested bystander, but must take on the participants' perspective by being "*both a participant in the world as well as an observer of the participant in that world*" (Chenitz & Swanson, 1986:7).

Every social worker brings his or her own perspective, expertise and experience to the primary care settings and it was important to understand how practising social workers perceive their role in the hospital. In addition, it was imperative to understand how social workers interact on the multi-disciplinary team, with the patients and their families as well as within the hospital organization. In the section below the different sub-themes on social workers' multi-dimensional roles in providing palliative care, which emerged from the data are discuss and interpreted.

In conceptualising and theoretical locating the study, I remained cognisant of the fact that the goal of the study was not to define social workers' roles in providing palliative care, but rather from the perceptions and narratives of the participants describe and create in-depth understanding of their roles in providing palliative care. This meant that I applied theoretical insights to my chosen qualitative grounded theory research orientation.

The hospital is a high-stress environment which requires social workers to fulfil several responsibilities, including providing palliative care. Key findings from the research can interpret the various roles of social workers (as counsellors, educators, facilitators/ liaisons, advocates, brokers, conducting referrals, discharge planners and mediators/ intermediaries, covered in chapter 4) as imperative in the provision of palliative care to patients.

The various roles of social workers are multi-dimensional, meaning that they are perceived and interpreted as providing counselling and psycho-social support to the patient and the family in coping with a life-limiting illness. In addition, the study found that social workers serve as educators providing information around the patient's care options as well as context interpreters and discharge planners for patients. The study found that social workers serve as liaisons, meaning that they liaise on behalf of the patient, between the patient the family and the multi-disciplinary hospital team and they refer patients to the next level of care. They serve as brokers, meaning that social worker link the patients and the family with internal and external resources and educating the patient and the family how to cope with a life-limiting illness. This study found that social workers advocate on behalf of the patients and their families. The majority of the participants in this study identified various skills necessary for palliative care social work consistent with the literature (McCormick *et al.*, 2007; McCormick *et al.*, 2010; Hartman-Shea *et al.*, 2011).

In the discussion below, the different sub-themes that emerged in relation to the social workers' perceived multi-dimensional roles are discuss and interpreted.

5.2.1 Role as counsellor

The most predominant role from the in-depth interviews revealed that the participants identified their role as counsellors and support persons as significant providing psychosocial support and counselling to patients. This evidence can be interpret as unique in that all of the participants introduced themselves to the patients and their families by identifying themselves as counsellors and support persons based on the meanings that their interactions with the patients have for them. Their role as counsellor can be interpret as important in sitting with patients and families after receiving their diagnosis (Worth, 2001), listening to their stories and supporting them through this difficult time was highlighted and key to provide good palliative care. This finding in the voices of the participants can be interpret as an empowering tool to help the patients to look at their life-limiting illnesses in different perspectives and to feel that there are actually people who cared for them.

In some instances, part of the social workers' role as counsellor was perceived and can be interpreted as breaking bad news of a diagnosis of a life-limiting illness. This finding on the social workers' role as counsellor can be interpreted as focussing on areas of acceptance of a diagnosis, forgiveness, self-worth and positive thinking where meaning is derived from and arises out of social interaction. The study found that the participants' perceived role as counsellors can be interpreted as providing counselling, which is aimed at helping patients to cope with the diagnoses of a life-limiting illness. Part of their counselling also meant adherence counselling in order for patients not to default on their treatment or medication. The study found that participants in the study perceived their role as a grief and spiritual counsellor, meaning preparing the patient and the family on issues of death and dying. Social workers provide bereavement counselling, which helps the patient and the family to cope with the death of a loved one (WHO, 2016; Reith & Payne, 2009). This finding is similar to that of Reith and Payne (2009). They argue that in cases of death and dying, which involve loss and transformation, the social worker is in a position to facilitate the therapeutic process to promote emotional healing and closure for the patient and the family. This also includes psycho-social support, addressing the physical, emotional, social and psychological needs of the patients. It also relates to the findings of the NASW (2010) which reports that social workers facilitate care planning through assessments and facilitating psycho-social education. In addition to providing support to patients and families, two of the participants in this study discussed their role as providing support to staff, consistent with the findings of McCormick *et al.*, (2007).

5.2.2 Role as facilitator and liaison

The study found that the key roles as facilitator and liaison between the patient, the families and the multi-disciplinary team to improve communication identified by the participants of this study are consistent with the literature (McCormick *et al.*, 2010 & Hartman-Shea *et al.*, 2011). The finding can be interpreted that social workers perceived their role as facilitator and liaison as important and it can be interpreted that this role encompasses facilitating the communication between patients, families and the multi-disciplinary team to help the hospital team understand the patient and the family's perspectives, and vice versa.

For example, in cases where the patient is classified disabled by the doctors, or in the case of a cancer diagnosis, it means that the social worker liaises with the doctor in order to make sure that the patient gets all the information and supporting documents needed to apply for the disability grant. Organizing and attending family conferences and providing supportive counselling to a family during diagnosis were additional roles that participants described. This can be interpreted as the social worker's interaction with the MDT, the family in the hospital.

5.2.3 Role as educator

One of the sub-themes that emerged from the data and identified by the participants of this study is that of educator. Through the various roles the social workers perform, this finding on the social workers' role as educator can be interpreted as central to dispelling some of the myths surrounding a cancer diagnosis, by providing patients with information and facts about a life-limiting illnesses such as cancer. Social workers' role as educator can hold an important meaning in improving communication, interaction, relationships and understanding in the hospital (McCormick *et al.*, 2010). The social workers perceived their role as an educator important in providing psychosocial education and conducting therapeutic group counselling sessions on the diagnoses of illnesses and treatment options. This can be interpreted as a key finding under the mesosystem of social workers' interaction with the patients, families and the MDT where social workers have an important role in educating the patients and families on medical terminology and the different options for available care. They also strive to improve the communication and understanding among the multi-disciplinary team members, the patients, the family and the caregivers (Cagle & Kovacs, 2009 & McCormick *et al.*, 2010). This study found that the participants discussed their role as educators, educating the doctors on the role of the social worker in the multi-disciplinary team, meaning that they educated the doctors and other members of the multi-disciplinary team on the importance of involving the social worker from the point of diagnosis. The participants of this study perceived it very difficult to be involved either only at the point where the patient has defaulted on his or her treatment, where the patient is bedridden or at the end-of-life.

It was found from the perspectives of the social workers that their role of as educators may be interpreted as educating the communities on their different roles and responsibilities and the services they deliver. These findings are consistent with previous studies that discussed the role social workers have in improving communication among the multi-disciplinary team (Hartman-Shea *et al.*, 2011; McCormick *et al.*, 2007; Rose & Shelton, 2006). This suggests similar perceptions of the social workers' role as an educator identified by the NASW (2010).

5.2.4 Role as broker

The study found that participants discussed their role as broker, meaning that their role as broker included linking patients and their families with the required resources or referring them to such resources. The finding of this study can be interpreted as for those patients no longer able to support themselves and their family, social workers in the provision of palliative care serve as brokers where they provide patients and their families with information and linking them with sources of funding (WHO, 2016). This finding is consistent to Blumer (1969), "*where there are complex interlinkages through constant movement and dynamic nature of organizations, institutions and networks*". This interaction (linkages) between social workers and patients inform meaning according to a specific situation and that meaning is interpreted within the minds of the participants (social workers, patients, families and or society/organizations), which results through social interaction and it is the outcome of an interpretive process (Blumer, 1969). From a symbolic interactionist position, while social workers try to understand the patient in the context of his or her ecology, different approaches, such as the role of the broker in linking patients with resources at macro level, help social workers realize and appreciate different realities. This finding on the social workers' role as broker can be interpreted as unique to the context being explored as part of the emergent sub-themes based on a grounded theory analysis. This finding provides fascinating insights from which a unique sub-theme and role as broker is articulated especially in its unique African Namibian context.

5.2.5 Role of assessment of patients

This study found that the social workers' role as an assessor can be interpreted as one of the important roles in the provision of palliative care. This study found that social workers in primary care settings (hospitals) have a crucial role to perform holistic assessments, meaning that they have to assess the patient in totality (physical, emotional, social and spiritual). This was consistent with the literature, which identifies that assessment is a key function of social workers providing palliative care (WHO, 2016; McCormick *et al.*, 2010; Delva *et al.*, 2002; Hartman-Shea *et al.*, 2011 and Ross & Shelton, 2006). The types of assessments varied for each participant, meaning that the participants, who viewed their role as discharge planners discussed assessment as a means to establish the reason for referral to the social worker, assess the support systems of patients, investigate the social backgrounds of the patients in order identify the next of kin and to locate the patient's relatives for decision making regarding the patients' care and needs of the patient for discharge in identifying the correct care and treatment options. The study found that social workers' role of assessment can be interpreted as a tool to assess the 'state' in which the patients are - 'state' meaning the physical, emotional, social and spiritual dimension of the person. Social workers' role of conducting assessments can also mean establishing whether the patients perhaps need a disability grant to use that money to buy toiletries. Whereas, other participants discussed their assessments as tools to understand the family dynamics, to gain insight into how the family understands the patients' illness, and what they can do to assist and care for the patient. This was consistent with the literature, which identified assessment as a key function of social workers in primary care settings (Delva *et al.*, 2002; Hartman-Shea *et al.*, 2011 and Ross & Shelton, 2006).

5.2.6 Role as advocate

It can be interpreted that participants perceived and discussed their role as an advocate, as important for the patients to get better treatment when the family members complain that the patient seems to be neglected. This finding is consistent with the work of McCormick (2011).

The finding in the voices of the participants can be interpreted that social workers' distinct perspectives, knowledge, skills and commitment to social justice can mean empowering them to serve as advocates and champions for the most vulnerable. In addition, their patients are repositories of stories of courage and resilience in the face of life-limiting illnesses. Social workers are trained on promoting self-determination and patient autonomy. Social workers provide palliative care and support through a strengths perspective lens. This requires social workers as professionals to critically and constructively challenge the medical culture and advocate on behalf of the patients and their families. Often in the hospital, patients may be too weak to voice their opinion on care or the patient and family may feel intimidated by the multi-disciplinary team and the technical language and environment. Through advocacy, social workers in primary care settings help the patients and the family to articulate their needs and wishes and to find ways of reconstructing normalcy after the major disruption of a life-threatening illness. Findings on the social workers' role as an advocate can be interpreted as important in understanding the patient's wishes, and then partnering with them to promote those wishes with the patient's family and the multi-disciplinary team. The findings identified different approaches to promoting patient autonomy. The participants' perspectives can be interpreted as locating and presenting the patients' desires to the multi-disciplinary team, sitting with the family to support the patient, helping the families to think whether the patient may have expressed their wishes if they were incapacitated, and also spending time with families to help support them cope with their emotions in regards to making important decisions congruent with the patient's wishes. The role of the social worker as the patient's advocate was a consistent response with many of the participants. Although the findings were not different from the literature, it was important to understand how the social workers perceive their role as an advocate. The range of approaches identified by the participants signifies the different beliefs of the social worker as an advocate. This understanding of each perception provides insight into how the social worker perceives their role, what actions they take and how they liaise between the patients, families and the multi-disciplinary team. This finding is similar to NASW (2010) on the role of the social worker as an advocate on behalf of the patient and the family.

5.2.7 Managing in-country and international referrals

The social workers' ability to manage in-country referrals by assisting those patients in need of disability grants and financial assistance as well as their ability to manage international referrals emerged as a new theme equally important in the role of the social worker in providing palliative care in the primary care settings in Namibia. This role can be interpreted as unique to the context being explored, as part of the emergent sub-themes based on a grounded theory analysis, which makes a unique contribution to the generation of new knowledge in the field. This study found that social workers have an important role to perform in managing in-country referrals of patients by assisting with their applications for a disability grant from the Ministry of Labour. Social workers perceived their role in managing international referrals (from Zimbabwe and Angola) as imperative in improving the quality of life of these patients by assisting with the renewal of medical visas and passports. This can be interpreted that social workers in Namibia perform an important role in assessing international patients visiting the country. For example, in cases where patients run out of essential medication, then the social workers refer them to the top offices be provided with the medication such as ARTs. Although this finding was consistent with the literature, which identified assessment as a key function of social workers in primary care settings, it is different in the sense that it is unique to the Namibian social worker's role, managing international referrals in the provision of palliative care to foreign patients.

5.2.8 Role as discharge planner

This research found that the social workers in primary care settings in Namibia have an important role to perform in discharge planning. Meaning that the social workers' role as discharge planner creates an opportunity for the social worker to become involved in aspects of palliative care that require them, for example, to prepare the patient for discharge. This finding can be interpreted as several important tasks are involved which include: conducting home visits and social background assessments on the living circumstances of the patients before the discharge; preparing the family on the patient's discharge; educating the family on the patient's medical condition and how to take care of the patient upon discharge.

Although this is consistent with Judd and Sheffield's research (2009), some findings in the voices of the participants shared several challenges they experienced in the Namibian context when it came to the discharge of patients. For example, when doctors discharged the patients without consulting the social workers in advance, this can be interpreted as a condition that hinders the social worker's role to conduct proper assessments in preparation for discharge planning and providing palliative care needed.

5.2.9 *Role as mediator or intermediary*

The study participants perceived their role as mediators between the patients, the family, the doctors, nurses and other members of the multi-disciplinary team. This finding emerged from the participants' experiences, for example, where they encountered cases where patients in most instances do not have the courage to ask the doctors certain information regarding their conditions, because they perceive the doctors as having a higher social status. The study found that social workers report been perceive by their patients as healthcare professionals that are approachable. This can mean patients feel that the social workers listen more to their problems, as compared to the doctors, who the patients think are extremely busy and never have the time to listen to their concerns. It emerged from the study that social workers serve as a mediator between the patients and the doctors, especially in cases where the doctors use medical jargon that the patients do not understand. The participants perceived their role as intermediaries, mediating between the family, the multi-disciplinary team and other programmes within the community. In addition, the participants' perceptions can be interpret that social workers serve as intermediaries at institutions where the patients can get assistance to improve their quality of life, making them feel humane, loved, cared for and helping them to cope with their life-limiting illnesses. This emerging new sub- theme suggests that the role of the social worker as an intermediary or mediator is an important factor in the provision of palliative care to patients with life-limiting illnesses in the primary care context being explore in Namibia based on a grounded theory analysis.

This chapter continues to provide a discussion and interpretation of social workers understanding of palliative care through their interaction and the meaning they assigned to it (Blumer, 1969). Further, it presents a discussion and interpretation of the conditions, which hindered or strengthened social workers' abilities to provide palliative care and provides insights on how social work education and training in palliative care influenced the practice of palliative care. In the section below, the different themes and sub-themes that emerged from the data are discussed and interpreted.

5.3 SOCIAL WORKERS' UNDERSTANDING OF PALLIATIVE CARE

One of the objectives of the study was to discuss and interpret the social workers' understanding of palliative care. A significant insight of the phenomenon studied was the way in which palliative care is understood by social workers in the primary care setting of Namibia. A starting theoretical premise was that the construction of meaning is negotiated through an ongoing interpretive process that occurs during interactions and over a period of time (Blumer, 1969). As such, it was necessary to first interpret the meanings ascribed to palliative care. In seeking to examine the social workers' perceptions of their role in providing palliative care, it was useful to first consider notions of the individual participants' understandings of palliative care. This included exploring what it meant. Thus, the construction and positioning of palliative care reflected the histories, cultures and experiences of participants rather than an objective truth that sat apart from participants. This section considers social workers' various understandings of palliative care.

This study found that the understanding of palliative care was a salient concept. The meaning assigned to palliative care by patient participants was more often focused on physical care with little or no reference to the psychosocial (social, emotional and psychological) and spiritual dimensions. This contrasts with the generally accepted association between palliative and holistic care. More specifically, the expertise of the palliative care team in the acute sector was conceived of in terms of technical strategies for symptom relief. Patient and the family's caregivers equated palliative care with treatment such as medication for pain.

This research found that less than half (only nine out of twenty) of the research participants were able to provide a working definition of palliative care. This finding is similar to that of the MHSS (2009) study, as discussed in chapter 2, which emphasizes a lack of knowledge and accurate information around palliative care as a key challenge. This section also discusses issues surrounding the lack of knowledge and training on palliative care among the research participants. My study found similar challenges around palliative care social work, namely the lack of knowledge and accurate information. As mentioned in chapter 2, the WHO (2002) highlights palliative care provision as an essential component of a comprehensive package of care for people with life-limiting illnesses. However, the lack of understanding of palliative care or the social workers' uncertainties of palliative care as a concept and as a specialized discipline of care as identified in this study, may result in failure of adequate palliative care provision. This is another major barrier limiting the appropriate access to palliative care, also found in a recent study (WHO, 2016). According to the research participants, social workers' uncertainties or lack of understanding of palliative care may be interpreted as resulting in untreated symptoms and suffering of patients and it may hinder an individual patient's ability to continue his or her daily activities. This finding means that social workers' understanding of palliative care as a concept and discipline can have serious health implications in the healthcare system, because the understanding of the concept palliative care is an integral part of holistic care, which includes the goals of enhancing quality of life, optimizing function, helping with decision-making and providing opportunities for personal growth. The difficulty in defining palliative care can be interpreted as reflecting tension between the institutionalization of palliative care in the primary care setting and the understanding and development of palliative care from its origins situated outside mainstream medicine. Furthermore, a patient's clinical situation and psychological readiness, a health professionals' knowledge (including that of the social worker), understanding, attitudes and preparedness and a system's ability to respond, all form part of the understanding of palliative care. This study found levels of uncertainty and differing and contradictory perspectives among the participants of what palliative care entailed, therefore that social workers are in need of palliative care education and training.

Social workers interact with patients on a daily basis, which provides an opportunity for earlier referral to palliative care. As such, it can be interpreted that social workers play a significant role in shaping the meaning of palliative care. In addressing the complexities or uncertainties around social workers' understanding of palliative care there is a distinction between a palliative approach to be provided by all health professionals and palliative care that includes specialist palliative care social workers. Social workers' uncertainties of understanding palliative care can also be interpreted as a difficulty for social workers in identifying where regular care ends and palliative care begins and this concept underscores the separateness of palliative care from everyday medical practice.

Another important finding indicates that despite the fact that more than half of the participants in this study received undergraduate training on palliative care, only a few were able to elaborate on the different dimensions (physical, emotional, psychological and spiritual) of the WHO definition on palliative care (WHO, 2002). This finding is also similar to the finding of the MHSS study (2009), because only a few participants in this study were able to elaborate on the different dimensions of the WHO definition of palliative care (WHO, 2002). Although previous work has not specifically addressed social workers' understanding of palliative care in a Namibian context, this study expresses concerns about social workers' understanding of palliative care, especially in performing their role to provide care to patients with life-limiting illnesses. The breadth and complexity of palliative care needs in Africa and in particular Namibia emphasize the importance of social workers' understanding and knowledge of palliative care. Social workers' understanding and knowledge of palliative care are sociologically important and an integral part of holistic care which aims to improve the quality of life of the patient and the family. Social workers' knowledge of palliative care is crucial in enhancing their competencies to practice adequate and comprehensive care to patients with life-limiting illnesses. Social workers' knowledge of palliative care does not only benefit the patient and the families, but it also benefits the society at large in the sense that social workers can use their knowledge when advocating for national palliative care policies which will ensure access and affordability for this provision. This demands a truly holistic understanding of palliative care, paying considerable attention to the social, educational and economic issues in society that are often consequential to life-limiting illnesses. However, these issues have not been prioritized in developing countries.

To improve the provision of palliative care social work, there is an urgent need to address social workers' knowledge of palliative care. The majority of the participants interviewed for this study demonstrated limited knowledge of palliative care.

Given the diverse coverage of hospitals from Namibia in this study, it might be safe to assume that knowledge about palliative care according to WHO standards is limited. Insufficient attention was given to social workers' understanding of palliative care. In addition, no research in this context has taken into account the importance for social workers having an accurate understanding of palliative care in their role in providing palliative care. In closing this gap in information, my study identified the need for social workers to be trained on the definition and elements of palliative care, which need to align to the WHO (2002) definition of palliative care that was adopted by Namibia. This understanding is vital in the provision of care to patients with life-limiting illnesses. The study aims to address the challenges on social workers' lack of understanding of palliative care, although it is not intended to cover everything related to palliative care social work. A report from ten countries of the African Palliative Care Association states that Namibia's status of palliative care activity is ranked at level 3a, indicating isolated palliative care provision (APCA, 2016). This status is characterized by the development of palliative care activism that is meagre in scope and not well supported, source of funding that is often heavily donor dependent, limited availability of morphine and a small number of hospices (palliative care services are often home-based in nature and relatively limited to the size of the population). Namibia only has palliative care services based in other community settings and there is only one hospice in the country affiliated under the Roman Catholic Church in the southern part of the country. It has limited palliative care services for patients with life-limiting diseases such as cancer or HIV and AIDS.

The next section below continues to explore social workers' perceptions and experiences about providing palliative care to patients with life-limiting illnesses.

5.4 SOCIAL WORKERS' PERCEPTIONS AND EXPERIENCES ABOUT PROVIDING PALLIATIVE CARE

This study found that there is no scientific information available about the proportion of social workers' work that focus on palliative care, specifically from the Namibian social workers' point of view. This broad research question is interpreted as the core of the study, which is in line with the second research objective. In the next section, implications for palliative care social work practice are discuss and interpreted. The findings, which were discussed included the participants' perceptions of the proportion of their work that focus on palliative care; perceptions and satisfaction with the management of palliative care services in primary care; perceived confidence in the provision of palliative care; satisfaction with the provision of palliative care services; perceptions and satisfaction with the role of the social worker in providing palliative care; perceptions on interactions with patients and family; perceptions about interactions with the multi-disciplinary team and skills needed as palliative care social workers.

5.4.1 Perceptions of the proportion of social work focusing on palliative care

When the participants have been, ask to explain what proportion of their work focuses on palliative care, most of the participants' work did not have a specialized focus on palliative care provision in their daily duties. The participants' responses ranged from between “*a little bit and not much*” for the district based hospital social workers to a “*100% specialization*” for the social workers based in the national referral hospital in Windhoek and the intermediary hospitals in Windhoek and Oshakati. Participants' perceptions can be interpreting as a shortage of social workers in Namibia and the lack of opportunities for specialization as palliative care social workers. This means that hospital social workers have double duties, operating as both generic hospital based and specialized palliative care social workers. It can also be interpret that this can be attributing to the lack of in-service training and lack of continuous education and training opportunities on palliative care.

However, a few of the participants had experiences as medical or specialized palliative care social workers in the national referral and intermediary hospitals. These findings are consistent with MHSS (2014), which found that Namibia faces a human resource crisis in the public health sector. This crisis is characterised by a shortage of health professionals, high vacancy rates for all categories of staff, high attrition rates (mostly due to resignations), lack of a human resources retention strategy, staff burn-out (and incomplete implementation of the Employee Assistance Programme) and inadequate capacity at local health academic institutions to produce the required number of needed health workers (MHSS, 2014). There are three health workers per 1,000/population in Namibia, above the WHO recommendation of 2.5 health workers per 1000 population. Specific health worker-population ratios include 1:13,519 for social workers, 1:2,952 for doctors, 1:704 for registered nurses, 1:10,039 for pharmacists, and 1:28,562 for health inspectors, among others. These figures, however, ignore a shortage in the public sector, which has barely two health workers per 1000 population. Moreover, within the public sector there are chronic shortages of frontline workers including social workers, doctors and nurses. The country depends heavily on the recruitment of expatriate doctors. There is a direct relationship between the ratio of health workers to population and survival of women during childbirth and children in early infancy. In Namibia, the health worker shortage has been a major impediment to attaining the health MDGs (MHSS, 2014).

5.4.2 Perceptions, experiences and satisfaction with the management of palliative care services

In response to the question to describe how palliative care is managed and whether the participants are satisfied with how palliative care is managed in their respective hospitals, five participants responded not being satisfied with how palliative care is managed. The participants' perceptions and satisfaction with the management of palliative care service can be interpreted as a condition that hinders social workers' abilities to render palliative care in cases where the nurses and doctors do not conduct proper assessments and diagnosis on the patients. For example, a patient may suffer from stress due to a life-limiting illness, but because the root causes of stress were not properly assessed and identified by the doctor and, the case referred to the social worker

for intervention. This finding may be interpreted as having implications on the social workers' workload since they must take time out of their busy schedules to conduct a comprehensive assessment in order to identify the root causes of the patient's condition for further interventions. The research participants shared that during their assessments, they found the patient suffers from a life-limiting illness which were not properly assessed and diagnosed by the doctor from the beginning when the patient first visited the doctor. It was found that the social worker had to refer the patient back to the doctor for a proper medical assessment and diagnosis. For many of the participants, time constraints and heavy caseloads limited their availability to those patients in need of palliative care. Even though some participants felt overwhelmed by heavy caseloads, those that reported more success working with the UNAM social work students during their palliative care clinical placements experienced that recently palliative care referrals from the doctors have increased. This can mean that awareness increased on palliative care by the social work students during their palliative care clinical placements at the Windhoek Central and Katutura hospitals. Those participants took a proactive approach and sought out the physicians to lobby for more referrals on palliative care cases. This study found that the participants were able to consult the doctors directly on referring palliative care cases to them. This proactive approach from these participants resulted in a slight improvement on referrals from the doctors to the social workers although more sensitization and referrals need to be conducted. This approach also resulted in relationship building, as some of the participants experienced doctors and nurses consulting them in the referrals and acknowledging the role of the social worker in the palliative care team. This can be interpreted as a factor strengthening the social workers' abilities to provide palliative care. The perceived lack of assessment skills of the doctors in order to make proper diagnosis on patients, who need to be referred for palliative care, may indicate a lack of training on how to conduct holistic assessments on the patients' health problems or those who suffer from a life-limiting illness. This study, through its interpretation of analysis may mean training on assessment skills for doctors and nurses to enable them to make proper referrals on palliative care patients to social workers, which may result in adequate palliative care.

Another significant finding in this study is the lack of sufficient human resources, for example, shortage of social workers, doctors and other healthcare professionals, including nurses and occupational therapists, dieticians and others. This finding is consistent with the MHSS study (2014). The lack of hospital accommodation also leads to quickly discharging the patient to go and die at home without consulting both the social worker and the family members. This was a significant finding and contributing factor, which may hinder social workers' abilities to provide adequate care. The social workers' concern about the doctors not consulting them when discharging the patient, could mean that social workers are failing to provide the necessary support to the patient and the family when it was evident that both needed counselling and psychosocial support. Inadequate teamwork can be interpreted as a symptom of a problem within the system. This analysis can also be interpreted as yet another condition that may hinder social workers' ability to provide palliative care to the patient and the family. This study found that social workers were very concerned about the practices where doctors discharge the patients without preparing and informing the patient and the family about the patient's medical prognosis, treatment options and the discharge. In response to this concern, the participants suggest for the government of Namibia to dedicate a special ward in the hospital where patients with life-limiting illnesses, especially those at the end-of-life in need of palliative care can be accommodated. This recommendation for a dedicated palliative care ward might contribute in fulfilling the aim of palliative care, which is to improve the quality of life of patients and their families by ensuring that patients have access to quality care provided by the doctors, social workers, the nurses and other members of the multi-disciplinary team.

The participants also recommended for more awareness and sensitization on the importance of consulting the family and the social worker on the discharge of a patient, which may result in quality of palliative care provision. Another significant interpretation on the participants' perceptions and satisfaction with the management of palliative care services is the given reality that *"little attention is given in the psychological aspects of the person ... it is by chance that they (doctors) refer some of them (palliative care patients) to us ... most of the times they don't"* (Aardvark

interviewed on 10 June, 2016). This may indicate that doctors only concentrate on the physical dimension of the patient's well-being by clinically treating the disease alone, neglecting the other aspects and psycho-social dimensions of the patient (emotional, psychological and spiritual). This finding is similar to that of Saunders' (1967), who found that the philosophy of medicine was in danger of disappearing – that patients in all their aspects and dimensions are the concern of the doctor, the nurse and the social worker, not the disease alone. Some of the participants in this study raised a concern that it seems doctors lack assessment skills in adequately addressing the psychological aspects of total pain management. This can be interpreted that doctors may need some training on total pain assessment and management in order to attend to the psycho-social dimensions of the patients in order to make proper referrals to social workers. The participants were also concerned about the low or lack of referrals of palliative care cases from the doctors to the social workers. It can be interpreted from the participants' experiences that doctors in primary care in Namibia are in need of referral skills training in order to make proper referrals. This study found that if doctors are trained in holistic assessment and referrals it may strengthen the social workers' abilities to provide psycho-social support and counselling to the patients and their family in need. This finding implicates more advocacy, training and sensitization on the importance of total pain assessment, management and referral on palliative care cases to the social workers, not only for doctors and nurses, but also for the entire multi-disciplinary team. The study also means training of the family members on how to take better care of the patient at home when the patient is discharge, especially when it comes to the end-of-life stage. This finding can also be interpreted as a condition that may strengthen social workers' abilities to deliver adequate care to patients and their families in need. Another interpretation on social workers' perceptions and satisfaction about how palliative care is manage, is describe in the next section.

This study found that those participants who worked as specialized palliative care social workers in the national referral and the intermediary hospitals were very satisfied and positive about how palliative care is manage in their respective units. Those participants reported having specialist doctors trained in palliative care working in their units. These specialist doctors know and practice the principles of palliative care.

For example, in a case where morphine needs to be administered, they will not only prescribe morphine alone, but they will also prescribe a laxative since morphine alone causes constipation. From the perspectives of those participants, the doctors who were train in palliative care were very knowledgeable and adhered to the palliative care principles. This study found that those participants trained in palliative care and practice as specialist palliative care social workers appear to be quite knowledgeable in terms of what palliative care is and how they should support patients suffering from life-limiting illnesses and their families. The study found that social workers who were trained on palliative care and who managed to practice as specialized palliative care social workers in a palliative care setting benefit in gaining knowledge on what should be avoided when dealing with a patient who is dying. For example, the social worker (Faith) at the oncology ward in the national referral hospital seems to be very satisfied with the management of palliative care in her unit where pain management medication is available for all cancer patients and other patients suffering from life-limiting illnesses and where the physicians apply the principles of palliative care. Faith was satisfied with the way palliative care is manage in her unit. The way it is managed provides patients the room *“not to feel like giving up easily and it is not making them lose hope, totally, we do not give them hope, but we also do not make them lose hope”* (Faith interviewed on 10 May, 2016).

Faith narrated her role as social worker as, *“sitting down with them and talk to them”* and providing the patient with information on what the doctor says about their condition to a point where the patients will say, *“okay, so that is what is happening”*. Then their fear is not really, *“I am going to die”*. *They manage to rise up and still see life there, although they know ‘this is my condition’*” (Faith interviewed on 10 May, 2016). This finding can be interpreted as a very important aspect of the role of the social worker in providing psychosocial support, counselling and psycho-health education to patients. Participants were pleased with how palliative care is managed. As Faith shared, social workers have a very important role in working hand-in-hand with the doctors in breaking the bad news of a diagnosis. She said, *“the care of the patient as very well the communication between the multi-disciplinary team members is very well”* (Faith interviewed on 10 May, 2016).

This approach can be interpreted as important in the team supporting each other in the work, as well as discussing approaches to moving care forward. However, on her level of satisfaction on how palliative care is managed, she responded that at times it can be challenging, especially “*when it comes to the rotation of doctors*” (Faith interviewed on 10 May, 2016). This can be interpreted as bearing a strain on the social workers’ ability to provide informed palliative care. This presents a challenge for the social worker not getting hold of the specific physician who initially admitted or diagnosed the patient with a life-limiting illness.

5.4.3 Perceived confidence in the provision of palliative care

In response to the question on the perceived level of confidence of the social workers in the provision of palliative care, the majority of the participants’ responses ranged from between “*very, very confident, very confident, confident, confident enough, scary at the beginning ...*” to “*a bit confident and quite comfortable*”. However, for one of the participants’ who did not receive any palliative care training during her undergraduate studies as well as no in-service training on palliative care, she responded “*I do not know first, I would really need to sit down and define palliative care before I can respond confidently to whatever is happening around the palliative word, it is a Greek word it is a strange word to me*”. It is evident from these findings that “*education and training on palliative care can help social workers develop confidence in their decisions, as well as the confidence and know-how to take appropriate action and tap into available resources when needed*” (Grady *et al.*, 2008: 6). However, this study found that there is a gap in the level of education and training as well as a difference in the level of confidence of the social workers due to the lack of education and in-service training on palliative care. The study identified several gaps in palliative care practice, levels of education, in-service training and level of confidence in providing care. For example, one of those participants expressed “*I do not have enough knowledge regarding palliative care which I can be confident to engage with a patient you know, effectively, I do not have that when, for instance, a case is been referred to you*”. The participants discussed a need for further education and in-service training on palliative care to teach the social workers the skill set of providing palliative care confidently.

5.4.4 Perceptions and satisfaction with the provision of palliative care services

It is important to understand the conditions that either hinder or foster a positive working environment and the social workers' abilities and competencies in the provision of palliative care social work. In response to the question on whether the participants were satisfied with the provision of palliative care in their respective hospitals, responses ranged from between being "*very satisfied, not 100% satisfied, not really well satisfied*" to "*not really satisfy*". Participants identified several conditions as fostering a positive working environment in the provision of competent care. These included education; training; in-service training on palliative care; clinical knowledge; teamwork and communication skills; opportunities to specialize as palliative care practitioners and having access to resources to provide the psychosocial needs of patients.

It is evident that a positive interaction takes place between the social worker and the multi-disciplinary team in the case where the team members were educated and trained on palliative care and specialize as palliative care practitioners. This study found that these conditions, as described above, strengthen social workers' abilities and positively influence their competencies to provide adequate care. However, several participants were not satisfied with the provision of palliative care services. They identified conditions that hinder a positive working environment and their abilities to provide palliative care. These included social workers not been consulted when it came to palliative care provision or the discharge planning of the patient. Participants in this study recommended for a palliative care unit in the hospital where patients with life-limiting illnesses are accommodate. Other conditions included issues around referrals of palliative care cases. Referrals needed to take place from the point of diagnosis in order to enable the social worker to provide psychosocial support and counselling to the patients from the beginning, and not for the doctors to wait until the patient has defaulted on the treatment and then make a referral to the social worker. The finding on the late referrals can be interpreted as a challenge that may hinder social workers' abilities to conduct early identification and assessments to provide psychosocial support and counselling to the patients and the family.

It is also evident from the narratives of those participants that patients experience adherence problems, because of other social needs that were not catered for. The lack of involving the social worker and late referrals of these patients can be interpreted as issues that hinder the provision of palliative care. Further, these issues prevent their ability in the sense that it hindered the social workers' ability to conduct an early identification and assessment. This study therefore is designed to fill this gap in advocating for and recommending that doctors refer patients with palliative care needs to the social workers at the point of diagnosis. This practice will strengthen the social workers' abilities to intervene early enough through comprehensive assessments, addressing and responding to the palliative care needs of the patients and the family in a competent manner.

5.4.5 Perceptions and satisfaction with the role of the social worker in the provision of palliative care

When the participants were asked about their perceptions and satisfaction with the role of the social worker in the provision of palliative care they were of the opinion that social workers are *"being under-utilized What they are doing is less than what they can do, if they know that the playing field is improved or they are equipped, I think social workers can do a lot more..."*. This points out the need for more training for social workers to be well-equipped to do more in the provision of palliative care. Another finding in this study suggested for social workers to be more actively involved in the provision of patient and family health education. However, there were differences in the participants' perceptions and satisfaction with the role of the social workers in providing palliative care. For example, some social workers employed by the Ministry of Health and Social Services perceived themselves as a *"Jack-of-All-Trades and Master of None"* meaning that they are doing everything in their ability to respond to the needs of the patients within the hospital, and also dealing with community development projects without having an opportunity to become a specialist palliative care social worker. It is evident from the finding that social workers in the primary care settings practice both generic and specialized social work in palliative care.

This study found that there is a need for specialized palliative care social workers, and therefore wishes to recommend that the MHSS create opportunities and appoint palliative care social workers.

5.4.6 Perceptions and experiences about interactions with patients and family

Social workers have an important role in interacting with the patient and the family in the provision of palliative care. Participants of this study perceived their role as a social worker conducting family conferences as very important and as *“one of the major roles involving the family members, because we believe that the family members are the key point, the foundation of successful interventions”*. This can be interpreted as an effective multi-disciplinary method for providing clear and accurate information in a supportive way for patients and families (Curtis & Vincent, 2010; Fineberg, 2005 & Werner *et al.*, 2004). The participants who discussed their experience in interactions with the patient, the family and the team as positive and collaborative also discussed their role in family conferences as a significant interaction. This can be interpreted that the social worker plays an important role in initiating, organizing and facilitating the family conference. However, not all of the participants discussed a similar role in the interactions with patients through family conferences. Some of the participants discussed their experiences, for example, when family members are not included in family conferences.

Lucky described, *“these are sometimes even the people who will influence the patient not even to adhere to the medication when they come in with cultural issues and traditions, because they are made to understand the conditions, they are the ones who might even think that this is a curse or something and they are likely to take the person for traditional healing ...then you find that the medication ...will not work out. So, if you involve them through family conferences, they are at the same level of understanding and then your challenges will also be less from your team as a medical team and also their side as family”* (Lucky, interviewed 03 June, 2016).

Limited involvement or lack of interaction with the family may be interpreted as preventing adequate provision of palliative care. This study also found that it is very important to involve the social worker at the point of diagnosis of a life-limiting illness. One participant described, “...it is important that immediately once a person is diagnosed, the social worker is involved ...the role of the social worker is to provide psychosocial support, emotionally, and mentally, immediately once the person is diagnosed and to start the counselling. I think it will help in preventing defaulting, because there is another holistic approach that social workers have whereby the basic counsellors may only focus on how they are feeling, but then the social worker will know the therapy that is needed to walk a mile with this person. So I think it is really important” (Faith interviewed on 10 May, 2016). It is evident from the participants’ experience that social workers play an important role as a member of the multi-disciplinary team. In particular, assessment of the patients’ needs is important in order to provide culturally sensitive and competent counselling, care and support. This support may prevent patients from defaulting on their medication.

5.4.7 Perceptions and experiences about interactions with the multi-disciplinary team

A key finding of the study was the social workers’ interaction with the multi-disciplinary team. Some of the participants shared some negative experiences about their interactions with the multi-disciplinary team.

Aardvark, for example, discussed her interaction with the multi-disciplinary team as “challenging, because social workers are seen as not so important and if you talk, sort of advocacy talk and trying to make demands and put your foot down, you are seen as this trouble-maker or always-fighting person, like ‘oh, social workers like fighting’...” (Aardvark interviewed on 10 June, 2016). This finding in the voice of this participant can be interpreted that the MHSS does not perceive social workers as essential or important staff in the hospital. According this finding from Aardvark, this perception is from the Ministry itself, its staff members, the nurses and other staff members including the community counsellors.

She said, *“I think it is a ministerial thing whereby it is saying Ministry of Health, so the health is seen as an emergency and is always put first and social services come in lastly...and they just feel like it is a profession for losers”* (Aardvark interviewed on 10 June, 2016). This can be interpreted as social workers not feeling as important staff members of the MHSS and the hospitals’ multi-disciplinary team. Another participant described his interactions with the multi-disciplinary team as *“not strong or non-existent in the hospital”*. His experience can be linked to and interpreted as a lack of training and education of doctors on palliative care and can also be ascribed to the shortage of health care professionals. The study found that due to the lack of training on palliative care for doctors, shortage of staff and full work schedules, doctors do not have the time that the social workers have to sit, assess and explore the patients’ problem. The study found that doctors just write the referral for a HIV defaulter to go and see the social worker. There is no feedback between the healthcare professionals. However, other participants discussed their experiences with the multi-disciplinary team as very important in the diagnosis of a patient with a life-limiting illness. They described their experiences on the team as positive and collaborative and their role in family conferences and case consultations as significant. Their interaction and their role as social workers in the multi-disciplinary team can also be interpreted as educative in terms of making sure that other members of the team understand the role of the social worker in the provision of psychosocial support and counselling. The participants discussed approaches to care, moving forward and could educate the nurses and physicians on how the social worker can help with each case. This approach can be interpreted as resulting in success for the participants and their interaction with the multi-disciplinary team and was describe as *“encouraging and it is motivating...”*.The participants, who were proactive, integrated education into their daily interactions with staff. This can be interpreted as an effective educative method in the hospital in raising awareness on the role of the social worker in the provision of palliative care. It can mean that it does not require taking time out of one’s daily schedule to lecture on the role and importance of social work. It can be interpreted as a natural and non-threatening way to educate and reinforce the role of the hospital social worker in the provision of palliative care.

Some of the keys to success identified were a need for multi-disciplinary team ward rounds, case consultations with the team members and a recognition and respect of the different roles that each member fulfilled. This approach to palliative care is an exemplary mode of care.

5.5 CONDITIONS THAT HINDER SOCIAL WORKERS' ABILITIES TO PROVIDE PALLIATIVE CARE

One of the objectives of the study was to discuss and interpret conditions that hinder social workers' abilities to provide palliative care to patients with life-limiting illnesses. This study found that social workers in primary care settings and in the palliative care field are face with several challenges. These include, their role as social workers are not understood; the lack of palliative care education and training; lack of in-service training; lack of continuous education and research on palliative care; communication barriers; incomprehensible medical jargons; shortage of specialized palliative care social workers and their workloads; the well-being of the social workers; lack of supervision, lack of debriefing and support from management; lack of appreciation for the role of the social worker in the provision of palliative care; lack of hospital bed space and other conditions that hinder the social workers' abilities to provide care.

The skills social workers need to learn are strong clinical skills; relationship building skills; understanding of the environment; understanding family dynamics; empathy, listening skills, patience, good communication, organizational skills; self-awareness, knowledge of resources and laws and investigative skills. However, the roles of the social workers in the provision of palliative care are not clearly understood by other health care professionals. The sub-themes below provide more information on the different conditions that emerged from this study, which may hinder social workers' abilities to provide palliative care.

5.5.1 Roles of the social workers in the provision of palliative care are not understood by other healthcare professionals

In this study, the participants identified role and boundary issues with the staff in the hospitals as well as problems being micro-managed by nurses and feeling unappreciated and devalued. This can be interpreted as important in understanding the factors that might foster a negative environment for the social workers. The conditions that the participants identified include: a lack of understanding of the role and skill set of the social worker; social workers' role in providing counselling; psychosocial support; conducting assessments; doing discharge planning and handling heavy caseloads. Theoretically, individual healthcare professionals' roles need to be differentiated in the multi-disciplinary treatment team. For example, the social workers fulfil separate roles in the multi-disciplinary team compared to nurses, doctors, administrators or dieticians (Northouse & Northouse, 1985: 96–97 and Northouse & Northouse, 1998: 79). Meaning that if role differentiation is clearly defined, effective teamwork can occur since miscommunication is avoid when providing care to patients. This study found that the role of the social worker is “*sometimes not really clear, I think to the other members, to the nursing staff. Sometimes it is not clear what type of cases to refer to the social workers, so anything that they do not understand, sometimes I think they neglect what they supposed to do...they just refer to the social worker, like if a patient come in with a headache or neck pain...*” (Catherine interviewed on 06 May, 2016). The study found that these problems are but just a few to mention within the hospital, which affected how the social worker interacts with the other members of the multi-disciplinary team.

However, there were significant differences between the participants in a negative environment compared to those who reported a positive team view. For example, one of the participants in this study stated that although “*there are others who do not understand our role and again sometimes it is not the problem of the professionals, perhaps it is ours as social workers, because we have not been able to explain ourselves before them...*” Another participant also raised a concern about the social work profession being “*seen for children's problems and when HIV started, now counselling is only for HIV people ...*”.

This finding raised a concern that the social work professionals “*themselves do not really advocate much or market their profession, so the lack of understanding due to this can also be a contributing factor*” (Edward, 2016 interviewed on 24 May, 2016). These findings can be interpreted that social workers need to take more proactive roles in educating and sensitizing other members of the multi-disciplinary team and the society on the roles of the social worker “*because there are other professionals who do not understand what social workers do, they would just think we are there to facilitate the provision of food or the provision of other services in the community, that is their perception*” (Edward interviewed on 24 May, 2016).

On the other hand, some of the participants had a positive view about supportive managers and supervisors who recognized the time demand and need for a social worker in the hospital or the ward. This can be interpreted that some participants felt comfortable discussing those difficult cases with his or her supervisor, processing their reactions to the case, and brainstorming ways to move forward with the case. Teamwork, found to be a vital aspect of patient care and therefore contributes in filling the gap in providing training on the effective differentiation of the responsibilities of the different health care professionals in the multi-disciplinary team. In addition, it can be interpreted that teamwork enables each member to be able to adequately address and respond to the different psychosocial needs of the palliative care patients.

5.5.2 Lack of palliative care training; in-service training; continuous education and research on palliative care in the Namibian context

This study found that training, continuing education and in-service training opportunities on palliative care are important to improve the practice of palliative care social work. The findings on the lack of palliative care training; lack of in-service training; lack of continuing education and lack of research on palliative care can be interpreted as conditions that hinder the social workers’ abilities to deliver adequate palliative care. These shortages negatively influenced social workers’ abilities and competencies in delivering palliative care as “*some social workers are afraid to work in a palliative care setting... they are afraid ...of death and dying ...some of the factors that may hinder social workers at my institution are a lack of refresher courses in*

palliative care” (Faith interviewed on 10 May, 2016). The lack of time to discuss, reflect and share case studies and best practices or to attend continuous professional development trainings can be interpreted as some other challenges highlighted by the participants. This study found that there are limited opportunities for continuous education and in-service training on palliative care, which implicates a need for further research into how this can improve. The findings of this study indicate that Ministry of Health and Social Services in collaboration with researchers need to look at ways to make in-service training and continuous education on palliative care accessible in order for more social workers to have equal opportunities to enhance their learning and practice. This could mean use of local experts who can go on-site to the hospital to provide continuous education to the staff. It can also be interpreted that social workers can receive continuous education units (CEU’s) at the completion of palliative care training.

The study found that it is important that hospitals create opportunities for social workers to go off-site for trainings as well as to bring innovative programs on-site. In Namibia, social workers have to be license to work in the primary care setting. As a result, many social workers need to seek out continuous education programs actively to obtain the necessary units to maintain their license registration. Easily accessible and interesting palliative care education programs may recruit more social workers to become palliative care specialists and maintain a discipline that is up to date on the latest research in the field.

5.5.3 *Communication barriers*

Theoretically, communication breakdowns between healthcare professionals occur for many reasons as already mentioned in this study. The issue of communication breakdowns is discussed in literature. This study suggest for effective communication and teamwork to be maintain in order for effective patient treatment to occur. The roles in the multi-disciplinary team need to be differentiated effectively in order for individual responsibilities to be carried out. The findings of this study indicate that the lack of consulting the social worker on patients’ discharges and the late referrals from the doctors result in poor palliative care to patients with life-limiting illnesses.

This was note from Alice and Edward’s experiences where they highlighted the lack of the social workers’ involvement and the gap in proper referrals from the doctors and or the nurses to the social workers. These were some of the factors hindering social workers’ abilities to provide adequate care. Healthcare providers are required to educate themselves on the tasks that each HCP performs in order to avoid requesting other HCPs to perform jobs that they are not responsible. All of the participants indicated that they had experienced some communication breakdowns in competently providing palliative care. They also experienced heavy caseloads due to the shortage of staff, “*in terms of communication, I think ...it can be that sometimes we got too busy here given our workloads*” This might be interpreted as another barrier in effective communication in the team. This study identified a gap in communication among health care professionals and therefore recommends training on communication within the multi- disciplinary team.

5.5.4 Delayed referrals from doctors and nurses to the social workers

Another condition that emerged from the study is the referrals from the doctors and the nurses to the social workers which are not mainstreamed. This meant that most of the participants experienced either a low, slow or lack of referrals from the doctors, which indicated that participants experienced that patients are discharge from the hospital without been referred to the social workers. This finding can be interpreted as a concern about the doctor’s practice of not referring the patient to the social worker at the point of diagnosis, but rather at either the end-of-life or when they defaulted from their medication. Aardvark shared, “*the moment we see them, they are almost just like bone and skin*”. Nanna described, “*social workers are not involved or rarely involved, or referred to the social worker*”. Nanna further suggested that it “*would be more effective if we could probably get the doctors to really refer cases that they think need further support ... if I am not involved, I would not be able to reach out to this patient...so this is what would hinder my ability, if I am not involved from the beginning*”. This study therefore interprets the meaning of referrals from doctors to social workers as a vital condition in strengthening the social workers’ abilities to provide palliative care in improving the quality of care.

5.5.5 Explaining medical jargons used by doctors with patients

The use of medical jargon by the doctors with the patients was another new theme that emerged from the study. This can be interpreted as another condition that may hinder patients' understanding of their conditions, and at the same time, it affects the social workers' time and caseloads, meaning that social workers must painstakingly take time out of the busy schedules to explain the diagnoses to the patients in simpler terms. This study therefore interpreted this as a need for training to provide social workers with clinical terminologies and different diseases. In addition, it can also mean that doctors need training in simplifying their language, especially when giving a life-limiting diagnosis.

5.5.6 Shortage of specialized palliative care social workers and workloads of the hospital based social workers

Other themes that emerged from the analysis can be interpreted as shortage of specialized palliative care social workers and the workloads of the hospital based social workers. The shortage of staff and the lack of specialized palliative care social workers, can be interpreted having a strain on the provision of adequate palliative care, for example, *"forgetting that social worker currently in the Ministry of Health and Social Services are not specialized and they are not specialized in one thing only is a great challenge"* consistent with MHSS's study (2014). Another participant, for example, mentions, *"a huge workload is a problem, because we do everything ... so for me then to think and worry about palliative care... it will be difficult"*. Competing functions of the social workers can also be interpreted as another factor that might hinder social workers' abilities to provide quality care, for example, Edward said, *"palliative care is very important, but it does not get the attention that it deserves, because it is one among many other competing functions that social workers have to undertake"*. The shortage of staff, the lack of opportunities to specialize as palliative care social workers and the heavy caseloads result in social workers feeling overwhelmed in functioning as both generic and hospital based social workers. In addition, it can also mean that social workers are feeling guilty for not being able to provide adequate palliative care to the patients.

For example, Alice said “... *looking from the point of the patient, I think I am not giving them as much attention as they require*”. In Alice’s primary care setting, the shortage of social workers resulted in “*it being impossible for social workers to join the doctors with the ward rounds, so we do not join them in the ward rounds, we just do our own ward rounds...*” Time and heavy caseloads thus can be interpreted as some of the other contributory factors that might hinder social workers’ abilities to render palliative care, as earlier stated. This analysis can mean that the MHSS should take a closer look at the staff establishment and workloads in order to create opportunities for social workers to specialize as palliative care social workers and to be relieved from the heavy caseloads.

5.5.7 Well-being of the social workers

The study noted that the well-being of most of the participants in the study was negatively affect by role overload; the role of social worker not understood; heavy caseloads; functioning both as generic and hospital based social worker and lacking opportunities to practice as specialized palliative care social workers. This can be interpreted that social workers feel overwhelmed and overstretched. It can theoretically mean that social workers as important members of the health care professional team can experience a lot of stress, as they attend to sick patients on a daily basis. Caring for a patient, who is going through the dying process emotionally, affect those who are involved. Role overload can be interpreted as contributing to the stressful conditions under which social workers operate. This can mean that social workers can experience burnout, due to the constant medical challenges they have to deal with on a daily basis (Kelloway & Barling, 1991: 294). All of the participants indicated that they experienced role stress in the form that the doctors and the nurses as well as the other health care professionals did not understand. This can mean that they experienced stress when not being involved, consult or acknowledged when it comes to patient discharge and treatment planning. This, from the participants’ experiences can be interpreted as feeling inadequate around the quality of care he or she is able to provide. This study can mean that measures need to be taken for social workers to take up proactive tasks in awareness and education on the role of the social worker.

In addition, it can also mean that the MHSS needs to re-evaluate the job descriptions of the social workers and create opportunities for social workers to specialize, which would relieve them from role overload and stress. On the other hand, it could be interpreted as a need for the MHSS to implement staff wellness programmes for social workers and hospital staff as a whole to cater for their well-being.

5.5.8 Lack of supervision; debriefing and support from management

The participants noted that their well-being is compromise due to the lack of supervision, lack of debriefing sessions, lack of staff wellness programmes and lack of management support. This can be interpreted as a need for supervision, peer support, and peer debriefing when working with patients with life-limiting illnesses in primary care settings. In primary care settings of Namibia, social workers are face with moral dilemmas, death and dying patients and crises that affect them emotionally. However, there is a gap in the Namibian hospitals between those who foster an environment of peer support, supervision and those who do not. This can be interpreted that there is need for investigation and further studies to understand how palliative care social work affects social workers and other practitioners, how they practice self-care, and methods to integrate and bring supervision and peer debriefing to them.

All the participants discussed the need for more time and a smaller caseload in order to improve the care they provide in the hospitals. In addition, it meant that many participants in this identified the need for a designated palliative care social worker to improve the field of palliative care. Further research needs to be conduct to measure the satisfaction rates of patients, family and hospital staff that have a dedicated palliative care social worker on staff. This study suggests additional research to be conduct on the positive impacts that a designated palliative care social worker brings to the hospital. Another key improvement recommended by the participants is increased supervision and peer debriefing. Self-care can be interpreted as important for social workers, as well as the other providers in the provision of palliative care. Compassion fatigue and burnout can be interpreted as real risks for those in organizations where there is little control of the workload (Maltzman, 2011). It is important to recognize the impact palliative care social work has on those involved.

This might mean that improved multi-disciplinary collaboration as well as a supportive department can aid in decreasing the risks for compassion fatigue and burnout. These findings are significant because there is a lack of research on the impact of palliative care social work on social workers. If social workers are not getting adequate support and do not know how to take care of themselves, the care they are able to provide will diminish.

5.5.9 Lack of appreciation for the role of the social worker in providing palliative care

The lack of appreciation for the role of the social worker in providing palliative care was another theme that emerged from this study. This can be interpreted as hindering the social workers' abilities to provide palliative care to patients with life-limiting illnesses. For example, despite Faith's efforts of taking unpaid leave from her employer to obtain a postgraduate Diploma in palliative care, she had to finance her studies from her personal funds. After obtaining the post-graduate Diploma in palliative care there was no incentive offered by the MHSS for the qualification and there was no acknowledgement or appreciation demonstrated from her employer. Faith's experiences and narration explain, "*...it can be very discouraging ... I go the extra mile giving it all my best, but my efforts are not acknowledged. They are not appreciating. So I think there's an important role, there is an important gap that there is in terms of lack of appreciating palliative care staff ... I feel that our hospital does not appreciate such effort...*". This experience resulted in Faith's resignation from her employer, consistent with the findings by the MHSS (2014).

Another condition that emerged from the analysis that might hinder social workers' abilities to provide palliative care was the lack of support from management. Faith in this study suggested that "*they be given further training...I think it should start from their training at university for them to appreciate the role that the palliative care social worker has to play her in the hospital*". Based on these findings, it might implicate the MHSS to implement paid leave structures that grant social workers the opportunity to develop themselves professionally in the field of palliative care and to put incentives in place to reward staff for qualifications successfully obtained.

This might mean retaining staff, boosting morale and keeping them motivated in their workplace to perform to the best of their abilities.

5.5.10 Shortage of bed space in the hospital

The lack of bed space for patients in the hospital was another emerging theme that might hinder social workers' abilities to provide palliative care. This study found that due to limited bed space in the hospital, the patients were discharged without the doctors and nurses involving or consulting the social worker. This can be interpreted that social workers were not able to conduct proper assessments on the social circumstances of the patient and the family, meaning that they were not able to provide the necessary psychosocial support and counselling services to the patient and the family. The shortage of bed space in the hospital also contributed to patient relapses, where they defaulted on their medication, resulting in high caseloads for the social workers. This might mean that there exists a need for the doctors and nurses to involve and consult the social workers in discharge planning in order to enable the social workers to conduct the necessary assessments and to assist the patients and the family in need of palliative care.

5.5.11 Other conditions that hinder social workers' abilities to provide palliative care

This study found that the limited resources affiliated with the work of the social workers such as limited budget allocations, lack of transport and breakdowns in telecommunication, such as telephone lines, computers and internet connections can be interpreted as hindrances in their abilities to provide care. As a result, this can be interpreted that palliative care in Namibia, still remains a growing trend and social workers in primary care are often face with a hospital that has limited resources for care provision. Another theme that emerged was the concern that palliative care was not featuring in the national work plans of social work, until Charlotte brought it to the attention of the management and advocated for it to be included.

Charlotte said, the inclusion of palliative care in the work plans of social workers are “*still new for some of them, they do not really think it’s their work, so they feel ‘if you say do this’, you have to try and every time repeat it, ‘no I did not get time’, but in the meantime the patient there needs it urgently...they feel it’s not their job descriptions, not their work...*”. This can be interpreted as resulting in some social workers not taking full responsibility in the provision of adequate palliative care for patients. This might mean not only including palliative care in the national work plan of the social workers, but to include it in the National Strategic Plan of the MHSS at all levels of service provision and health care.

5.6 CONDITIONS THAT STRENGTHEN SOCIAL WORKERS’ ABILITIES TO DELIVER PALLIATIVE CARE

One of the themes that emerged from the findings and in line with the fourth objective of this study was to discuss and interpret conditions that strengthen social workers’ abilities to deliver palliative care. The results of this study highlight the conditions that strengthen social workers’ abilities to deliver palliative care. The sub-themes also highlight some of the skills social workers used in order to strengthen their abilities to provide palliative care. The sub-themes are discussed and interpreted below.

5.6.1 Palliative care social work education; in-service training; continuous education; research and a national palliative care policy

All the participants in the study perceived training on palliative care in the undergraduate social work education program as a very important component in influencing social workers’ competencies to deliver palliative care. Some of the participants commended the UNAM Social Work Department for the integration of palliative care into the social work undergraduate degree and for the clinical placement exposure on palliative care. One participant shared, “*that it will go a long way in giving social workers the competencies that are needed in working in a palliative care setting*” (Faith interviewed on 10 May 2016).

However, they also suggested that the palliative care practical clinical placements be strengthened through the establishment and provision of a centre of excellence for palliative care where students can learn first-hand experiences and best practice approaches in palliative care. The participants also advocated for more palliative care clinical sites where “*it could have been ideal if students could get more time ... spent more time within a palliative care setting...*” (Faith interviewed on 10 May, 2016). This can be interpreted that the establishment of a centre of excellence on palliative care and the expansion of more clinical placement sites can strengthen social workers’ abilities and competencies to provide adequate care and it will mean lessening the burden on the already overloaded social work system, which has limited field supervisors. This study found that social work education on palliative care help to boost the confidence of social workers in terms of providing palliative care services. It can also mean helping the social worker to understand their duties and expectations in a palliative care setting. Education can be interpreted as helping to equip social workers with the necessary information on palliative care, working with patients who are dying and working with grief and bereavement issues. Social work education in palliative care can mean a yielding component for social workers, who are knowledgeable, especially if education is pair with practice, in terms of clinical placements. Palliative care clinical placements are indispensable to palliative care, because theory on its own is not enough. Forrest and Derrick (2010) find social work education to be the best place for multi-disciplinary learning, because social work focuses on strengths based perspective of “*starting where the patient is.*” This study found that social workers value teamwork and relationship building, and focus on communication. The findings by study participants can be interpreted as meaningful contributions in further strengthening of the Bachelors of Arts (Honours) program in social work at the University of Namibia to include the integration of palliative care clinical placements opportunities. This study also found that there is a need for continuous education and in-service training on palliative care, the principles of palliative care, ethics, how to communicate with a dying person and how to deal with a patient diagnosed with a life-limiting illness, consistent with Bomba *et al.*, (2011), and Morrissey (2005).

The continuous education and training programmes in social work can be interpreted as a need to incorporate information on how to work with patients diagnosed with a life-limiting illness, how to work on a multi-disciplinary team, how to facilitate family conferences and overall palliative care social work (Fineberg, 2005; Grady *et al.*, 2008). Fineberg (2005) found that of the social work students who received training on providing palliative care, their family conferences were successful, as it increased their confidence, provided new approaches and increased their understanding of each disciplines' role. Social work education and training have evolved in the last few years. It now is offering concentrations in working with vulnerable populations including children, the aging, school social work, and mental health.

This study found that there is a lack of research of the role of the social workers in providing palliative care in the Namibian context. Knowledge of how social workers understand palliative care, perceive their role in providing palliative care, investigating conditions that might hinder or strengthen their abilities to provide palliative care and gaining insight into how education and training influence social workers' abilities to deliver palliative care can make a scientific contribution. In particular, it would help to increase our awareness of ways in which we can strengthen and increase the value the role of the social worker in providing palliative care social work practice in primary care settings in Namibia. Further, research into the work of the social worker providing palliative care in primary care settings in Namibia is long overdue. It is important to understand how social workers perceive their role in providing palliative care, conditions that may hinder or strengthen their abilities to perform that role and how to improve the education and training on palliative care. It is evident from Ashley's excerpt that there is a need to have a national palliative care policy for better service delivery. She said, "*I think a policy should be put in place regarding palliative care as I feel that there isn't one at the moment. Maybe a palliative care policy should be put in place for better services*"

5.6.2 Collaborating with the multi-disciplinary team

A key finding is that of the role of the social worker collaborating with the multi-disciplinary team.

Those participants who collaborated with other health care professionals in the multi-disciplinary teams found them as a great resource. The study found that participants were proactive in seeking out the physicians and the nurses to gain updates on the patients as well as in the formal setting of ward rounds. The proactivity of these social workers in the provision of care can be interpreted as best practice approaches by the social workers to be share in strengthening their abilities to deliver care. The study found that social workers benefitted from clinical knowledge and skills through case conferences regarding the patients' needs and interventions. The participants through their collaboration with the MDT benefited from training on palliative care and became more comfortable with the provision of palliative care. This resulted in improved levels of confidence providing care. Several participants benefitted from the collaboration with the multi-disciplinary team, and one described their experience as “*awesome*” in strengthening their abilities to provide palliative care.

5.6.3 The role of the social worker in the provision of palliative care

Some participants discussed the idea for social workers to be more proactive in taking the initiative to explain their roles in providing palliative care and what they can contribute to the multi-disciplinary team. However, the participants had a varied level of comfort providing palliative care. McCormick (2010) found that with palliative care training, the interventions of the social workers improved. In Namibia, more research is needed to provide palliative care training to practicing social workers. The goal being to decrease the inconsistency throughout the field of palliative care social work and increase social worker's comfort level with providing palliative care. Hartman-Shea *et al.*, (2011) discuss the need to develop guidelines for social work in palliative care settings. Some potential for those guidelines include an assessment of every palliative care patient within 72 hours of admission; asking about wishes and goals of care within this time frame, and to determine the next of kin or health care proxy. Delva *et al.*, (2002) also noted the need for social work to focus within the first 72 hours on assessment, providing information, providing emotional support and helping to solve practical problems. Further research is necessary to develop a national policy framework for palliative care social workers to improve the care delivered in primary care settings in Namibia.

5.6.4 Mainstream of referrals of palliative care patients from doctors and nurses to social workers

Multi-disciplinary teamwork in the hospital has been link to family satisfaction with care (Campbell & Guzman, 2003). However, this research highlighted the different experiences that the participants had with members of the multi-disciplinary team when it came to patients' referrals not been mainstreamed. Some participants felt there was no multi-disciplinary team in the hospital making referrals, only individuals working separately to provide care to the patients and families. Others felt well integrated into the multi-disciplinary team. More research is necessary to understand how the two can relate more constructively in regards to referrals. In addition, there needs to be a better understanding on how to define the role of the social worker in the hospital when it comes to referrals, how the multi-disciplinary team functions, strategies to improve how they work together in mainstreaming referrals and providing care to the patients and the families. There is a growing trend to incorporate the social worker in the multi-disciplinary palliative care team in the hospital. Many of the participants in this study discussed the role of his or her hospital's multi-disciplinary team in relation to palliative care referrals. However, there was inconsistency with how the multi-disciplinary team utilized referrals, what the social worker's role becomes when the multi-disciplinary team is involved, and how the palliative care social worker interacts with the various members of the multi-disciplinary team. Social workers still need to provide and be able to provide palliative care in hospitals. They cannot always rely on the multi-disciplinary team or the palliative care social worker to take on the role of supporter and facilitator. As seen in the research, many hospitals do not have a palliative care team and of those that do, they are quite small. Further research needs to investigate how the palliative care team and palliative care social worker can best work together. Questions such as, how would the social worker and palliative care social worker share cases? Who would be responsible for the needs of the patients and families as they arise? Palliative care social workers cannot rely on the multi-disciplinary team to take over all the psychosocial needs of patients and families. The multi-disciplinary team has to refer these patients to the social worker for psychosocial support and counselling.

5.6.5 Designated palliative care social worker

The participants were asked to discuss ways they felt could improve the field of palliative care social work. The importance of having a designated palliative care social worker was found, which could result in increased time to develop relationships with the staff, more time to provide support to patients and families and an opportunity to organize and run support groups. The social worker would have the opportunity to begin other initiatives in the hospital that would result in increased patient and family satisfaction, as well as satisfaction for the staff. These interventions would include increased education for the staff to understand the role and potential of the social worker and developing increased palliative care resources. Further research is necessary to consider increasing the number of social workers about the demands of social services.

5.6.6 Network with other stakeholders

This study found that networking relationships with other stakeholders, such as pastors to take care of the spiritual needs of the patients and the families was identified as an important factor in strengthening social workers' abilities to provide palliative care. Other key stakeholders such as government ministries, environmental health inspectors, non-governmental organizations such as the Red Cross and the regional councillors were also identified as important key stakeholders in providing the palliative care needs of the patients.

5.6.7 Strengthen the skills of palliative care social workers

The participants identified the social workers' ability to listen to and articulate patients' needs as a skill that strengthen social workers' abilities to render palliative care. The study also highlighted social workers' abilities to take care of themselves as an important component in their abilities to render care to those in need.

5.7 SOCIAL WORK EDUCATION AND TRAINING IN PALLIATIVE CARE

5.7.1 Experiences on undergraduate social work education and training in the palliative care module

In analysing how social work education and training influence social workers' competencies in practicing palliative care social work, the study found differences in participants' experiences in the undergraduate social work education and training in their Bachelors of Arts (Honours) Degree. For some of the participants who graduated in social work prior to 2012, their undergraduate training in social work provided them with little to no opportunities on a palliative care course or an internship. Their fourth year internship did not include palliative care clinical placements. They only had exposure to one chapter in the Mental Health Approaches module on how to deal with end-of-life and death and dying. Consistent with the current literature, the participants discussed different course content for the palliative course prior to 2012 (Berzoff, Dane & Cait, 2005; Csikai & Raymer, 2005; McCormick *et al.*, 2010). The topics were: understanding one's own experience with loss and how that influences one's practice; a discussion on grief and loss utilizing Kubler-Ross's stages of grief and understanding the cultural differences and beliefs around loss. However, more than half of the participants noted getting training in a semester module on palliative care in the Bachelors of Arts degree in social work at the University of Namibia. In this respect, their undergraduate training prepared them for the provision of palliative care in the primary care settings. Some had internships in a primary care setting, which impact positively in their current palliative care practices.

5.7.2 Limited undergraduate palliative care curriculum

Seven participants indicated that their undergraduate social work curriculum did not include training in palliative care. While one participant said he only received training on palliative care as a chapter in a module, other participants discussed wanting a full course on palliative care. It is evident from the findings that there are some improvements in the undergraduate education and training curriculum since 2012 with the integration of palliative care as a semester course.

However, it can also be interpreted that the difference and inconsistency in the training curriculum prior to 2012, resulted in some social work practitioners lacking education, training, knowledge and skills in practicing palliative care social work. This study therefore identified the need for these practicing social workers to be educate and train in order to competently provide palliative care to patients and their families.

5.7.3 Clinical placements on palliative care in the Bachelors of Arts in Social Work Degree

In addition to the coursework, the participant's clinical placements or internships also shaped their learning experience. Just over half the participants had a clinical placement or an internship on palliative care that took place in a medical setting. For those participants the clinical placement or internship on palliative care helped prepare them for their work in a medical setting. However, a few of the participants did not have a clinical placement or an internship that centred on palliative care practice. The benefits they found were learning the culture of the hospital, working in a fast-paced environment, working in a multi-disciplinary team, conducting assessments, providing counselling and psychosocial support, discharge planning and crisis management. Only two of the participants identified a supportive supervisor as key to their learning. For the majority, the exposure to the environment was the greatest experience for their educational preparation. The limited clinical placement opportunities and gaps in Bachelors of Arts programs prior to 2012, lead to inconsistency in the field of palliative care. This resulted in different approaches and comfort levels to social work palliative care practice. Some of the participants (who received palliative care training since 2012) took an active role in palliative care the in primary care settings, whereas others (who did not receive palliative care training) deferred to other providers to explain and educate patients and families on treatment options. Findings from this study can be interpreted that clinical placements in palliative care are indeed an important component of any palliative care training for service providers to put the palliative care approach in practical context. The study also found that there are limited clinical sites where healthcare providers can obtain clinical experience in delivering palliative care services. There needs to be a cultural change to incorporate palliative care into the educational and practice opportunities for social workers.

5.7.4 Continuous education and training on palliative care

In Namibia, hospital based social workers are pushed and pulled in many different directions, being generic social workers, developmental social workers, community and hospital-based social workers. Christ and Sormanti (1999) found that many do not have time for continuous education programs or training due to the demand in the multi-dimensional roles, they must perform. This impact on the palliative care social work practice in Namibia creates inconsistency in the delivery of palliative care as social workers lack professional development training on palliative care. Csikai and Raymer (2005) found inconsistencies in how palliative care is taught. As a result, Csikai and Raymer (2005) found that many social workers felt unprepared to provide palliative care after graduating from a social work program. In addition, there have not been many continuous education programs on palliative care available in the Ministry of Health and Social Services. Many of the participants rely on their department's in-services continuous education and training for professional development because they do not have the time or flexibility to go off-site for trainings. However, there are many limitations to those in-services continuous education programs as described by the participants. For example, the in-services rarely discuss palliative care, which is gear towards other disciplines, primarily nurses and doctors. These findings are important, because there is limited literature and research on the impact of continuing education training for current social work practitioners. In Namibia, social workers are mandate to have their license as practitioners. As a result, many are required to get 30 CEUs or credits per annum in order to maintain their license registration. License registration is renewable annually and continued education is vital to maintain a practice that is informed by current research and that is diverse. Palliative social workers are expose to a vast array of cases. The social worker may be working with a patient who is ill and undocumented (for example, foreign patients from Angola and Zimbabwe who need medical visas in order to undergo treatment in Namibia), a patient who dies with no family or contacts, or with a family who brings their young children in to see a dying patient. It is imperative that social workers have access to continuous education that informs their practice in this regard.

Another related key finding identified in the MHSS (2009) study is the need for social workers to be train and educate on palliative care as a discipline in order to orient them in their role to provide adequate care to patients. This was similar to a finding in my study. Despite a recommendation by the MHSS (2009), “*social workers be trained on palliative care so that they can provide adequate care, particularly in the areas of psycho-social support, social welfare, spiritual care and positive living*” (MHSS, 2009: 60), my study found that eight of the participants interviewed in this study, were not trained in palliative care, but were expected to deliver palliative care in their respective primary care settings. This finding can be interpreted as indicating the need for social workers to receive in-service training on palliative care in order to provide adequate and quality care. The focus of this study advocates for the advancement of social work education, training and practice as well as strengthen the multi-disciplinary teams in providing palliative care. It contributes to the sociological relevance in societies that have high morbidity from non-curable disease and especially in ageing societies where the majority of the population is aged or facing mortality.

5.7.8 Continuous education and training topic suggestions

The participants expressed a desire to be train on the aspects of palliative care and to specialize as palliative care social workers. They expressed a desire to be train on bereavement to be able to provide bereavement counselling to patients, their families and caregivers who experience grief, loss and bereavement. The participants wish to be train in communication skills and strategies, the roles and responsibilities of the multi-disciplinary team and how to overcome communication barriers, for example, in the case where the social workers were not consulted by the multi-disciplinary team. Some of the continuous education and training topic suggestions were “*training on what is palliative care, the principles of palliative care, the ethics, communication, communicating with a dying patient, and dealing with a patient diagnosed with a life-limiting illness*”. Dealing with issues of death and dying may create a strong sense of helplessness among social work practitioners if they are not adequately educated. A stronger focus on education and preparing social workers on how to communicate with a dying patient and dealing with the ethics involved, would help social workers bridge this gap.

5.8 THE SOCIOLOGICAL SIGNIFICANCE OF SOCIAL WORKERS' ROLE IN PROVIDING PALLIATIVE CARE

Blumer (1969, as quoted in Medieta, 2015) states that according to the tenets of symbolic interactionism, all objects have a given meaning which is a significant component of human action, the meaning we assign to objects results from interacting with other individuals, and the meaning resulting from interaction is interpreted by each individual. Palliative care by social workers lends itself to be view from the sociological perspectives of dramaturgy, which views everyday life as theatre with actors, scripts and interactions. The implied roles of the social workers in providing palliative care affect the interactions between micro-level interactions in the everyday lives of the patients and at the meso level, which include the family, caregivers, case managers and other healthcare professionals in the multi-disciplinary team. This study emphasizes creating a constructivist grounded theory of social workers' multi-dimensional roles in providing palliative care, as crucial in improving the quality of life of the patients with life-limiting illnesses. This study expands the sociological significance of social workers' multi-dimensional role in providing palliative care to patients with life-limiting illnesses, applying symbolic interactionism. The creation of a constructivist grounded theory supports the multi-dimensional roles played by social workers as described in this study, meaning that it is perceive as providing counselling and psychosocial support to the patient and the family in coping with a life-limiting illness. Social workers facilitate and provide information around the patient's treatment and care options and serving as context interpreters and discharge planners for the patients. It emerged from the study that social workers conduct multi-dimensional assessments of physical, emotional, social, spiritual and cultural needs, values and preferences of patients and families in close collaboration with the multi-disciplinary team of the hospital. The study found that patients and their families have information and communication needs and often they are often in need assistance from the social worker and other healthcare professionals in the organization of their care. This finding indicates that it is important for the social worker to determine the patients' needs as a pre-requisite to formulate the best plan of care. Patients and families may also need emotional and social support, and they will need bereavement counselling at the end-of-life and after the death of the patient.

As the needs of the patient and the family change, holistic assessment of the patients' needs is something that will be required repeatedly from the social workers and other healthcare professionals throughout the course of the disease. It emerged from the study, that social workers serve as liaisons between the patient, the family and the multi-disciplinary team and they refer patients to the next level of care; they serve as brokers linking the patients and the family with internal and external resource and serve as educators, educating the patient, the family, as well as the staff on different social issues. The study found that social workers advocate on behalf of the patients and their families. The majority of the participants in this study identified various roles and skills necessary for palliative care social work. This was also consistent with the literature (McCormick *et al.*, 2007; McCormick *et al.*, 2010; Hartman-Shea *et al.*, 2011). The sociological significance of social workers in their everyday role is emphasizing by the importance for social workers in society in general and in their work in providing palliative care in primary care settings. This study suggests that in addition to social workers, doctors, nurses, supervisors and spiritual leaders influence the patients' experiences with a life-limiting illness. This theoretical and sociological revival is an important element to be considered as the Namibian healthcare system faces multiple challenges. The study contributes to research on social workers' perceptions of their role in providing palliative care from the data collected at the study research sites, namely Oshakati hospital, Gobabis hospital, Swakopmund, Keetmanshoop, Windhoek Central and Katutura hospitals.

The study draws attention to the "front stage" and "back stage" aspects of palliative care social work and explains how palliative care social work can be informed by symbolic interactionism. First on the "front stage", it is critical to understand the social workers' role in absentia and the imminent influence it imposes on role dynamics in the multi-disciplinary team. Second, the authoritative role of the patient's family and advocacy for the patient's best interests may be mutually exclusive. Third, roles and role-taking in the multi-disciplinary team create confusion and subsequent fragmentation in human interaction. Fourth, language used by doctors creates confusion with the patients, resulting in some patients not understanding their diagnoses and the seriousness thereof and then eventually defaulting from treatment because of lack of understanding.

In order to better understand the “back stage” and the role of living with a life-limiting illness it is obligatory to understand the dominant roles of social workers in providing palliative care, which include the patients’ family members, the caregivers and other healthcare professionals in the multi-disciplinary team. This new holistic perspective of social workers’ roles and identities in the multi-disciplinary team providing palliative care fills the gap of previous qualitative studies, which focused on a given role rather than the different actors and roles in palliative care in primary care settings. This study established the importance of social workers’ understanding of palliative care. Social workers’ uncertainties or lack of understanding of palliative care may result in untreated symptoms and suffering of patients and it may hinder an individual patient’s ability to continue his or her daily activities. In this regard, the study highlights the sociological significance of social workers’ understanding of palliative care as a concept and discipline as an integral part of holistic care, which aims to improve the quality of life of patients with life-limiting illnesses. The data collected from the narratives of social workers clearly indicate the sociological relevance of how the study contributes to new knowledge on conditions that hinder or strengthen social workers’ abilities to provide palliative care. Findings of the study also contribute to the limited research on barriers that hinder social workers’ abilities to provide palliative care. The findings also contribute to existing knowledge on conditions that strengthen social workers’ abilities to deliver palliative care. The study further provides deep insights into how social work education and training in Namibia contributes overall to the social worker’s competencies in providing palliative care. This was a conceptual contribution of the study. The data collected also contribute empirical insights on how social work education and training influence social workers’ competencies to render palliative care (as discussed in chapters, 4 and 5). The successful outcomes of this study contribute to the existing body of knowledge in the areas of sociological health care as well as immediately benefiting patients with life-limiting illnesses; social work practitioners and social work education and training on palliative care as explained below.

5.8.1 Patients with life-limiting illnesses

The breath and complexity of palliative care needs of patients (which include pain control and symptom management, emotional, financial, spiritual support, food, shelter, legal

assistance and respite care) in a diverse Namibia emphasizes the importance of a competent response by trained palliative care social workers and other healthcare professionals. Palliative care education and availability have a positive impact and increase the access to palliative care for patients. This study established the need for palliative care and social work to be integrated into the existing health care structures at all levels of health care services delivery in order to improve the quality of life of patients and their families facing life-threatening illness. In order to achieve this, clear policies and guidelines need to be in place. Consequently, this study will be utilized to advocate for the implementation of palliative care policies and guidelines that will benefit the patients to enable them to have access to improved palliative care services.

5.8.2 Social Worker practitioners

In examining social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses, this study discovered important multi-dimensional roles of social workers in providing palliative care in order to improve the quality of life of the patients and their families. The analysis demonstrates that social workers perceive and consider their roles in the provision of palliative care as multi-dimensional. These multi-dimensional roles include *assessors, brokers, educators, advocates, facilitators providing information, conducting patient follow-up home visits, outreach, conducting family conferences, discharge planners and managing in-country and international referrals*. The study also discovered major barriers that hinder the social workers' abilities to provide palliative care, such as social workers' roles not understood by the multi-disciplinary team members and hence not receiving the support they should be receiving. Social workers' interaction and engagement with a patient and their family could be short-term in nature due to the timing of referrals and a rapid progression of the illness. In this regard, the participants in this study expressed a concern about the well-being of practicing social workers in the primary care settings in Namibia working with limited supervision and limited debriefing opportunities available.

5.8.3 Social work education and training on palliative care

While some participants reported receiving basic training in palliative care, there is a lack of in-service training and continuous education on palliative care, bereavement and the roles and responsibilities of the multi-disciplinary team. The study adds to the limited existing knowledge on palliative care social work practice within a Namibian context. Policy guidelines and further research on the role of the social worker in the provision of palliative care is necessary to identify ways to improve the field of palliative care social work. This can be achieved through the education and in-service training of social workers, providing additional debriefing and supervision opportunities for practicing social workers, conducting community awareness on palliative care for patients with life-limiting illnesses, mainstreaming patient referrals to social workers and establishing a Centre of Excellence on palliative care as a clinical site for internship placements.

5.9 INTERPRETATION OF THE FINDINGS ON IMPLICATIONS FOR PRACTICE

There is a great deal of diversity among how social workers provide palliative care in the primary care settings in Namibia. In this study for example, when the participants were asked to talk about what proportion of their work focused around palliative care, there were vague and unclear responses. This broad research question was therefore analysed and interpreted as the core of the study, which was in line with the first research objective of the study, examining the role of the social worker in providing palliative care. In interpreting the findings on the implications for palliative care practice, the study found that only a small proportion of their work focused on palliative care. In fact, most of the participants' work did not have a specialized focus on palliative care in their daily duties. This can be ascribed to the shortage of social workers in Namibia, the lack of opportunities for specialization as palliative care social workers, and multi-dimensional roles to perform as hospital, community and palliative care social workers.

In response to the participants' perceptions and satisfaction with how palliative care is managed in the primary care settings, five of the participants responded not being happy because nurses and doctors do not conduct proper assessment or diagnosis. In addition, doctors do not mainstream referrals of patients to the social workers, which impacts negatively on the time and workload of the social workers. The lack of enough bed space in the hospital was identified as another factor, which influences negatively on palliative care social work practice as it results in patients with advanced life-limiting illnesses or at the end-of-life to be discharged by the doctors to die at home without consulting the social worker and the family members. This practice is perceived as a factor hindering social workers' abilities to provide adequate care and resulting in them lacking to provide the necessary counselling and support to the patient and the family. Lack of consulting social workers and family members prior to the patient's discharge, lack of proper referrals and inadequate teamwork can be interpreted as a symptom of a problem within the health care system. Findings from the participants in this study can be interpreted as advocating for doctors to consult and refer the patients to the social workers prior to discharge. This study advocates for the Namibian government to dedicate a special palliative care unit to patients with life-limiting illnesses. In addition, the findings of the study established an inconsistency in the practice of palliative care, whereby participants who worked at the national referral and the intermediary hospitals were satisfied and positive about how palliative care is managed in their respective settings. They reported having specialized trained palliative care health care professionals in their MDTs providing palliative care. Some participants, for example, discussed a comfort level on their perceived confidence when delivering palliative care. Whereas, the majority of the participants responded being confident to provide palliative care, however, some of the participants had a varied level of comfort providing palliative care, for example, one of the participants who did not receive palliative care training responded saying, "*I do not know...*" It is evident from these findings that "*education and training in palliative care can help social workers develop confidence in their decisions, as well as the confidence and know-how to take appropriate action and tap into available resources when needed*" (Grady et al., 2008:6).

This study reveals that there is a gap in the level of education and training of social workers on palliative care, as well as a difference in the level of confidence of the social workers providing palliative care. McCormick (2010) found that with palliative care training, the interventions of the social workers improved and thus more research is necessary to provide palliative care training to practicing social workers. The goal of improved training on palliative care is to decrease the inconsistency throughout the field of palliative care social work. The responses on the participants' perceptions and satisfaction with the provision of palliative care services and their satisfaction with the role of the social worker in the provision of palliative care, perceptions on interactions with patients and family, perceptions about interactions with the multi-disciplinary team and skills needed as palliative care social workers were key issues presented and analysed in chapter 4 and further interpreted in this chapter (chapter 5) of this thesis.

5.10 CONCLUSION

This chapter provides an in-depth interpretation of data collected on social workers' perceptions of the role in providing palliative care to patients with life-limiting illnesses. This study finds that the multi-dimensional roles of the social workers within this care should be clearly articulated in creating a constructivist grounded theory of social workers' role in providing palliative care. The time is right for the social work profession in Namibia to build on the Namibian government's commitment towards the global resolution on palliative care by the World Health Assembly (WHA 67.19, 2014) which calls upon WHO and Member States to which Namibia is a signatory to, "*to improve access to palliative care as a core component of health systems with an emphasis on primary healthcare and community or home-based care*" (WHA 67.19, 2014). Palliative care social work aims not only to '*support people to live and die well*' but sets out a vision for an '*integrated social and healthcare*' approach (Department of Health, 2010a:11). This study argues that in creating that incorporate, the social work profession with its values, culture and experience (particularly from the patients) is well qualified to participate in this process. Themes and sub-themes were discuss, interpreted and provided information on the different dimensions of data that emerged.

This study highlighted the multi-dimensional roles social workers perform in primary care settings, which include roles and identities as assessor, advocate, broker, counsellor, educator, facilitator, liaison, discharge planner, intermediary and managing in country and international referrals. The conditions that hindered the social workers' abilities of providing palliative care are their roles not understood by other healthcare professionals and therefore they receive inadequate support. There is a lack of in-service training and continuing education in palliative care. The well-being of social workers is another concern with limited debriefing opportunities available. Furthermore, there are inadequate palliative care practice opportunities for social work students at the social work undergraduate level. This study has provided the necessary building blocks to strengthen a palliative care social work concentration in practical opportunities in the social work Bachelors of Arts (Honours) program as well as to enhance continuing education. Finally, the study advocates for policy guidelines and further research needed to identify the ways to improve the field of palliative care social work. This can be achieved through formal education, palliative care practice opportunities and in establishing a Centre of Excellence of providing palliative care. This study has added to the existing research through identifying areas for further research and learning, as well as gaining a comprehensive understanding of the roles and skills practicing palliative care social workers perceived necessary for the work. It is important to understand the social worker in his or her environment (Bomba *et al.*, 2011). As palliative care social work begins to evolve, social workers in Namibia need to be on the frontlines providing the care, and in administrative roles, affecting policy on macro level. The next chapter provides overall conclusions and recommendations of the entire study.

CHAPTER 6: CONCLUSIONS AND RECOMENDATIONS

This chapter provides a summary of the key findings, recommendations and concludes the discussion. In the previous chapter, I provided a discussion and interpretation of the research findings. As explained in chapter 1, the aim of this qualitative study was to examine social workers' perceptions of their role in providing palliative care to patients in the primary care settings in Namibia. In order to answer the main research question in this study, I used the theory of symbolic interactionism to kindle the process of association in using a constructivist grounded theory. In constructivist grounded theory, the researcher is not starting from a clean slate, as the researcher in this study, I brought with me external and relevant information, which influenced the induction process when categorizing themes from the data as discussed in the literature review in chapter 2 and explained further in chapter 3. The study used a qualitative research approach, involving twenty practicing social workers from six social work offices spread across six hospitals in Namibia to obtain in-depth information during the fieldwork process. The focus of the study intended not to generalize findings, but to obtain first-hand lived experiences in the data from practicing social workers on perceptions of their role in providing palliative care at different research sites.

There are implications in the findings of this research in areas that include palliative care social work practice itself, training, education, research and policy formulation and implementation, which explore opportunities for broader application. This concluding chapter summarizes the main findings and recommendations of the study with specific emphasis placed on the key contributions, the study limitations and suggestions for further research in the field of palliative care practice, social work education, training, as well as for policy and programme recommendations. By choosing a qualitative methodology, the perceptions and lived experiences of twenty practicing social workers were present. This was done using in-depth, face-to-face interviews as a data collection method, explained in chapter 3. Owing to the inductive and flexible nature of the qualitative research design employed in the study, insightful discoveries emerged, such as a constructivist grounded theory of social workers' multi-dimensional roles in providing palliative care and the understanding of the definition of palliative care.

The participants in this study indicated how conditions hindered or strengthened their abilities to provide palliative care. This study discovered how social work education and training in palliative care influenced their competencies to render palliative care (all the research objectives as presented and analysed in chapter 4, discussed and interpreted in chapter 5). The participants also suggested recommendations on how to improve the field and practice of palliative care social work in Namibia and beyond.

As a researcher, I was able to obtain rich and meaningful data as I immersed myself as an observer and co-participant in the field, owing to the qualitative nature of the methodology, which opened up new avenues for discovery along the way. The findings of the study produced original and authentic data. The thematic analysis discussed in chapter 4 and interpreted in chapter 5 explained how multiple layers of meaning emerged throughout the inductive research process.

6.1 RECOLLECTING THE STUDY OBJECTIVES

In order to achieve the aim of this study, five key research questions were developed and a summary of the findings for each of the questions answered are provided below:

The first question related to how social workers perceive their role of providing palliative care to patients in primary care settings in Namibia. For the most part, key findings from the research demonstrate that the various roles of the social workers are imperative in the provision of palliative care to patients with life-limiting illnesses. Social workers perceived their roles in this study as multi-dimensional, meaning they perceived their roles in identities as *counsellors* providing counselling and psychosocial support to the patient and the family in coping with a life-limiting illness; *facilitators* providing information around the patient's treatment and care options; *context interpreters* and *discharge planners* for the patients. Social workers also serve as *liaisons* between the patient, the family and the multi-disciplinary team and they refer patients to the next level of care; they serve as *brokers* linking the patients and the family with internal and external resources and *educators*, educating the patient, the family on life-limiting illnesses as well as the staff on different social issues. Social workers *advocate* on behalf of the patients and their families.

The majority of the participants in this study identified several roles and skills necessary for palliative care social work. This is also consistent with the literature (McCormick *et al.*, 2007; McCormick *et al.*, 2010; Hartman-Shea *et al.*, 2011). The research participants also explained their role as dependent on others, for example, referrals from members of the multi-disciplinary team, especially from the medical doctors. In general, social workers in the hospital did not have a clear profile of patient cases. As a result, many social workers in this study were therefore not working on a regular basis with these patients and their families, in fact, for many, their experiences in palliative care was minimal. Consequently, there was a lack of opportunity to build up knowledge, understanding and expertise about palliative care practice.

The second research question concerned the social workers' understanding of the definition of palliative care. It emerged from the findings that less than half (nine) of the research participants were able to provide a clear definition of palliative care. This finding is similar to that of the MHSS's (2009) study, which emphasized the key challenge around palliative care, was the lack of knowledge and accurate information. This study found that while there are several challenges that hinder the development of palliative care social work on the continent, a key challenge is also the lack of knowledge and accurate information around palliative care social work. As mentioned in chapter 2 of this study, the WHO (2002) highlights palliative care provision as an essential component of a comprehensive package of care of social work services for people with life-limiting illnesses. However, the lack of social workers' understanding of palliative care as a concept and discipline of care as identified in this study, may result in failure of adequate palliative care service provision, which is another major barrier limiting access to palliative care (WHO, 2016). Social workers' lack of understanding of palliative care may also result in untreated symptoms and suffering of patients and it may hinder an individual patient's ability to continue his or her daily activities. In this regard, social workers' understanding of palliative care as a concept and discipline is an integral part of holistic care, which aims to improve the quality of life of patients with life-limiting illnesses. Another important finding indicates that despite the fact that more than half (12) of the participants in this study received undergraduate training on palliative care in their social work programme, of those who shared their understanding of palliative care, only a few were able to elaborate on the

different dimensions (physical, emotional, psychological and spiritual) of the WHO's (2002) definition on palliative care. This finding is similar to that of the MHSS's 2009 study in which the definition and situation surrounding palliative care in Namibia was investigated and discussed. Similar to the finding of the MHSS's 2009 study, only a few participants in this study were able to elaborate on the different dimensions of the WHO's (2002) definition of palliative care. The majority of the participants could not provide a clear definition of palliative care. This study found that it is clear from the definitions provided by the participants of this study that a gap exists in knowledge on palliative care. It highlights the challenge that palliative care as a concept and discipline are not well understood across Africa, and its development is still embryonic in many countries, of which Namibia is no exception. Although previous work has not specifically addressed social workers' understanding of palliative care in a Namibian context, this study expresses concerns about social workers' understanding of palliative care, especially in performing their role to provide palliative care to patients with life-limiting illnesses. So far, there has been very little discussion about social workers' understanding of palliative care. Insufficient attention therefore has been given to social workers' understanding of palliative care. In addition, no research has taken into account the importance for social workers to have an accurate understanding of palliative care in their role to provide care. In filling this gap, my study supports a remedy to that shortcoming by identifying the need for social workers to be trained on the definition of palliative care which could be aligned to the WHO's (2002) definition of palliative care. Social workers' understanding of palliative care in Namibia is vital in the provision of care for patients with life-limiting illnesses. The study aims to address the challenges on social workers' lack of understanding of palliative care, although it is not intended to cover everything related to palliative care social work. Further research is necessary on additional issues in palliative care social work.

The third question investigated the conditions that hindered social workers' abilities to provide palliative care to patients. The study found that the role of social workers is not well understood by the other healthcare professionals in the hospital. The lack of palliative care in-service training, lack of continuous education and research on palliative care in Namibia, communication barriers, for example, medical jargon used by the doctors, shortage of specialized palliative care social workers and heavy

workloads, multi-dimensional roles as being generic rather than specialized, the well-being of the social workers, lack of supervision, lack of debriefing and support from management, lack of appreciation for the role of the social worker in the provision of palliative care and lack of hospital bed space emerged as some of the factors that hinder the social workers' abilities to provide care. The study established that social workers are in need of several essential skills. These include: clinical skills training; relationship building skills; understanding of the clinical environment; understanding family dynamics; empathy; listening skills; patience; good communication; organizational skills; self-awareness; knowledge of resources and laws and investigative skills.

The fourth question focused on conditions that strengthened the social workers' abilities to deliver palliative to patients with life-limiting illnesses. The research findings confirmed several key conditions that strengthened social workers' abilities to provide palliative care. These include palliative care social work education and training; research on palliative care in a Namibian context; a national palliative care policy and guidelines; collaboration with the multi-disciplinary team; acknowledging the important role of the social worker in the provision of palliative care; mainstreaming of referrals of palliative care patients; a designated palliative care social worker and networking with other stakeholders. The study also highlighted some of the clinical skills social workers used in order to strengthen their abilities to provide palliative care.

The final research question asked for insights from the views of the participants on how social education and training influenced social workers' competencies to render palliative care to patients with life-limiting illnesses. A key finding identified in the MHSS (2009) study which is relevant to this study, was the need for social workers to be educate and train on palliative care as a discipline in order to orient social workers in their role to provide adequate care. My study found that eight of the participants interviewed in this study were not train in palliative care, but they were expected to deliver palliative care in primary care settings. This finding seems to indicate the need for social workers to get in-service training and continuing education in order to provide adequate and quality palliative care.

This study fills the gap in this under-researched area in the lack of in-service training and continuous education. By identifying this need, the study thereby recommends in-service training and continuous education on palliative care for social workers. Social work education has evolved in the last decade and is now offering concentrations in working with the aging and with patients with life-limiting illnesses. However, there is a need to develop a concentration on medical social work with a focus on palliative care social work as a specialized field.

Given the reality that hospital social workers in Namibia are pushed and pulled in many different directions to perform multi-dimensional roles in serving simultaneously in different identities as hospital-based social workers, community workers -, developmental - and palliative care social workers, many do not have the opportunity for continuing education programs or training to build their competencies. This resonates with the finding by Christ and Sormati (1999). This results in a negative impact on palliative care social work delivery in the Namibian context and results in inconsistencies in the delivery of palliative care as social workers lack in-service training and professional development training on palliative care. As a result, this study found that many social workers felt unprepared to provide palliative care (Csikai & Raymer, 2005). In-service and continuing education training opportunities are important to improve the practice of palliative care social workers.

This study found that there have been limited continuing education programmes on palliative care for professional development organized by the Ministry of Health and Social Services in Namibia. The results of this study also highlighted the need for further investigation into the provision and availability of in-service training and continuing education on palliative care for social workers, which will influence their competencies and inform their palliative care social work practice. There is an urgent need for increased palliative care clinical placements in the undergraduate social work programme as well as continuing education opportunities for practicing social workers (Bomba *et al.*, 2011 & Morrissey, 2005).

Researchers need to look at ways to make continuing education accessible in order for more social workers to have equal opportunities to enhance their learning and their competencies in providing palliative care. There needs to be further research into how in-service training and continuing education on palliative care can improve. Forest and Derrick (2010) find social work education and training to be the most suitable place for multi-disciplinary learning, as social workers focus on the strengths based approach of “*starting where the patient is*”, meaning they value teamwork, relationship building and communication. It is important that the hospital and social work management create opportunities for social workers to go off-site for continuing education and training on palliative care. This may motivate social workers to maintain a discipline which competently responds to the needs of the palliative care patients and who is familiar with the latest research on contemporary issues in the field of palliative care.

6.2 SUGGESTIONS ON HOW TO IMPROVE THE FIELD OF PALLIATIVE CARE SOCIAL WORK

In order to improve the field of palliative care social work there is an urgent need to address several constraints, which have been mentioned in this study. Issues around a national policy on palliative care at macro level need to take priority. The issue of lack of human resources and trained palliative care social workers could be alleviated by improving education and training to increase the numbers of palliative care social work practitioners. Quality of care can be improved through the provision of supervision, debriefing and mentoring. Patients with life-limiting illnesses and their family require a quality of life that can be achieved through provision of good palliative care social work that is available and accessible through several initiatives as described below.

6.2.1 National Policy on Palliative Care

The findings revealed that the lack of a national palliative care policy in Namibia leaves a guidance vacuum in the provision of palliative care social work. Being aware of the influences that a national palliative care policy has in the delivery of palliative care social work allows the practicing social worker to be an effective advocate for the client

and family living with a life-limiting illness. The growing unmet needs of patients with life-limiting illnesses and their families fuel the growth in palliative care despite the lack of official status of a national palliative care policy in Namibia.

6.2.2 Undergraduate training; in-service and continuing education and conferences in palliative care for social workers

Globally, a wide range of training opportunities in palliative care social work exist that provide training for social workers interested in or working in the field of palliative care. From social work students to practitioners, such resources help to enhance the competencies of social workers providing palliative care. However, from a practitioners' perspective as a palliative care social work practitioner and educator as well as a researcher and personal experiences, I found that palliative care training in Namibia is especially challenged by the residual taboo against talking of death and illness, with witchcraft often still viewed as the reason for an incurable or life-limiting illness. This study found that many patients still visit the traditional healers before consulting trained professionals in Western methods. As a result, patients present themselves to the doctor at an advanced stage of the illness. In order to eliminate this practice, additional education, training, awareness and research are necessary. This study found that the majority of the participants indicated the need for in-service training, continuing education and conferences in palliative care for social workers. The data also revealed that palliative care should be integrated not only in the undergraduate curriculum of the social workers, but also for other health care professionals such as the doctors, nurses and pharmacists.

6.2.3 Palliative care internship & clinical placements sites

The study findings suggested palliative care clinical placements that move theory into practice.

6.2.4 Designated palliative care social workers

The participants were asked to discuss ways to improve the field of palliative care social work. The recommendation discussed by seven of the participants suggested having a designated palliative care social worker. The participants explained that because of the shortage of social workers in the country, they have to operate as both generalist and hospital based social workers. This results in heavy caseloads, feeling overwhelmed and pulled in many different directions and having to juggle several different responsibilities, compromising the quality of care.

6.2.5 Research in palliative care

Research conducted by social workers impacts social work practice in significant ways and can play a critical role in improving the quality of psychosocial service, especially in palliative care. Research in social work that aims to develop interventions, innovative programs and treatment models to assess the effectiveness of programs are major tenets of the social work profession. According to Altilio and Otis-Green (2011), evidence-informed interventions and evidence-based practice has become the standard used to determine quality in the health professions. APA (2005); Gambrill (1999); Sackett, Straus, Richardson, Rosenberg and Haynes (1997, as quoted in Altilio & Otis-Green, 2011) define evidence-base practice “*as the process wherein the practitioner (e.g. social worker) combines his or her expertise (often called “practice wisdom”) with the best available evidence (research) while taking into consideration the values and expectations of his or her work settings and patients or clients*”. All social workers are ethically bound to provide interventions that are effective. There are many ways social workers can use the interconnectedness of research and clinical practice to their advantage. Altilio and Otis-Green (2011) found that the demand for professional social workers with specific knowledge, skills and expertise in palliative care and end-of-life care has dramatically increased in the past decade. Given the fact that social workers focus on the improvement of the quality of life in enhancing the social functioning of the patient and the family, research in palliative care is essential and much needed. Benefiel (2009), an expert social work practitioner in palliative and end-of-life care (as quoted in Altilio & Otis-Green, 2011: 727) states, “*to advance palliative care, we must*

educate ourselves about research and collaborate with our team members to design research studies so we can provide solid evidence to support our social work models” (Palos, 2009). Social workers are in a unique position to provide valuable research information given their interactions with the patients, taking into account a wide range of social, economic, medical, community influences from a multi-disciplinary, family-centred, and community based approach. We need evidence-informed practice in the provision of adequate palliative care. Altilio & Otis-Green (2011: 735) describe, *“evidence-informed research as a term used to describe a way of merging research and practice that is different from rigid conceptualizations of evidence-based practice”*. Thus, there is the need for social workers to participate in research to improve care for the patients and families and to advocate for patient and family participation new interventions. In this extract, for example, Faith explained, *“we need research on social work interventions within a palliative care setting. We need to learn best practice models”*.

6.2.6 Mainstreaming of palliative care patient referrals to social workers

Catherine suggested for referrals to be mainstreamed to the social worker stating, *“I think if it could be done earlier as from the word go then it will really help, help much if the support can start from the beginning and not from the time the patient has gone into a depressive mode... The changes that I would want to see mainly are, maybe for the doctors to refer these cases early enough and for it to be a must”*.

6.2.7 Awareness and education on palliative care

The findings of the study recommended awareness and education on the importance of palliative care provision. Participants in the study emphasized the importance for the Government to be educated and train on palliative care in order to integrate it at all levels of primary care provision.

6.2.8 Supervision and debriefing opportunities

Shane recommended having retreats to refresh. He said, “*that is why you really need that retreat, at least for one week to be able to be refreshed and when we are coming to start, at least we are very energetic*”.

6.2.9 Other suggestions on how to improve the field of palliative care

One of the participants in the study (Charlotte) suggested a national association for the registration of caretakers.

6.3 STRENGTHS AND LIMITATIONS OF THE STUDY

The study rigorously adhered to the grounded theory methodology. Rich data were collected that allowed for the emergence of themes, which in turn made it possible to interpret the data and construct an original theory: A constructivist grounded theory of social workers’ multi-dimensional roles in providing palliative care. An iterative approach was applied throughout to refine and develop the data collection, analysis, and interpretation of the results. Constant comparison, combined with discussions amongst the authors, was utilized to reduce bias. These discussions contributed to more in-depth analysis. Having a variety of participants representing a range of ages and work experiences, from several hospitals in different locations caring for different populations of patients, made it possible to do theoretical sampling and reach theoretical saturation. The constructs of multi-dimensional roles described in this study have similar features to those found in previous studies. In the literature, these elements of social workers’ role in providing palliative care appear in a number of workplace environments and professions. Whilst a constructivist grounded theory of social workers’ role in providing palliative care here specifically derived from social workers’ perceptions in primary care settings in Namibia, it shares commonalities with extant literature, which may be applicable to a number of palliative care social work settings.

The study contributes to advancing palliative care social work practice, education and training as well as strengthening the multi-disciplinary teams in providing palliative care. It appears from the findings that social workers at the national referral and intermediary

hospitals embraced palliative care enthusiastically and competently, others less so. There were differences in participants' experiences in the undergraduate social work education and training in their Bachelors of Arts (Honours) degree prior to 2012. For example, some participants who graduated in the social work undergraduate training programme prior to 2012 had little to no opportunity on a palliative care course or an internship in the hospital. Their fourth year internship did not include palliative care clinical placements. Some of the participants only had access to a chapter in the Mental Health Approaches module on how to deal with end-of-life and death and dying. Consistent with the current literature (Berzoff, Dane & Cait, 2005; Csikai & Raymer, 2005; McCormick *et al.*, 2010) the participants discussed different course content for the palliative course prior to 2012. The study further provides deep insights into how social work education and training in Namibia contribute overall to the social workers' competencies in their role in providing palliative care. By doing so, the study contributes to recommendations on potential ways to strengthen the provision of social work education and training on palliative care. This thesis contributes to the knowledge about social workers' understanding of palliative care in order to promote the health and well-being patients with life-limiting illnesses with whom they have contact in their everyday work. While the experiences and views are from a small group of practicing social workers based in the primary care settings, there are themes that are relevant to other social workers in other settings. This study extends the knowledge about the practice and provision of palliative care social work, which is currently under-researched within the Namibian context. As the perceptions, experiences, opinions and insights presented are based on those of a limited number of hospital-based social workers, it cannot be assumed that the findings are representative of all. Indeed, as the participants in this study were self-selected and volunteered their time, there is an assumption that they had an interest in the topic. However, those who did participate supplied rich data, which was gathered through in-depth, face-to-face interviews through broad questions in an effort to widen the information base which is one of the strengths of this study.

This thesis contributes to the knowledge on social workers perceived roles and identities in providing palliative care to patients with life-limiting illnesses in order to improve their quality of life. However, this is a one-dimension study rather than a multi-voiced reconstruction (Guba & Lincoln, 1994: 115) in the sense that no other health care

professionals or patients with life-limiting illnesses were involved in the research process. The study lacks information from the other professionals involved with the social workers in the provision of palliative care to safeguard and promote the welfare of patients, in particular members of the hospital's multi-disciplinary teams. The roles that these professionals play have an influence on the way in which social workers are able to carry out their roles and responsibilities concerning providing palliative care. As a qualitative study, the results are not generalizable because of the design and the fact that the participants were not randomly assigned. Although this was a small sample size, saturation was reached with the participants. Morrow (2005) states that there is not an exact number to fit a qualitative study; rather data should be collected until saturation is reached. In addition, the interviews were in-depth and the sample represents four different types of hospitals in the primary care settings in Namibia. Two of the hospitals were large city university teaching hospitals, one was a national referral hospital, one was a regional training hospital, two were intermediary hospitals and two were district hospitals. However, not all of the hospitals in Namibia were represented in this study. In addition, as the researcher in this study, I engaged in bracketing and reflexivity. This is the process whereby I as the researcher made my biases known in order to set them aside while conducting the study and analysing the data (Morrow, 2005).

Palliative care in the hospital is provided by many other disciplines, for example, physicians, nurses and palliative care teams. Due to heavy caseloads, social workers are not always able to be present in the multi-disciplinary teams at all times, relying on the other team members to consult with them as needed. However, without gaining an understanding of the perceptions of healthcare professionals from other disciplines, as a researcher, I am not able to collect a comprehensive understanding of palliative care in the hospital. Interviewing members from other disciplines can provide insight into how hospital social workers are perceived, how palliative care is perceived in the hospital, and how to identify potential opportunities for improvement in care in the hospital and to identify how improvement in the multi-disciplinary teamwork, collaboration, communication and education.

6.4 RECOMMENDATIONS ON HOW TO STRENGTHEN POLICY, PRACTICE AND RESEARCH

Since this was a qualitative study with a small sample of research participants, general conclusions and recommendations should be treated with circumspection. This study has implications for organizational policy, social work palliative care practice, and future research directions. In a diverse country like Namibia, policy needs to be formulating in relation to the social aspects of health care and palliative care access and provision, as indicated in this study. Policy and decision makers should ensure that palliative care is a core part of practice, the training and continuous professional education of social workers, doctors, nurses, chaplains and other health care professionals. Further research is necessary by interviewing social work educators on the place of palliative care in the social work curriculum, which could be used to improve social work education and training in palliative care. This information may give guidance to organizations and social workers about which social worker is best suited, skill wise, to positively impact patient outcomes, informing both organizations' hiring practices and staffing decisions and social work clinical practice. In the primary care setting in Namibia, a multi-disciplinary team approach needs emphasize, to achieve effective patient care. Sufficient palliative care specialists should be train and supported to facilitate this education. Further research is necessary in exploring other healthcare professionals' perceptions on the role of the social worker in providing palliative care, along with gathering more knowledge of what both the multi-disciplinary team and the palliative care social workers uniquely bring to the patient encounter may also provide guidance for decision making about practice, roles, and division of responsibilities. Addressing the role of the social worker in the provision of palliative care from these directions may alter the existing theory and contribute to a more global theory of the role of the social worker in providing palliative care. A more global theory of the role of the social worker in providing palliative care could be of benefit to a broader variety of professionals working in areas within and outside of healthcare.

However, I draw my conclusions and suggest recommendations on conceptual grounds in relation to the theoretical constructs used in the study and the empirical findings of my research. Healthcare organizations need to invest in supporting healthcare professionals in keeping up to date with recent developments in palliative care, especially in holistic pain assessment and symptom management, in developing and

maintaining their assessment and communication skills, and in using all available resources. The primary care settings in Namibia need to develop cultures and working practices that allow the best use of palliative care skills of healthcare professionals, including spending sufficient time with patients and families. In order for palliative education to be delivered in the most efficient way possible, integrated into existing programmes and translated into everyday practice, it is essential that a strong partnership arrangement exists between specialist palliative care, education institutions and healthcare organizations. This process would benefit from a national strategic plan to avoid individual courses from becoming isolated and to ensure that learning is accredited and cumulative. The priorities and activities outlined in the principles and action points of the national health strategy should be framed with explicit reference to palliative care education and provision at all levels. The following recommendations on how to strengthen the practice, education and research on palliative care social work emerged from the data are, indicated below:

6.4.1 National policy and guidelines on palliative care

To achieve adequate quality of palliative care social work, national policy, guidelines and strategies on palliative care need to be established. As Namibia continues to plan for the further integration of palliative care in its healthcare system, some gaps and challenges need to be addressed. The lack of a stand-alone national palliative care policy and guidelines coupled with strategic plans are critical for the future sustainability of palliative care social work and the country's deliberate investment in palliative care services. Findings of this study highlighted the need for a national policy and guidelines in the provision of palliative care social work.

6.4.2 Undergraduate training; in-service and continuous education for social workers on palliative care

Palliative care training is vital for strengthening and expanding the provision of palliative care social services and to ensure adequate responses to palliative care needs. Given the acceptance of palliative care as an essential human rights component of

healthcare through the WHA Resolution, there is an opportunity for increasing education for palliative care, particularly in the light of the still increasing burden of communicable and non-communicable diseases. The development of effective palliative care social work in Namibia is contingent on the development of a competent workforce. A means of ensuring professional accountability and credibility to the social work and healthcare professions is to embed more high quality training within the academic setting. Training within an academic setting needs to move from modular sessions within healthcare and social care courses to dedicated undergraduate and postgraduate courses in palliative care and to ensure in-service training and continuous professional education opportunities on palliative care not only for social workers, but for all healthcare professionals such as the doctors, nurses and pharmacists. This study recommends undergraduate -; in-service training and continuous education in palliative care for all healthcare professionals in the multi-disciplinary team.

6.4.3 Palliative care clinical placements opportunities and sites

Effective learning from theory to practice highlights the need for pre-service training through palliative care clinical placements opportunities and sites. Palliative care clinical placements are recognized in this study as educational and interactive work integrated teaching and learning methods. Clinical placements emphasize and enrich case-based learning as an effective teaching method. This study identified this need and recommends for palliative care internship and clinical placements sites. For example, Faith said, “*clinical placements are indispensable to palliative care, because theory on its own, it’s not enough. So there is need for theory and also the patients, the studentsthe social work students, to be placed on clinical placements, for them to see first-hand experience...what goes in, on in palliative care settings.*

We need more clinical placements sites, you know. Palliative care clinical placement sites could have been ideal if students could get more time if we could’ve spent more time within a palliative care setting”. In addition, Gift suggests, “I think it can be improved, we should do much practical work in visiting health facilities... if permission is allowed. If it is not allow, we understand If we are given such liberty, at least to meet a cancer patient in Stage four, in terms of social work practice. Then we need on-

going training. I am strongly talking about those trainings, we need them once in a while at least in each and every year we should have training”.

6.4.4 Designated palliative care social workers

When the study participants were asked to discuss ways to improve the field of palliative care social work, seven of them suggested having a designated palliative care social worker. The participants explained that because of the shortage of social workers in the country, they have to operate in several identities as both generalist and hospital based social workers. This resulted in heavy caseloads and the feeling of been overwhelmed by having to juggle many different needs and responsibilities, compromising the quality of care provided. In addition, to a designated palliative care social worker, participants identified wanting more time and a smaller caseload in order to provide palliative care adequately. More research needs to explore the benefits of a designated palliative care social worker in the primary care settings in Namibia.

6.4.5 Further Research

Palliative care research is important for shaping policy and informing needs for palliative care to underpin service standards and models of service that work. In Namibia, palliative care research is not well developed. Embedding research components within the training and educational opportunities as well as creating research groups with other health and social care academics, is one way of ensuring that the palliative care services provided, in fact meet the needs of those they serve effectively.

A study by Campbell and Guzman (2003) demonstrated how multi-disciplinary teamwork in the hospital setting has been link to positive patient health outcomes and family satisfaction with care. However, this study highlights the different experiences the participants had with the members of their respective multi-disciplinary teams in their hospitals. Some participants felt there was no interaction with the members of the multi-disciplinary teams, whereas the participants who were based at the national

referral and the intermediary hospitals felt positive, appreciated and enthusiastic to be part of the multi-disciplinary team of the hospital. Further research is necessary to understand how the social worker in close collaboration with the multi-disciplinary team can interact more productively and constructively in the best interest of the patients and their families. As seen in this study, many hospitals do not have a specialized palliative care social worker or a palliative care multi-disciplinary team and of those that do, many are a small team of social workers, nurses and doctors for the entire hospital. More research needs to examine how the palliative care team and the palliative care social worker can collaborate in the multi-disciplinary team to provide palliative care in the best interest of the patients and the families. The study recommends for social workers to take more proactive roles in promoting the social work profession by conducting marketing and awareness on the social work profession, not only in the hospital, but in the society at large which defines the role of the social worker in the hospital, in the multi-disciplinary team and on strategies how to improve collaboration and communication among the team in providing care. A further recommendation is that a longitudinal study on the role of the social worker in providing palliative care can be conducted at different Namibian social work offices country wide to test the conceptual contributions. The conceptual contributions are theoretical grounded but need further exploration at an empirical level in the future. Another recommendation is for further research to be conducted on a larger sample size at additional social work offices in the country in order to explore the role of the social worker in providing palliative care and multi-disciplinary teamwork on a larger scale. Larger-scale studies would make it possible to generalize the research on this topic.

6.4.6 Mainstreaming of palliative care patient referrals to the social workers

This study established the need for mainstreaming of palliative care patient referrals from doctors to social workers. Social workers can offer a range of interventions including counselling, psychosocial support, patient health education, mediating and advocating on behalf of the patient and conducting discharge planning. In addition, social workers can include palliation when necessary within a single service or

coordination between existing healthcare structures ensuring that palliation is integrated into the care and discharge planning of patients with life-limiting illnesses. This study therefore advocates for the mainstreaming of palliative care patient referrals to social workers to enable the social worker to provide palliative care to the patients where needed. For example, Catherine suggested for referrals from the doctors to be mainstreamed to the social worker and *“I think if it could be done earlier as from the word go then it will really help, help much if the support can start from the beginning and not from the time the patient has gone into a depressive mode... The changes that I would want to see mainly are, maybe for the doctors to refer these cases early enough and for it to be a must”*.

6.4.7 Awareness and education on palliative care

A general lack of awareness and education surrounding palliative care comes at a great cost. Freedom from pain is a universal right and must be rooted in the concept of humanity. We all need to have an awareness and understanding of palliative care and what constitutes palliative care, in order to be able to implement the essential elements of the right to palliative care. Although it appears to be a straight, forward exercise to ensure accessibility of palliative care and freedom of pain for patients with life-limiting illnesses, there are still a number of significant barriers such as a lack of awareness, knowledge and understanding of palliative care. These barriers include lack of political awareness and support; social and cultural issues and inadequate education and training of social workers, doctors, nurses and other healthcare professionals. Public leaders, healthcare professionals and the society, at large need to be made aware and educated on palliative care through evidence-based research.

The excerpt from Linda recommends awareness and education on the importance of palliative care provision. She expressed, it is very important for the Namibian government to be educate and trained on the importance of palliative care in order to integrate it at all levels of primary care provision *“apart from people receiving training and students coming in for the practice, I think it should be, I don’t know how, but the government should be made aware of the importance of palliative care so when they are aware of it, they’ll be able to understand what it means, because I find it to be very*

important, because most people they have life limiting illnesses. Then they are not given that much attention in a category of saying 'get the medication, get well, why you don't get well', without really paying attention as to what this is all about. If the social work department or the, how, I don't know how they can get this one to be known by our minister, maybe it will be a good thing, then people will seek proper care". In addition, Alice advocated for "more training, more campaigns, awareness, like media awareness. I just remembered that in my school years, there was a lot of awareness regarding palliative care, but I do not see it a lot currently now. So, if more awareness campaigns can be done regarding palliative care, maybe it can improve palliative care in our country".

6.4.8 Supervision and debriefing opportunities

The research found a need for supervision, peer support and peer debriefing opportunities when working in a palliative care setting. Shane recommended having retreats and supervision to refresh "*that is why you really need that retreat, at least for one week to be able to be refreshed and when we are coming to start, at least we are very energetic*". Supervision and peer support were identified as factors that will enable social workers to revitalize and debrief in order to perform better in their respective role in providing palliative care. The findings revealed that they will feel supported and it will enable them to process their reactions to difficult cases. In the provision of palliative care in the primary care settings such as the hospitals, social workers are face with death and dying patients, moral dilemmas and other life-limiting illness related social problems that affect them emotionally and mentally.

A further investigation is necessary to understand how social workers practice self-care and methods to integrate and provide supervision and debriefing opportunities.

6.5 FINAL REMARKS

This novel, emerging constructivist grounded theory of social workers' multi-dimensional roles in providing palliative care include identities of advocate, assessor,

broker, counsellor, educator, facilitator, patient liaison, mediator, discharge planner and manager of in-country referrals. The constructivist grounded theory provides a structure for understanding how the organization and meaning of social contexts can potentially enhance or hinder palliative care. As a result, this study found that the multi-dimensional roles of the social worker in the provision of palliative care need to be understood. Research that identifies specificity in the application of the social workers' role in providing palliative care is fundamental to issues of access to services, sustaining levels of care, quality of life and well-being. This new awareness must inform palliative care social work practice, education and policies at the organizational and practitioner levels. The barriers hindering social workers in providing palliative care identified here are not unique to the field of social work; they have been noted in the literature to be present in a variety of multi-disciplinary interactions. Social work can now draw more liberally upon and apply information about communication best practices and role negotiation from the existing multi-disciplinary and teamwork literature to develop their own guidelines. Maintaining a consistent and high standard of care is good for the profession of social work, the organizations where they work, and for patients and families.

This study adds to the limited existing knowledge about the perceived role of the social worker in providing and practicing palliative care social work in the primary care settings in Namibia. If the scope of palliative care social work in the primary care settings of Namibia is not acknowledged, promoted and appreciated more widely, then it is likely that the discipline will remain a *'service in the shadows'*.

This study advocates for the multi-dimensional roles of the social worker to be acknowledged, appreciated and optimized in the provision of palliative care and for palliative care to be developed and implemented regardless of practice settings at all levels.

“All social workers, regardless of practice settings will inevitably work with clients facing acute or long-term situations involving life-limiting illness, dying, death, grief, and bereavement. Using their expertise in working with populations from varying cultures, ages, socio-economic status, and non-

traditional families, social workers help families across the life span in coping with trauma, suicide, and death, and must be prepared to assess such needs and intervene appropriately” (National Association of Social Workers, 2004).

This study has discovered that social workers have multi-dimensional roles in providing palliative care to patients in primary care settings in Namibia, therefore creating a constructivist grounded theory of social workers’ roles in providing palliative care. Interactive communication and proper referrals is core requirements for ensuring that effective palliative care is provide to patients with life-limiting illnesses and their families. Competent patient-centred palliative care by social workers is necessary in the public healthcare system in Namibia, since it has to accommodate the diverse population of the country. Interactive health communication between social workers, other healthcare professionals, patients and their families ensure that the individual patient’s perspective on healthcare are catered. For a life-limiting illness such as cancer, social factors need to be considering in the medical system to ensure that the social workers and other healthcare professionals in the multi-disciplinary team of the hospital provide effective patient care. The aspect of family as a support system contributes positively to patient-centred care and social workers in close collaboration with other healthcare professionals. Therefore, there is a need to integrate a patient’s family members in managing palliative care for life-limiting illnesses.

This study provided a descriptive analysis of the social workers’ perceptions of their role in providing palliative care to patients with life-limiting illnesses and on their understandings of palliative care. It also explored conditions that hindered or strengthened social workers’ abilities to provide palliative care and how social work education and training influence social workers’ competencies to provide palliative care. The qualitative methodology was suitable for examining the social workers’ perceptions of their role in providing care and it contributed positively in providing an in-depth analysis of the social workers’ understanding of palliative care. The findings of this study can be used to improve palliative care social work practice, education, training and research in the Namibian healthcare context. Therefore, the study makes a

scientific and meaningful contribution to the field of sociology, social work, palliative care and healthcare in creating a constructivist grounded theory of social workers' role in providing palliative care to patients with life-limiting illnesses in the primary care settings in Namibia and beyond.

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APPENDICES

APPENDIX 1: DEMOGRAPHIC INFORMATION

Interview Number:

Date:

Time:

Location:

Pseudonym:

1. What is your age?
2. What is your gender?
3. What is your ethnicity?
4. What are your religious beliefs?
5. How long do you have your social work degree?
6. How long are you working as a social worker?
7. What services do you provide?
8. *What proportion of your work is focussed around palliative care? Explain.

**This question is left in, because it is the crux of the study. It is meant to open up the respondent's - either experience with, or lack of experience with – palliative care. If participants do not know about it, they will say no experience. Furthermore, the study wants to gain a grounded approach to understanding palliative care even if much (as on pages 4-6) has been written about it. In the case of Namibia, it has not been written about specifically from social workers in Namibia's points of view, therefore the reason for introducing this open-ended question.*

APPENDIX 2: INFORMATION LETTER & CONSENT FORM

Title of the Research Study:

Social workers' perceptions of their role in providing palliative care to patient with life-limiting illnesses: A qualitative study among social workers in primary care settings in

Namibia.

Introduction: My name is Rachel Johanna Freeman and I am a doctoral student at the University of South Africa (UNISA), in the Department of Sociology. I am also a full-time Social Work Lecturer at the University of Namibia. In the above-mentioned study, I set out to examine social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses in primary care settings in Namibia.

Purpose: The main purpose of the study is to examine social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses. This study is for research towards my PhD thesis. The aim of the study is to gain deeper insight and a better understanding of social workers' perceptions of their role in the provision of palliative care to patients with life-limiting illnesses. Unstructured in-depth face-to-face interviews will be conducted in order to unearth conditions that might hinder or help social worker's ability to provide palliative care. The in-depth face-to-face interviews will be used to examine the ways in which social work education in palliative care contributes to social worker's competency in providing palliative care.

Procedure: Primary data will be collected mainly through in-depth face-to-face interviews with a volunteer sample of twenty social workers in primary palliative care of patients with life-limiting illnesses. Unstructured interviews will be tape recorded with prior consent of the participant and names to be used only by the researcher in signing a consent form in this regard.

The researcher will personally transcribe the tape-recorded interviews making sure to keep all information anonymous and securely protected from any intrusive acquiring of it. All information will remain confidential and their names will be removed from the interview and a pseudonym will be assigned. The information will be locked away. The first interview will include demographic background information. The second interview will be on social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses. The interviews will be transcribed and reviewed. Upon completion of both interviews, a third session will take place where the researcher will apply member checks in order to check back with the participants and to allow them to comment. You are being asked to take part in a research study of your own personal choice. Your participation is entirely voluntary, which means that you can choose whether or not to participate. If you decide not to participate there will be no loss of benefits to which you are otherwise entitled. Before you make a decision you will need to know the purpose of the study, the possible risks and benefits of being in the study and what you will have to do if you decide to participate.

The researcher will talk with you about the study and give you a consent form to read. If you do not understand anything you are reading, do not sign it and rather ask the researcher to clarify for you. Please ask the researcher to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to sign this form and a copy will be given to you for record. Keep this form, in it you will find contact information and information about the study. You may ask to have this form read to you if you prefer.

Why was I asked to participate in the study?

- You are being asked to join this study because you are a social worker in primary care setting.
- You are between the age 30 and 50 years.
- You have been selected for this study because you are currently working in this career for two years or more.

How long will I be in the study? How many other people will be in the study?

- The study will take place over a period of one year or additional if needed. This means on one day the researcher will ask you to spend 1-2 hours in an interview. With your approval at this first meeting, the researcher may request follow-up and further debriefing meetings with participants.
- You will be one of 20 people in the study.

Where will the study take place?

- The researcher will meet you at a pre-determined location close to your job. This space will be a private area, with minimal noise where you will feel comfortable to discuss and answer all questions without fear of being overheard.

What will I be asked to do?

- You will be asked to meet with the researcher for tape recorded interviews that will last up to a maximum of 120 minutes. You will be asked questions regarding your role as a social worker providing palliative care to patients with life-limiting illnesses.

What are the risks?

- There are no anticipated risks to you, all information will remain confidential.
- Your name will be removed from the interview and a pseudonym will be assigned.

How will I benefit from the study?

- There is no direct benefit to you. However, your participation could help us better understand practices for palliative care by social workers in primary care settings, which can benefit you indirectly.

What happens if I do not choose to join the research study?

- You may choose to join the study or you may choose not to join the study.
- Your participation is voluntary.

- There is no penalty if you choose not to join the research study. You will lose no benefits or advantages that are now coming to you, or would come to you in the future.

How will confidentiality be maintained and my privacy protected?

- The researcher will make every effort to keep all the information you tell during the study strictly confidential, as required by law.
- Any documents you sign, where you can be identified by name will be kept in a locked drawer in the researcher's home office.
- These documents will be kept confidential. All the documents will be destroyed when the study is over. The methods of this study are qualitative, utilizing thematic analysis to review and analyse the data.
- Only the researcher in this study will have access to the information gathered for the study. The file created for you will not contain your name, and a pseudonym will be used. All interviews will be audio recorded.
- The recordings will have your name removed to ensure that your information remains confidential. The files will be stored in a locked cabinet in the researcher's home. Only the researcher will have access to the information with your name and pseudonym.
- All information reviewed by the dissertation committee will be de-identified and will only have a pseudonym attached.
- The interviews will be transcribed by the researcher herself. The interviews will be sent to the dissertation committee without any identifying information.

Who can I call with questions, complaints or if I'm concerned about my rights as a research participant?

If you have questions, concerns or complaints regarding your participation in the research study or if you have any questions about your rights as a research subject, you should speak with the researcher; Principal Investigator myself: Rachel J Freeman at +264812520601 or my research promoter, Dr. Zanetta Jansen, who can be reached at +27124296322. I thank you in advance for your positive consideration.

When you sign this document, you are agreeing to take part in this research study. If you have any questions or there is something you do not understand, please ask.

You will receive a copy of this consent document.

Signature of Participant: _____

Print Name of Participant: _____

Date: _____

Signature of Investigator: _____

Print Name of Investigator: _____

Signed copies of this consent form must be: 1) Retained on file and 2) Give to the Participant.

APPENDIX 3: INTERVIEW GUIDE

Introduction to the Interview

The **purpose** of this interview will be to summarize issues from the first interview and to focus on social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses. You were recruited for this study, because of your role as the social worker in the provision of primary care. The focus of the questions in this interview will be on your role as a social worker looking at factors that might hinder or help social worker's ability to provide palliative care. This in-depth face-to-face interview will be also examine the ways in which social work education in palliative care contributes to social worker's competency in providing palliative care. Everything you say during the interview is confidential.

Examine social worker's understanding of palliative care:

1. What is your understanding of palliative care and patients with life-limiting illnesses?
2. How would you describe how palliative care in the primary care is managed?
3. How satisfied are you with how palliative care is managed in your hospital?
 - i. Probe: If you could change how you deliver palliative care, what would those changes be?
 - ii. Probe: How confident are you providing palliative care?

Exploring social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses:

4. How do you perceive your role and responsibilities providing palliative care?

5. How do you perceive your interactions with the patients and their family members in providing palliative care?
6. How do you perceive your interaction with the multi-disciplinary team members?
 - a. What is your experience working on the multi-disciplinary team?
 - b. What is your role on the multi-disciplinary team?
 - i. Probe: Who do you work with primarily on the multi-disciplinary team?
 - ii. Probe: How do you feel about the interaction between the different medical providers?
 - iii. Probe: Tell me about the communication between you and the physicians, nurses, and other members of the medical team.
 - iv. Probe: Give me an example of how you work with the physician on the team.
 - c. How do you initially get involved with a palliative care case?
 - i. Probe: Do you get a referral from other providers? If so, who and how?
 - d. Are you comfortable being the first provider to initiate a palliative care conversation? If so, do you feel supported by your multi-disciplinary team members in initiating that palliative care conversation?
 - e. Are you involved in family conferences?
 - i. Probe: If yes, what is your involvement?
 - ii. Probe: Can you take me through how a family meeting is organized and run in your primary care setting?
 - iii. Probe: What would you change in your role with family conferences for you to be more effective as well as with the members of the multi-disciplinary team?
7. How do you perceive what social workers are doing to what they could be doing in the provision of palliative care to improve the quality of life of patients with life-limiting illnesses?

Investigate conditions that might hinder social workers' abilities to provide palliative care to patients with life-limiting illnesses:

8. How does your department view your role with providing palliative care?
9. What are some of the factors in your department that hinder your abilities to provide palliative care?

Investigate conditions that might strengthen social workers' abilities to deliver palliative care:

10. What are some of the factors that might strengthen your abilities to deliver palliative care?

Social workers' perceptions on how social work education in palliative care contributes to social worker's competencies in the provision of palliative care to patients with life-limiting illnesses:

11. Have there been any continuing education programs that have helped you with your role in providing palliative care?
 - i. (Probe): If yes, what were they and how did they help you?
 - ii. (Probe): What was it about them that influenced your practice?
12. What topic or area of interest would you be interested in learning more about for your continuing education?
 - i. (Probe): What topics may be useful to improve your understanding of how to provide palliative care?
13. Were there any courses in your SW Education Program/Curriculum that help you in your work with palliative care?
 - i. (Probe): What were they?
 - ii. (Probe): How have they influenced your practice?

- iii. (Probe): What kind of coursework do you wish you had in your Social work education to prepare you for the work you do now?
- iv. (Probe): Did your Social Work internship experience prepare you for your current position?

14. How do you think the field of palliative care social work could be improved?

15. Is there anything that I should have asked that you would like to discuss regarding palliative care in primary care in Namibia?

APPENDIX 4: UNISA ETHICAL CLEARANCE



SOCIOLOGY DEPARTMENTAL RESEARCH ETHICS REVIEW COMMITTEE

1 December 2015

Dear Ms Freeman

Ref #: 2015_SOCDERC_009
Name of applicant: R1 Freeman
Student #: 45610398

Decision: Ethics Approval

Name: Ms R Freeman (Supervisor: Dr Z Jansen)

Proposal: Social workers' perceptions of their role in providing palliative care to patients with life-limiting illnesses: A qualitative study among social workers in primary care settings in Namibia

Qualification: Doctoral degree

Thank you for the application for research ethics clearance by the Sociology Departmental Research Ethics Review Committee for the above mentioned research. Final approval is granted for the duration of the project.

The application was reviewed in compliance with the Unisa Policy on Research Ethics by the Sociology Departmental Research Ethics Review Committee on 1 December 2015.

The proposed research may now commence with the proviso that:

- 1) The researcher/s will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
- 2) Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study, as well as changes in the methodology, should be communicated in writing to the Sociology Departmental Research Ethics Review Committee. An amended application could be requested if there are substantial changes from the existing proposal, especially if those changes affect any of the study-related risks for the research participants.
- 3) The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study.

Note:

The reference number (2015_SOCDERC_009) should be clearly indicated on all forms of communication (e.g. Webmail, E mail messages, letters) with the intended research participants, as well as with the Sociology Departmental Research Ethics Review Committee.

Kind regards,

Dr CG Thomas, Chair of the Department of Sociology



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APPENDIX 5: APPROVAL OF RESEARCH FROM MHSS



REPUBLIC OF NAMIBIA

Ministry of Health and Social Services

Private Bag 13198
Windhoek
Namibia

Ministerial Building
Harvey Street
Windhoek

Tel: 061 - 203 2510
Fax: 061 - 222558
E-mail: Ester.Sisaria@mhs.gov.na

OFFICE OF THE PERMANENT SECRETARY

Ref: 17/3/3

Enquiries: Ms. E.N. Shaama

Date: 06th April 2016

Ms. Rachel Freeman
P.O. Box 55150
Rocky Crest
Windhoek

Dear Ms. Freeman

Re: Social Workers' Perceptions of their role in providing palliative care to patients with life-threatening illnesses: A qualitative study among social workers in primary care settings in Namibia.

1. Reference is made to your application to conduct the above-mentioned study.
2. The proposal has been evaluated and found to have merit.
3. **Kindly be informed that permission to conduct the study has been granted under the following conditions:**
 - 3.1 The data to be collected must only be used for completion of your Doctorate of Philosophy in Sociology;
 - 3.2 No other data should be collected other than the data stated in the proposal;
 - 3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects' information should be observed and adhered to, any violation thereof will lead to termination of the study at any stage;
 - 3.4 A quarterly report to be submitted to the Ministry's Research Unit;
 - 3.5 Preliminary findings to be submitted upon completion of the study;

APPENDIX 6: EXAMPLE OF TRANSCRIBED INTERVIEW WITH PARTICIPANT 3

Transcription of Interview 3 (Faith)

Interview 3: Part 1

Rachel: Ok, good afternoon Faith, um thank you very much for volunteering to participate in the study.

Faith: Thank you Rachel for choosing me as a participant in your study.

Rachel: Um...so as I have introduced myself I am, a PHD student with the University of South Africa and the main purpose of my interview for today is to obtain rich and detailed information from you particularly on your role as a social worker in the hospital setting in providing palliative care to patients with life-limiting illnesses. The study is for academic purposes and it will strictly be managed under the ethical codes and guidance of the University of Africa, in other words the information that you are going to share with will not be shared externally or it will not be used for commercial purposes. And your participation as you have agreed already to voluntarily participate will be anonymous and it will be confidential. In other words we will not use your real name and during the interview I will also provide you [clears throat] with an information letter that will also have informed consent form. Ah should you decide to participate then you can just sign that form for me. So are you willing to participate?

Faith: Sure

Rachel: Ok

Faith: Ah I'll participate ah, voluntarily.

Rachel: Ok. So thank you very much for participating in the study. Now perhaps you can just tell me what services do you provide?

Faith: A-am, I work as an oncology medical social worker, at the Windhoek Central Hospital. Windhoek Central Hospital is a National referral hospital in Namibia, where...all the specialised um services are rendered to patients in terms of oncology, cardiac services, dermatology, all the specialist areas that you can, aa, think of.

Rachel: Uhu

Faith: So I work within a medical team, multidisciplinary team set up. Um, in this team, my duty is um, to provide um psychosocial support to patients and their families. I also offer counselling, group work, community work. Basically we, umm, practice all the social work methods.

Rachel: Ok. Thank you. So, what is your understanding of palliative care?

Faith: Alright. Palliative care is a multidisciplinary...approach, that is meant to improve the quality of life of patients, and families. Umm particularly patients ah, diagnosed with life limiting illnesses such as ah cancer and HIV whereby they is no cure for these umm, these diseases. So the aim of palliative care is to-o-o a-alleviate pain, and umm needless suffering. We want ah, the patient's life's quality to be enhanced, so that they can... ah live, enjoy, that they can enjoy life. Ja, palliative care is not there to sort of ah prolong their life or hasten their death, but just to make sure that each and every day is enjoyable and is pain free. (3.54.2)

Rachel: Ok. Thank you so much. Now how would you in your, if you look at your setting, the primary care setting, how would you describe how palliative care is managed?

Faith: Ah do you mean to say within this hospital setting?

Rachel: Yes

Faith: How is palliative care managed?

Rachel: Managed. Yes.

Faith: Alright.

Rachel: In the particular setting where you are working.

Faith: Umm [pause] In... the oncology setup, ah, palliative care is managed ah from a holistic, ah perspective, whereby we involve all the various hospital professionals aa such as the medical doctors, the nurses, the dieticians, the occupational therapists, physiotherapist, the social worker and also chaplains. We have a volunteer chaplain who came to offer spiritual support ah to patients and their families. So within this ah multidisciplinary set up we use make use of referrals. If the doctor identifies a social problem, they refer to the social worker. If there is need for a patient to have ah assistive devices or wheelchairs, they refer to the occupational therapist. If there is need for the patient to get some physio, they refer to the physio...therapist and if maybe the patient, due to ah the nature of the [not clear], if the patient maybe is wasting away, you know, or the patient is not able to eat properly because of an obstructive tumour, then the doctors can refer to the dietician to prescribe aa, umm an appropriate aa meal or nutritional supplements which the patient is able to take.

Rachel: Ok great. Thank you so much. So how satisfied are you in terms of how palliative care is managed in your hospital?

Faith: I'm-m very much satisfied. Um ... one, we, we have specialists in palliative care we have doctors ah who were trained in palliative care. They know the principles of palliate, palliative care, so they try to ah implement, ah implement those principles. I'll give for, for, for instance, with regards to morphine, ah you know a doctor trained in palliative care

should know that, he cannot just prescribe morphine. He has to provide morphine plus a laxative because morphine causes constipation.

Rachel: Uhum

Faith: Ya, so, so our doctors are very knowledgeable and they try to, no, adhere palliative care ah, principles. And also ah I as a social worker I, I have a specialist diploma in palliative care.

Rachel: Uhum

Faith: Ya, so I'm quite, um, knowledgeable in term of ah, what is palliative care? Ah how should we support ah patients suffering from life-limiting illnesses and their families.

Rachel: Uhum

Faith: And also you know, they're, ...what should be avoided, you know, aa, when dealing with a patient with, aa, who's dying in terms of medication, in terms of even communication.

Rachel: Uhum

Faith: Ya, so I, I can say I'm extremely satisfied, even...ahm, because we have am, like the medication is available for cancer patients and other patients aa suffering from life limiting illnesses, because palliative care says that ahm, if a patient's physical pain is not well managed or well controlled by a certain drug, for, for example Panadol, you should aa step up the medication to give stronger medication such as codeine. If codeine doesn't work go to morphine. So our hospital has got the facilities, they have got the medication that available. They've got ah the staff. The only challenge is that ahm, the staff are few, they're, ahm short staffed and they're quite limited so they may not be able to render the services at aa, ahm at an expected ahm, place, to the expected extent because they are short staffed. But otherwise in terms of quality, the quality of

services that, that are rendered to palliative care patients, I am very much satisfied.

Rachel: Ok

Faith: Also our patients they get free assistive devices, such as wheelchairs, leg prostheses, breast prostheses even the food, all the food that they want, the nutritional dietary requirements that they require within the hospital they get free of charge. And some time, the hospital, they, they actually go to an extra extent of providing, buying expensive nutritional supplements such ensure. And these are small tins that are very, very expensive, but the hospital they buy it and give it free of charge to, to the patients requiring it.

Rachel: Great. Thank you so much. You have only mentioned about palliative care being, holistically managed from a holistic perspective. And also you made reference to the multidisciplinary team approach. And you have also talked about doctors having specialist training.

Faith: Aha

Rachel: Yourself as the social worker responsible for the oncology unit. Then also I would like to, to know more about the involvement of the other multi-disciplinary team members. How satisfied are you in terms of their involvement, managing palliative care?

Faith: Ok. We, have had um challenges in terms of a lot of ah other staff such as occupational therapists, dieticians, resigning, because due to various reasons. So at some point in time we, we have stayed without like an OT. Like, um, since the beginning of this year we, we were not having an OT, but I'm glad to say that ah we finally got a new OT who started two weeks ago.

Rachel: Ok

Faith: Ya, and also the dieticians, we, we have had a long period without a dietician, but of late we, we have some dieticians. They are still new.

Rachel: Uhum, in terms of the contribution from the nurses' side?

Faith: Uhum. No they, the nurses, with the nurses I'm, I'm very much, um, satisfied with their contributions and also they've got a, a passion for working like in the palliative care setting

Rachel: Uhum

Faith: Ya, so I can't really complain.

Rachel: Great. Then if you, if you had a chance to, to make a difference or some changes in how palliative care is being delivered, what would you like to change?

Faith: Alright. [Sigh] Within our hospital setting, I would want more staff to get training in palliative care. In terms of ah workshops or postgraduate courses in palliative care. But ah, as far as I remember the only palliative care training we received in the department was in 2015, in January 2015 and that was all. So I would appreciate if we, if we, if we could have refresher courses on palliative care, especially seeing that we are always having ah staff retiring, resigning for various reasons and new staff coming in. So it's important that we are all on board regarding what palliative care is all about. Ah, because in the curricula of some of the professions there is no training on palliative care. People they, they just come across palliative care for the first time when they are placed in the hospital setting. Even for me when I trained as a social worker, ah there was no palliative care in our curriculum. Aa it was only here, when I was put in an oncology setup that I felt that I really need to pursue a course in palliative care in order for me to make a meaningful difference in the lives of the patients that I serve.

Rachel: Hum

Faith: Ah I also feel that, ah there is need, for the hospital to fully put ah the principles or um some of the, you know tools, palliative care tools into practice. Like pain rating scales, you know, they are a lot of different pain rating scales that can be used with children or with adults, but I, I have seen that the doctors they never ah, use the pain rating scales, they just assess by maybe looking at the patient's face and say ummm... that one seems to be in pain.

Rachel: Um

Faith: Ya, ah that one ah no she is ok. That's the basis that they use to increase the dosage. But you know they are some, like in Namibia cultures or tribes that are taught that you must be brave, you must not show pain.

Rachel: Uhum

Faith: Ya, even if when they are in pain they don't show it. So, so now, our doctors won't be like functioning from that, you know cultural perspective. So they will just say, you know that, that patient is ok, because he is not showing any pain. So I feel that our, clinical staff has to start using pain rating skills so that can adequately treat the pain that the patients are experiencing.

Rachel: Thank you so much. So um, you have mentioned that you have eh, equipped yourself with postgraduate diploma in palliative care.

Faith: Yes

Rachel: Um, how confident are you in providing palliative care? (14.59.3)

Faith: I am ah very, very um confident in providing palliative care, because the training that I got, it was very, very, aa, thorough and it was also-o-o accompanied by a lot of ah, case studies and ah eh a lot of ah practicals. So, and also the curriculum was quite ah comprehensive it

covered um ethical issues in palliative care, communication skills, team work in palliative care, it talked about grief and bereavement, palliative care with children, it also talked about ah pain ah management, it also talks, talked about doing research in palliative care. It, so the training was really comprehensive and I, the institution where I did my course is internationally renowned, is one of the best palliative care training institution in Africa, if not in the whole world. So I really am extremely confident ah in the knowledge and skills that I have.

Rachel: Ok. Thank you so much. So, um if we have to explore your perceptions in terms of the role of a social worker...

Faith: Ya,

Rachel: ...in providing palliative care to patients with life limiting illnesses, how do you perceive the roles and the responsibilities of a social worker?

Faith: Alright

Rachel: In providing palliative care?

Faith: Ahm, I feel that the social worker works as an intermediary, between the patient and the doctors.

Rachel: Uhum

Faith: You know, sometimes the patient they don't have the confidence or the courage to ask the doctors, ah certain information regarding their um condition or regarding their family members, because doctors are perceived as ah having a higher so, social status and the patients are perceived as having a lower social status. But the patients they feel more comfortable to come to the social worker. They feel that the social worker listens more to, to their problems, as, compared to the doctors who they think, who, doctors they will be extremely busy and they don't

really have time to listen to, um, patients concerns so sometimes they um, patient comes to the social worker to get um, information.

Rachel: Uhum

Faith: Ya, regarding their families, or their family member or their own um medical condition. At the same time ah, I have seen that the doctors they use medical jargon that the patients don't understand. The doctor can just say no your, your cancer has metastasized, your cancer is terminal, but the patient doesn't know or understand what that is. So some, at times after speaking to the doctor, the patient comes to the social worker and says the doctor told me that my cancer is terminal can you please explain more.

Rachel: Uhum

Faith: Ya, so sometimes you have to break, breakdown that jargon and explain in more simple terms what the doctor is, um, trying to say. But in all in all this [Stammers] I work in consultation with, with the doctor, I don't work independent of the doctor. We, we're we work as interdependent ah, team members.

Rachel: Uhum

Faith: Ya and I also point out to the doctors ah, where patients need clarification...

Rachel: Uhum

Faith: ...because, sometimes you know, a patient [pause] says to me, ah, they were never told that they've got cancer.

Rachel: Um

Faith: You know. Ah then I explains to the doctor that the patient says they were never told that they've got, cancer. But due to communication breakdown the doctor might have said ah no you've got osteosarcoma.

But not really explained it in explicit terms that you know you've got this, and it is called cancer (19.16).

Rachel: Uhum

Faith: Ya, so that is one of my, ah roles within the palliative care setting. Ah another very important role is to counsel patients...

Rachel: Uhum

Faith: Ya... on to help them cope ah with cancer to help them see that they are not the first ones to get cancer, other patients have also been diagnosed with cancer and also can share with each, with them ah coping mechanisms. I, also use, utilise group work to help patients with similar ah, struggles or similar diagnosis just to support each other to cope. For them just to realise that they can still enjoy life, they can still be life after a cancer diagnosis. It doesn't mean that their life has to end the day that they are diagnosed with cancer. I also play an import role in acquiring toiletries and second hand clothing donations for the patients. What happens is that ah, patients, cancer patients are... sent or initially they are diagnosed from outside Windhoek. Ja, so usually when ah its detected that a patient has got cancer they are sometimes just put on a bus without any preparation as to how long they are going to stay in Windhoek and told that, you are going to Windhoek.

Rachel: Uhum

Faith: So when they come here, they, they will be shocked to, to learn from the doctors that they have to stay for about eight weeks, ah getting radio therapy, or about three to six months ah on chemotherapy, without them go, ah, going home. So, now, the, the, the, patients first reaction will be shock, and then later on they will start stressing

Rachel: Uhum

Faith: One, they, they didn't come with enough clothing, maybe they just came with one extra set of clothing.

Or they didn't come with enough toiletries they only brought maybe, one small, small bar of soap. They don't have family in Windhoek, to them, Windhoek is actually a strange place from, and for them they have never been in Windhoek they are not employed so they stress a lot. And some of them can want to default on treatment because of that, because of toiletries they,...you know they want to maintain their dignity by, you know keeping themselves hygienic and smelling good, but if that is missing they will... chose to default on treatment and go back home instead of continuing with the treatment.

Rachel: Um

Faith: So I look for donation of ah, clothing and toiletries from families and other well-wishers. Ah by families I mean ok, ah close ah friends, I mean friends, churches and other well-wishers. Ja, ah, as a social worker, um, I also play an important role of educating the patients on cancer, trying to, just trying to dispel the myths, you know give them the facts about cancer. Some will say no I was bewitched, ah you know that's why I am having cancer, you know and ah [pause] and, and so many myths that they might have but I try to give them the facts that, cancer is a disease that has to be treated by radio therapy, surgery or chemotherapy.

Rachel: Um

Faith: Yaa. So it also helps to put some of their fears at rest,

Rachel: Uhum

Faith: Ya, and also I...coordinate a centre for cancer patients, ah whereby they can come and watch TV, there is a microwave where they can come and ah, warm their food there is a fridge for them. There is DSTV that is ah sponsored by Cancer Association, they are relaxing chairs, and it's a relaxing environment outside of the normal hospital so that centre provides a form of escape for the patients. Ja, its aim ... is just to provide

that warmly environment, whereby patients can come together, they learn together, they support each other, they relax and they have fun.

Rachel: Ok

Faith: Ya.

Rachel: Great. Thank you so much. Um, how do you perceive your interaction with the patients and their family members in providing palliative care?

Faith: Or, ok

Rachel: Your interaction

Faith: My interaction ...

Rachel: and the family members

Faith: Uhum. I..., you know as a social worker I, I have a lot of, I make a lot of interactions

Rachel: Uhum

Faith: With the family, on a, on a daily basis. Aam, like ah with the patients, in terms of ah counselling, in terms of ah listening to their problems, in terms of ah listening to their challenges and also in terms of ah giving them psychosocial support. So no, a social worker plays um a very big role, you know in interacting with the, with the family. And throughout my interactions, you know I have to adhere to a strict, strict ethical code whereby you know, I individualise the cancer patients, you know I treat, I treat our interactions with the strict, strictest of confidentiality, you know I respect their autonomy, their right to self, ah, determination. I..., treat them with a non-judgemental attitude. You know, some of the cancers they are caused by life style ah, bad life style habits such as smoking, you know, such as ahm, drinking alcohol. So like when a patient come to me, ahm with lung cancer that I know was caused by smoking, I, we don't have to judge them, I don't judge them, I will just treat them with respect and a non-judgemental attitude.

And also I respect the diversity the diversity of clients, you know Namibia is a.... diverse nation that is made up of so many different are different from my own, so you know I have to, to respect um, diversity as well. Yaa so I think that's what I can say.

Rachel: Ok, good.

Faith: Um.

Rachel: Thank you. So when you look at the ... your interaction with the multidisciplinary team, how would you perceive that.

Faith: Um. It is I can say it's excellent.

Rachel: Aha

Faith: Because ah the multidisciplinary team they value the-e-e role and input of the social worker.

Rachel: Uhum

Faith: And several times they have verbalised it, that Peggy, you know, we value your input ah in this team as a, as a social worker. And, ah we keep ah constant, ah communication, aah telephonically, if, they need help with a certain patient, they need to make a referral they just follow, phone me then I can attend to that patient and I can also give them telephonic feedback. And also each week we have time forward rounds, multidisciplinary rounds...ah whereby ah we go from bed to bed in the wards until we, we have seen and assessed each patient.

Rachel: Uhum

Faith: And also during that time they make referrals, I also give input ah regarding certain ah patients. So, I can say our interaction is excellent.

Rachel: Ok

Faith: Um

Rachel: When you aah, what is your, your experience working on this multi-disciplinary team?

Faith: Um, can you explain more...

Rachel: Maybe it might be linked to the previous question on how you perceive your interaction, maybe just your experiences. What have you gained? What have you experienced in working with this team?

Faith: Ok. Um...in working with this multidisciplinary team I have grown a lot.

Rachel: Uhum

Faith: Ya, ah even my practice as an oncology social worker has been enhanced, because I learn, you know, we learn from each other. We, learn from each other. The doctors learn from me I learn from them. Ah you know, you learn all this ah various ah medical jargon that is used in, within the palliative care setting. I also, you know, learn their, expectations of me... you know, as a, as a social worker and you know, I have to, also to clarify, you know, ah you know, sometimes they can have incorrect, ah perceptions on the role of the social worker.

Rachel: Uhum. Social worker

Faith: So to me those multidisciplinary team interactions I have to clarify what is my role. This is my role. This is not my role, because sometime I have seen like some doctors, especially those ones coming from medical school... ya, referring a patient to the social worker for a wheelchair.

Rachel: Ok

Faith: Then I have to tell them that no, um role as a social worker is this and this and that. I don't do this and that...

Rachel: So you have mentioned about working with this multi-disciplinary team and that they value your contributions. So, if you look at your role in particularly as a social worker on this team, how would you describe your role there?

Faith: Ok

Rachel: What is it that you are doing on this particular team?

Faith: Ok. Ah in relation to patients?

Rachel: In relation to patients providing palliative care.

Faith: Ok

Rachel: Eh especially when you have your ward rounds.

Faith: Uhum

Rachel: When you have to work with the patients.

Faith: Alright. I have, I play an important role of ah doing some psycho-social assessments that enable us to apply for financial assistance from the Cancer Association.

Rachel: Ok

Faith: Ahm, because ah, once a patient has been diagnosed with cancer they have to come to the hospital for numerous, countless follow ups.

Rachel: Uhum

Faith: Sometimes a patient is ah required to be in the hospital, for follow up Monday to Friday for the next, mm.., one or [pause] five months.

Rachel: Um

Faith: And mostly our patients they lack the financial means.

Rachel: Ok

Faith: in terms of transport...

Rachel: Um

Faith: ...to come for follow up, ja, so where, if we, identify a vulnerable patient without family support, without the income to, to come for follow up, then I can, we can make an application to cancer association, because there is no point like, ah, you know, oncology treatment is very expensive.

Rachel: Uhum

Faith: There is no point in starting a treatment where, when the patient won't be able to come for consecutive follow ups, so my role is to make sure that all patients, ah, adhere to the follow ups, the schedules.

Rachel: Uhum

Faith: Ya, and also my, my role, is also as I mentioned, ah to do counselling to the family, to the patients and their families and also group counselling, but, because ah, like, I'm the only social worker working in the oncology setting it's ah my, my role, the amount of work that I can do you know as a single social worker, ah, in a department that, that has ah, at any one point in time more than one hundred and fifty admitted patients.

Rachel: Um

Faith: I am not talking about the out patients. My role is quite limited, because I am the only one. I would love to do more, but because I am, I am alone, I can do only this much.

Rachel: Uhum

Faith: Ya, but I try my level best, know, to, to give it my, my, my all. But I would appreciate if we could get more social workers, ahm, who would come to work within the palliative care setting.

Rachel: Um

Faith: But the thing is palliative care, you need to have the heart for it, because you are working with ah, patients that are very, very sick, that are very, very frail.

Rachel: Um

Faith: So you need to be patient with them. Even when it comes to communicating with them, you have to speak slowly and you have to be patient, some, of the patients they stutter, and they are not able to communicate smoothly, so you need to be very patient with the, with the patients and also their families. Some of the cancers they smell very, very bad.

Rachel: Uhum

Faith: Ya, and, the sight of some of the cancers is terrifying.

Rachel: Um

Faith: So you need ah to have the heart for palliative care. I believe that palliative care is not for every social worker, it's not for every social worker. And also You need that ah emotional maturity also to work, ah within the, oncology department. I also play an important role in linking ..., qualifying patients with disability grants.

Rachel: Uhum.

Faith: Ya, ahm, when...ahm, some of the patients are rendered disabled because of cancer, ah, I ah, eh liaise with, with the doctor, and I also do my assessment to make sure that ah, the patient has got all the supporting

documents that, that is needed for the application, because there is no, it's no use like, having a doctor fill in a disability grant application form and, eh but at the end of the day realise that the patient doesn't have even an ID you know. So I make my thorough assessment first of all to see that the patient has got a birth certificate, the patient is a Namibian citizen, the patient has got that to make sure that the patient will submit ah the form within the stipulated time. So, those are some of the roles that I play. I play linkage roles, I link patients aah to, you know, to ...

Rachel: Different service providers...

Faith: Different service providers. I also advocate on behalf of the patient, if I feel that the patient is not being listen to, by the doctors, or the patient is lacking a well-deserved service so I have to advocate for the patient, also, you know play a role as a broke as a mediator, within ah, the oncology setting, and also a role as an educator, to educate the patients, aah, on cancer. What does it mean to, to live with cancer.

Rachel: Ok, so on your multidisciplinary team, who do you work with primarily?

Faith: Ok. I work with all, all the team members. I work with the doctors, I work with the nurses, I work with the OTs especially. Ah, to a certain extent the physiotherapists. Ah, the problem with some team members ah, is that they are critically short staffed. And like the OTs, we only have, ah, let me talk about the physiotherapists. We have three physiotherapists for the whole hospital and those physiotherapists are supposed to work with each and every department in the hospital. I think within the hospital we have more than ten departments, so it is impossible for them even to attend, ward rounds on the on the wards. And at any one point in time there could be five ward rounds taking place at the same time in the hospital, and the physiotherapists are supposed to be on, in all of them. So because of that you won't see them

coming because they don't have the capacity and at the same time they should be attending to patients within their department.

Rachel: So um, how do you feel about the interaction between the different medical providers?

Faith: Uhum... I think the interaction is, is quite good. We, ah, treat each other as equals. Ja, we of course, you know, the, the doctor is the head of the medical team...But ah, I, I feel, each and every team member is valued, each and every team members, member ah is respected and treated on an equal level and they are also consulted in, issues, related to their profession.

Rachel: Uhu, great. Tell me more about the communication between you, and the physicians, the doctors, the nurses and other medical teams. Especially between you as a social worker

Faith: Uhum, usually ah the communication is ah verbal.

Rachel: Uhum

Faith: Ya, we, communicate verbally face to face. Sometimes we communicate telephonically, and we also communicate through ah, written, ah notes in patients' ah passports and ah, files.

Rachel: And how would you describe that communication?

Faith: Uhum. I, I, I can say its, its good.

Rachel: Great, give me an example of how you work with the physicians on the team.

Faith: An example of how I work with the physicians. Well ahm, as I said we, we work as a multidisciplinary team. Ah, I can, I can give an example of the ward rounds that I have earlier alluded to earlier on... and in this ward rounds we see patients from bed to bed. The doctor can ah give, his

or her input regarding [inaudible] condition of the patient. I can give an input regarding the, the social circumstances that may ah hinder adherence to treatment or I can, ah, talk about the psycho-social, ah issues that are contributing to the patient's stress.

Rachel: Ok.

Faith: Sometimes we can go on ward rounds and the doctor can say oh, this patient is just complaining of headaches or complaining of insomnia... Then I tell them that no, ah this patient has got some, ah unresolved family issues, I saw this patient for sessions and she told me that she is having unresolved family issues that are contributing to the insomnia. So the doctors can, you know give the medication then I see the patients ah for counselling. Ya, so we combine our efforts.

Rachel: Great, so eh, if you have to look at involvement in a palliative care case... maybe you can tell me more about how do you initially get involved in such a case?

Faith: Ok. Ah my point of departure is the ward round during ward rounds that's where we see the new referrals, you know, from the, from the regions. Ahm so when it's a new referral usually the patients, some of them they don't even know what, they know that they've got cancer, but they don't know what it is. What does it mean to have cancer? What is cancer? Where did it come from? You know they've got so many unanswered, ahm questions. Ya, so with the referrals I'm supposed to see each and every new referrals, but because ah we are limited in terms of capacity, in terms of numbers, I, I can, I only [pause] ah give attention to the critical cases, when I see that this patient doesn't seem to be coping quite well. Other patients can be new referrals but they will be coping quite well. So the ward rounds are a very important, ah point, of departure, you know, and also ah, you can also give, that's where, where, that's the only time where all the team members meet you know. Ya, so

you can report ah to, to the team, all the team members all at once instead of saying, telling this to this doctor on time, then the other doctor, you just say everything once, so the ward rounds are very, very, very important.

Rachel: Thank you. So, um, if you get a referral, do you also get referrals from other service providers?

Faith: I get referrals ah from the doctors usually. The referral comes, come within the team, ah setting.

Rachel: Ok

Faith: They can come from the OT, ah, if the OT realise that there's a need for a social worker to intervene with, with a particular, ah client.

Rachel: Uhum

Faith: Ya, and sometimes the patients refer themselves, they come themselves and also the families they can also refer a client to the social worker. They can say no ... my mother was diagnosed with cancer she doesn't seem to be doing well, can you please see her for counselling. So usually the referrals are from the multidisciplinary team members, the patient himself and from family members.

Rachel: Thank you so much. So um, if you are being, eh, if, referral new cases being referred to you, are you comfortable being the first provider to initiate a palliative care conversation?

Faith: Sure. I, will, the, with my training I got ah the competency, you know to, to fully communicate with patients, regarding, ah palliative care, regarding death and dying, you know. Ah so I feel that I have knew the correct knowledge and skills and experience as well. Ah, you know, to, to function in this role. So I believe that I'm fully, ah competent in with regards to this role...

Rachel: And when, when, these cases are being referred to you, do you also feel supported by the other multidisciplinary team members?

Faith: Yes, I feel supported the only issue is that I sometimes I feel overwhelmed. I there's, so, so much work that need to be done. There are so many things that I desire, so many initiatives that I do desire to do. You know as a social worker, but I'm limited, I'm not able to do, because I'm all alone. So, ya, that's the only issue that sometimes I feel overwhelmed.

Rachel: Ok, um, I want to stand a little bit still on the issue of feeling overwhelmed. Do you have any support structures in place to alleviate those feelings of overwhelming, eh in terms of maybe debriefing or group debriefing, multidisciplinary team debriefings, case debriefings?

Faith: Unfortunately not. It's, like, ah, within the hospital setting, everybody is just busy attending to the patient's needs, that we forget, you know to care for the carer. And there are no resources that are availed even you know for such services, um, in terms of caring for the professionals, you know. And also we don't have um a wellness program in place just to, you know, even to do, those debriefing, ah sessions, even just aaah you know, just to relax to go outside the hospital environment, you know, and socialise. We don't make such provisions it's like, we are here fulltime for the patients. The staff must take care of their own welfare there is no one to take care of the staff. Even our supervisors it's like they're only concerned about patients' wellness and not staff wellness.

Rachel: Ok

Faith: Ya, it's quite unfortunate.

Rachel: Uhum

Faith: Ya, so, because people get burnout. People get burnout. Ya, sometimes people are booked off sick, because they're overwhelmed with work,

they, they are burnout. And sometimes because the staff is short-staffed, ah people can make medical errors, you know, especially the medical doctors in terms of prescribing, or the nurses in terms of dispensing the medication or the pharmacist as well. Yaa

Rachel: Um

Faith: So there is a great need for, you know, caring for the carers.

Rachel: Um [Pause] Ok. Thank you so much. Eem, do you have any family conferences?

Faith: Family conferences ...

Rachel: Uhu

Faith: Um, ya! I, I meet ah, you know, I always, you know, in social work we were taught to use the systems, ah perspectives. So, we, we look at the systems in the person's life that can support the patient during, ah, this difficult period in their lives. So we work, not only with the patient in isolation, but we work also with the family members.

Rachel: Uhum

Faith: Ya, so that we can use ah that social capital, that family social capital to support the patient to cope with cancer. Ah in some cases, if the case warrants it I can meet, ahm, ah with the family alongside the doctors. Ya, but, because the doctors have strict, or tight, schedules, treatment schedules, they don't really have time, ah usually to sit with the family members. So that role is usually left for the social worker.

Rachel: ...social worker...maybe you can take me through a, a case that you have handled with a family.

Faith: With a family. Ah, there are so many cases. So I am trying to, to see which one I can give you. Ah well, I, I I've seen a case of a family,

whereby ah their family member was diagnosed cancer, it was their mother. But now the family was fighting for the mother's inheritance, whilst she is still alive.

Rachel: Um

Faith: So now, the mother instead of focusing on getting better she was now, getting a lot of stressors from the family.

Rachel: Um

Faith: They wanted her car they wanted, each, each, everyone wanted her ATM card. Somehow the kids they got hold of her ATM pin. So they just took the card, everybody they took turns to, ah take the pin, ah the card and go and withdraw the money from her savings, from her pension. And ah the patient ah had recently bought a car and one of her sons took the car for a ride and ah he was involved in an accident with the car. Fortunately he didn't die, but he crushed the mother's car and the mother is sick, she is on a wheel chair, you know, she is trying to get better she is not getting any support from the family. Ya, the family were actually causing her a lot of stress, stress and emotional pain and hurt, so I had to sit with the family to realise what they are doing to the patient, that they are causing a lot of emotional pain on top of the physical pain that is already ah, experiencing, and also the patient was ah struggling with issues of death and dying because she knew that she was dying, but she had not fully accepted that so this is um... an example of a case that I have, um dealt with. It was a very complicated case.

Rachel: Um

Faith: Ya,

Rachel: Ok. Thank you. So what would you have changed in your role with the family conferences, for you to maybe make a more effective impact?

And maybe also in terms of involving the multidisciplinary team members.

Faith: Ah, at the moment I can say ah they is nothing that I can change, you know, ah in terms of this family ah, ah conferences, because I, I feel that I'm doing what is required of me, you know, as a social worker to sit with the family, to educate them on cancer, to help them ah, you now team up to support ah the, the patient and also sometimes bereavement counselling, and sometime ah pointing ah to them that ah the patient is dying and they, they need to make ah preparations in terms of maybe writing a will or coming, making peace in the family. Sometimes you see that there is a lot of unforgiveness, there is a lot of ah, in-fighting that is happening. Ya, [Maybe you can put it on pause]. ya.

End of Part 1 of Interview 3

Interview 3 (Part 2)

Rachel: Ok. Aaah when you look at, how do you perceive what social workers are doing? To what they could be doing in terms of providing palliative care. Particularly to improve the quality of life of the patient with life limiting illnesses.

Faith: Alright. Aaaahm, looking at the other hospital dep, departments, I feel that my, the other some of the social workers they don't have an adequate knowledge of what constitutes palliative care.

Rachel: Uhum

Faith: They don't have, ah an adequate knowledge on the, of the, principal, principles of, of palliative care. So as a result they don't function, ah fully within a palliative care setting, because they, they don't have the experience they don't have ah the knowledge they don't have the training in palliative care. And they are not confident in dealing with palliative care, cases. Sometimes they, rather refer to somebody, or just aah say no

me I don't aah, see palliative care aah, patients, because they don't have the competence

Rachel: So if we have to look at factors that might hinder social workers abilities, to provide palliative care, how does your department view your role, with providing palliative care?

Faith: Ok. Should I talk about the factors that may hinder,

Rachel: That may hinder, yaa.

Faith: social workers from, aah providing ah pallia...

Rachel: Special..., specifically their abilities and competencies

Faith: Ok. Aaah, lack of training in palliative care, yaa. And also looking at the.., I don't know whether you want me just to focus, aah, social workers in general or social, social workers here at my institution.

Rachel: Maybe at your particular department

Faith: At my, my particular department. Ok, some of, some social workers are afraid, to work in a palliative care setting, you know. They rather work in a ward, whereby aaaah they are no palliative care cases.

Rachel: Uhum

Faith: Yaa, they don't have, aah, they're afraid, you know of death and dying

Rachel: Ok

Faith: Yaa. And also some of the factors that may, hinder social workers at my institution from, aah offering, good palliative care services is lack of, you know, refresher courses

Rachel: Uhum

Faith: You know on palliative care. And also we don't sit as a department to discuss you know best practices, you know, to share, aaah, cases, you know, to, to discuss, like, even case studies, you know, to share our experiences. We don't have time for that. So it's like the experience that I have, you know, in, as a palliative care social worker, we don't make time to share,

Rachel: Uuum

Faith: you know. Others, other social workers are not learning from me because each one is just busy in their own departments. We don't really, have time, you know, for you know, continual professional development, you know,

Rachel: Uum.

Faith: for professional growth, the time that we have it's just to attend to clients' needs that's all.

Rachel: Um

Faith: But you know, if you don't sit and share you know, best practices I believe that we are actually doing a disservices to the ah, profession

Rachel: Uhum

Faith: Yaa. And also another challenge that I see is lack of support, like in terms of ah you know, debriefing, you know, you don't have, you know, professional support, just to, you know, to support you as a, you know counsellor in a palliative care setting, you know aahm, so, that one is also a very big, challenge.

Rachel: Ok. Thank you so much. So aam if you look at for instance the factors that might strengthen

Faith: Uhum

Rachel: social workers ability to deliver palliative care, what are some of those factors?

Faith: Factors that may strengthen, the,

Rachel: Um, the ability.

Faith: Alright. Before I talk about that let me talk another, about another challenge

Rachel: Challenge. Ok

Faith: We don't have local...., like you know the information on palliative care that we normally utilise is western, based. We, there, there isn't so much research, even like, if we are to look in the Namibian...scenario you know we don't have local information on palliative care. we don't have research on palliative care, we don't have research on social workers' role in a palliative care setting, you know we don't have case studies, social case studies on palliative care. There, there's so much information that is missing

Rachel: Uhum

Faith: in terms of palliative care in the Namibian context

Rachel: Namibian. Ok

Faith: So that one is a very big limitation that will limit social workers ability to render palliative. Like culturally,

Rachel: Uhum

Faith: Specific and context specific palliative care services. Ah looking at the factors that may, maybe promote, the social worker the social worker to you know, provide better, palliative care, settings, palliative care, services I mean training, training is very, very important. We need to, to get training on what is palliative care. The principles of aah, palliative

care, the ethics, communication, how do you communicate with a dying patient. How do you with a, aah patient diagnosed with a life limiting illness

Rachel: Uum

Faith: So we need training in terms of aahm, [pause].. in terms of aah workshops, extra curriculum, courses. But I'm glad to, I'm glad that UNAM introduced a-a-a, palliative care module, in their social work for, in their training for the third year social workers. That will go, a-a-a long way in giving social workers the competencies that are needed in working in a palliative care setting

Rachel: Uhum

Faith: And, um..., and also aahm, what is needed within the Namibian setting is to for us to have, aahm..., a centre of excellence

Rachel: Ok

Faith: for palliative care, where various professionals from various parts of the country can come and learn, you know, best practices, you know, how palliative care should be done.

Rachel: um

Faith: You know to ah learn the ideal, you know, of what has to, to, what needs to be done within a palliative care setting. And there is also need for supervision.

Rachel: Ok.

Faith: There is no supervision, like, well! I'm, I'm somebody who can function, independently, you know. Aah, but eehm, for a, somebody new, you know, the person may struggle

Rachel: Uum

Faith: If they're just, put in an oncology department, you don't get, ah supervision from anybody, but you're just, tol, ah expected to work. You know, somebody can find, aaah, experience a lot of challenges, so there is need for, for supervision. And also there is need for, for appreciation. You know, for-o-r for you to be, to feel that you are being appreciated by, your employer, you know aaah, in as far as the work that you are doing,

Rachel: Uhum

Faith: Even if somebody, you know, there should also be incentives, you know, for people to pursue palliative care training. And also for, for effort to be acknowledged, even when, like I went, aahm to get that aah postgraduate diploma in palliative care, I took unpaid leave, you know, I...went at my own expense, I stayed for a month, aaahm, I obtained my, my qualification after the, thee, the course ended, but my, my, my hospital did not even acknowledge it. Although like, aah you know the qualification is, is benefitting aahm the hospital

Rachel: Um

Faith: and also I was um, the first, um, social worker from Namibia to, not from Namibia, I'm, I was one of the first two social workers to enrol for that palliative care course

Rachel: Um

Faith: in, in Uganda. But my, my employer didn't seem to really even, see it as some, as a, as a big achievement [laughs]. So it can be very discouraging

Rachel: Um

Faith: that you know, I, I go an extra mile

Rachel: Um

Faith: you know, giving it all my best but my efforts are not acknowledged, you know. They are not appreciated. So I think there's eh-eh-eh important role there is an important gap that is there in terms of lack of appreciating palliative care staff, because it takes, you know a big heart, you know, it takes dedication, takes co, commitment, takes patience you know to work in a palliative, care setting

Rachel: Um

Faith: But, I feel that our hospital does not appreciate such effort

Rachel: Uhum

Faith: Yaa

Rachel: Ok. Thank you so much for sharing that.

Faith: Uhum

Rachel: Perhaps, Faith you can also share on your perception on how, eeh, social work education in palliative care contributes to the social worker's competencies, in providing palliative care

Faith: Palliative, yaa. I believe that aah, that social work education in palliative care, it helps to boost the confidence of social workers, in terms of aah providing palliative care, ah services is ah concerned. It also helps that aah, you know, tooo, to know, their duties and what is expected of them, in a palliative care setting. Like aaahm, after graduating from University, as I said I didn't have any knowledge in palliative care, I didn't know what was expected of me within a palliative care setting, so I had to learn it on my own, I had to consult, you know, the various ah hospital team members, for them, to, so, for me to be better able to understand what was my role you know, as a, social worker, within the, ah palliative care setting.

Rachel: Uhum

Faith: And also, education helps tooo, aaah, you know, to equip social workers with, with the fact, you know, the facts, the information that they need to know, with regards to, aah palliative care, and aaah working with patients, aaah, who dying, working with grief and bereavement, aaah issues. So social eh, education in palliative care it plays a very very big role in aaahm, like aahm training, or yielding, competent ah social workers who are very, ah knowledgeable, of, about the principles of palliative care and who are able, to apply, especially if the education is, clinical placements. Yaa clinical placements is, are indispensable to, palliative care. Cause theory on its own, it's not enough. So there is need, for theory and also the patients, the students,

Rachel: Um

Faith: the social work students, to be placed on clinical placements, for them to see first-hand experience what goes in, on in palliative care settings. Like, aah several weeks ago I had some students, they thought that working in a palliative care setting is just gloomy, it's just death and dying there's no joy at all but they were shocked and surprised to see that some patients were very happy. Some of them saw some of the patients they were knitting, some they were playing their radios, some they were singing, some they were so very positive and bubbly. They were e-e, shocked. They didn't think that [stutters] they didn't expect to see that they thought that, we, they're just coming to see patients sitting on the beds who are dying. Sometimes a patient can have an oxygen mask,

Rachel: Uhum

Faith: But because, the, the pain is controlled by, by aah palliative care, you know, the physical pain is under control, the emotional pain is under control, the spiritual pain is under control, you see that the patient is, on an oxygen mask, but they're the happiest person that you have never seen on earth, because, they're, because of palliative care. Yaa, so palliative

care plays, a very important role in ... improving the quality of life of patients and eliminating pain

Rachel: Uhum

Faith: Yaa.

Rachel: You've earlier mentioned that eh, there needs to be more continuous educational programs

Faith: Uhum

Rachel: Perhaps maybe you can tell me have there been any continuous education programs that have helped you in your role in providing palliative care?

Faith: Aaaahm, well! I only attended aah, from the hospital side, from my employer's side, it was only one training that was aah organised in 2015

Rachel: Uhum

Faith: In, for all the oncology staff. Unfortunately that training was not repeated, it was just once off.

Rachel: Ok

Faith: Yaa. And some of the ah very important continuous ah professional development that I got, was through the African Palliative Care, Association

Rachel: Uum

Faith: Aaaah it's sad that aaah their offices closed down,

Rachel: Um

Faith: But I, I saw Africa as playing a very important role in, you know educating, ah health professional in what is palliative care

Rachel: Uhum

Faith: How should, eh, a professional function within a-a-a, a palliative care setting, how should we treat the patients. So I can say even my inspiration to go and do an undergraduate, postgraduate course in palliative care, came because of APCA.

Rachel: APCA yes.

Faith: Yaa

Rachel: Maybe perhaps you can just tell me more about what were some of the topics that, during that continuous education program and how did they influenced or helped you in your practice.

Faith: Ok. Ah some of the topics, ahm, one of the topics was re, related to total pain management

Rachel: Ok

Faith: I learnt that pain is not only physical,

Rachel: Uhum

Faith: Eh, person can have aaah, a multiplicity of pains at the same time. A person have physical pain, emotional pain, social pain, spiritual pain, that are contributed aaah by, aaah a, a myriad of factors

Rachel: Um

Faith: Yaa. And also I learnt about aaah doing an impeccable assessment,

Rachel: Uhum

Faith: of pain, you know, and other symptoms

Rachel: Um

Faith: you know that a patient, aaah presents. So I can do a thorough pain assessment

Rachel: Uhum

Faith: Aaaahm, looking, based on you know psycho-social assessment

Rachel: Um

Faith: And also, you know, the doctors, you know, each and every multidisciplinary team, team member has got a role in managing that pain

Rachel: Uum

Faith: But, the, the baseline is assessment. There is no way that you can manage something that you have not assessed

Rachel: Um

Faith: So there's eh a big, I learnt that it's very, very important to do an aah impeccable assessment of pain or any other symptoms that a patients is, aaah being aaah, is experiencing. And also there're principles of pain management

Rachel: Um

Faith: Let me talk about the WHO ladder

Rachel: Uhum

Faith: for pain management, you know. it talks about, you know, aaah that pain, [clears throat] medication, aahm should be given by the clock

Rachel: Um

Faith: Not to, you don't have to wait until the cancer patient is screaming with pain.

Rachel: Uhum

Faith: Just, keep the, aaaahm doses, aaah you know, at an optimal level by giving pain medication, aaah at certain hourly intervals

Rachel: Um

Faith: And also I learnt that you know, id Panadol is not working for that type of pain you have to scale up

Rachel: Um

Faith: the, the, the aah pain, aaah medication. Don't just, you know, Panadol is not enough, in, like for a patient in extremely pain,

Rachel: Um

Faith: so you will be actually doing more harm to the patient by just giving, sticking to that pa, pain that is, pain treat, pain killer that is not aah working,

Rachel: Um

Faith: I alsoooo learnt, aaahm, you know, that pain management is a human right, you know. It's a human right to be free of pain

Rachel: Um

Faith: You know. And I also learn about aaah about the regulation of morphine.

Rachel: Uhum

Faith: Yaa. We learn that, like morphine is the strongest pain killer there is. However, and also its, it's very simple and cheap inexpensive to dispense if the pharmacists are taught, how, how to dispense it, so there's, important ah role, for training

Rachel: um

Faith: Pharmacist on how to dispense, ahm, that ah morphine. But I, we've seen that in Namibia, ah morphine is under utilised

Rachel: Uhum

Faith: They order the morphine but it's underutilised because the pharmacists they don't have knowledge of, of palliative care

Rachel: Uhum

Faith: and most of the time the morphine it expires, whilst patients are screaming in pain

Rachel: um

Faith: You know. And morphine is only available in the big hospitals

Rachel: um

Faith: and those patients, you know from, you know, the periphery, from the small clinics, and the rural areas, they are not, aah they don't have access to morphine, you know. So policy, there is need for policy you know, for palliative care policies that focus on medication, you know, regulating the medication making it very available country wide. There is also [stutters] an important role in educating ah palliative care professionals, giving them the, adequate, ah skills so that they don't cause needless pain and needless harm to the patient. Ahm we also did aah, a- a-a module on spirituality. Learnt that you know, spirituality is very, very important in the lives of aah patients. Ah people may not be, all of us may not be religious but we identify, we have spirituality, all of us can identify to spiritual issues, whether you're religious or not.

Rachel: Uum:

Faith: And aaaahm, we learnt that, there is important, a-a-a, it's an important component that, that should not be neglected in a palliative care setting.

Rachel: um

Faith: That's why within our hospital setting we've got ahm, some chaplains, volunteer chaplains who come to pray for cancer patients, and give them spiritual ah, support, and you know, sometimes patients when they are dying they want to do some spiritual rites so yaa, the chaplain can link them, ah, even to, to their respective ah pastors. We also learnt the importance of communication within, ah palliative care. Communication to the patient, ah communication, ah within team, ahm... within a team, setting you know, to, communication needs to be clear, you know, it need, to it shouldn't be full of a lot of jargons, you know, it should be simple and straight forward you know. And I also learnt about a lot of barriers to communication, and we learnt about ethical principles in palliative care,

Rachel: Ok.

Faith: You know, respecting ah, you know, ah we did a lot of medical, the pill, three pillars of medical ethics

Rachel: Medical ethics

Faith: Yaa. And also did ah, ethics in, in research, with palliative care

Rachel: Uhum

Faith: Ah patients. We, also, learnt, we did a module on how to do, conduct research ah, in, in palliative care.

Rachel: Uhum

Faith: So I can say that the, the course was very comprehensive it covered all the aspects of palliative care.

Rachel: And that was your post graduate,

Faith: That was my post graduate diploma

Rachel: Diploma. Where there any course in your social work education, curriculum that helped you in your work, in, as palliative care provider?

Faith: Definitely. Ah, you now within, ah social work, ah, we learnt ah communication.

Rachel: Uhum

Faith: We le, learnt about ah active listening, you know, counselling skills,

Rachel: Uhum

Faith: We learnt about, ahm, ethics, you know, ethical adherence to a strict ethical code, you know. We learnt, we learn how to deal with people. So I, I, say, aahm, I can say that ahm, my social work am, course, gave me the basics that I was able to build upon, ahm, through this palliative care course. In actual fact I didn't really struggle in that course because most of aahm... the, the modules they were actually related to social work except for one or two that were, were dealing with ah physical pain and, and pharmacology.

Rachel: Um

Faith: Otherwise the rest were social work related.

Rachel: Related

Faith: Yaa.

Rachel: And how have they helped eh, or influenced your practice

Faith: I am more knowledgeable, in terms of, aah, the role of a social worker within a palliative sett, care setting,

Rachel: Um

Faith: and I also know what is expected of other, professional within a palliative care setting.

Rachel: Um

Faith: So I can easily make referral because I know, the OTs is, ah, is supposed to do this and this and that, so it's, it's also easier for me to do referrals. Aahm, we, because, ah, you know, I, I think I grew even emotionally

Rachel: Uhum

Faith: You know. Ah in terms, or..., I also became more empathetic, I know, to cancer patients and other patients suffering from life limiting, ill, illnesses. Yaa, so I say I...learnt so much ah, from the course

Rachel: Uhum

Faith: Yaa, and aahm, the course also, you know helped me to identify this important gap in terms of research in palliative care.

Rachel: Um

Faith: It's just that, aah my work load doesn't really allow me, you know, to also focus

Rachel: Um

Faith: on, on on research, but it's something that I have a passion for

Rachel: Uhum

Faith: Yaa.

Rachel: Aaa, if, if you have to ... if you, if you, for instance, a-a-a have to look back into the time when you did your internship,

Faith: Uhum

Rachel: Your internship experience, did it prepare you for your current position as a palliative care provider.

Faith: Not at all.

Rachel: Uhum

Faith: Frankly speaking, throughout my for year training, I never made contact with a hospital

Rachel: Uhum

Faith: The first time that I was placed in the hospital, setting was on my day of appointment,

Rachel: Uhum

Faith: But during my four year training as a social worker, I never had any placements within a hospital setting

Rachel: Uhum

Faith: I... work, of course we did one module on, like specialised a-a-am, specialise fields in social work.

Rachel: Uhum

Faith: Whereby, we, we just discussed about ah mental health.

Rachel: Uhum

Faith: But really even that course didn't even prepare me you know, for medical social work

Rachel: Um

Faith: because it was not accompanied by field placements

Rachel: Ok

Faith: Yaa. ...and my internship was at the prison, I was working with inmates

Rachel: Ok

Faith: Yaa

Rachel: Eh, if you had a chance to give any input on the current internships

Faith: Uhum

Rachel: Eh, spe, specifically in terms of exposing the interns to palliative care what would be,

Faith: Ok

Rachel: your ... recommendation?

Faith: Alright. I feel, ah UNAM is on the right track. The only challenge that we have is ah lack of, ah placements, placements site. We don't have clinical sites to, to ah, to place these ah, these students. And also because, you know, palliative care hasn't been fully rolled out

Rachel: Uhum

Faith: you know, across the country

Rachel: um

Faith: It's only here at the Windhoek Central Hospital, aaah because, aaah the staff themselves, they've got aaaah, you know, training in palliative care that they got using their own initiatives, and that they've got passion in, in improving the quality of lives of, you know, oncology patients

Rachel: Um

Faith: That's where, you know, you, you meet patients, doctors, nurses really practicing palliative care. And palliative care is not only for cancer,

Rachel: um

Faith: But aaah I can't really say that palliative care is being practiced in all the de, departments of the hospital, but I can say, I, confidently that within the oncology setting palliative care is being practiced.

Rachel: Ok

Faith: Yaa.

Rachel: Ehm how do you think the field of palliative care social work in particular, can be improved?

Faith: Alright. Research

Rachel: Uhum

Faith: We, we need research, you know, on, on social work interventions

Rachel: Uhum

Faith: Aa within a palliative care setting. We, we need, ahm to learn best practice models. Ahm ... we need, ya, more clinical placements sites, you know, palliative care clinical placement site. Ahm, well! it could have been ideal if students could get, ah more time, you know, if we could spent more time within a palliative care setting, but it's not ah possible. Ya, because even the supervisors they're few, and they're... overwhelmed with their own workload, so taking students is like ah extra, an extra, workload

Rachel: Um

Faith: you know, on an already burnt out, loaded staff. And also aaaahm,.... I've talked about research, we talked about ah, sites yaa. I feel that UNAM is on the right track. Yaa. It's just that their policy limitations you know. We need our government, advocacy, you know, social workers have to advocate for, and lobbying, for the government really to take, aaah, priority, aaah palliative care seriously.

Rachel: Um

Faith: And I know, aaahm there is this aaahm United Nation Charter that, talks about integrating palliative care in all aspects of social work training

Rachel: Uhum

Faith: Aaah training for pharmacists, doctors and nursing, but I'm glad to say, with that, you know ah Namibia is, is on the right track

Rachel: Um

Faith: But! We need more placement sites you know, the, the, palliative care is not only for Windhoek, you know,

Rachel: Um

Faith: We need palliative care in every, place where eeeh patient, in every clinic, in every hospital, every home, no ca-, ca- cause palliative care is not only for health facilities where a patient is with life limiting illnesses is found. Yaa. So that's what we need. So we need willingness, you know, from the government has a very import, role, to play in rolling out ah palliative care across the country. I know, we've got the cancer association, but I, perceive their role as more of fund raising

Rachel: Um

Faith: You know, aaahm, for cancer patients, but ah we need our nurses, our doctors, you know, to be trained, you know. To be sent for courses in palliative care, those continual professional development activities. We need conferences. Palliative care conferences, social work conferences, you know. Yaa, we need Namibia to host even international conferences where researchers even share their, aaahm ideas, their, studies that they carried out, you know on palliative care. Ya, we need to hold international days, you know, whereby we just support, you know, patients re-, receiving palliative care.

Rachel: Uhum

Faith: Yaa.

Rachel: Ok. Thank you so much, eh Faith. Is there anything that I should have asked that you would like to discuss regarding palliative care in the primary care setting in Namibia?

Faith: Uuum [Pause]. I think, I, I see a need for hospices within the country, you know. Cause our-r-r-r hospital setting is overwhelmed.

Rachel: Uhum

Faith: you know, with palliative care cases

Rachel: Uhum

Faith: Some of the cases they don't necessarily need aah admission,

Rachel: Um

Faith: but because we don't have hospices, we see that ahm, you know, our hospital, our wards are very full, you, you see, you see patients lying in the corridors, sometimes in bathrooms, because the hospital is full.

Rachel: Um

Faith: You know. Some patients are just here for pain management, you know, but it's something that can be done at home,

Rachel: Um

Faith: But I don't see that we are, you know, there are many different models of home based, of palliative care. Ya, but I see Namibia we are focusing on, you know, hospital based, you know, palliative care, you know, there is no home based care, ah even clinic based palliative care, you know ah, those ah, outreaches, palliative care outreaches. We are not doing it so it, the end result is that our hospital facility is ah overwhelmed, with a lot of palliative care cases because we are just using one model, one model of palliative care. Soo, it also has to do with ah policies, you know, but, as I

understand we don't have a focal person within the Ministry of Health for palliative care.

Rachel: Ok

Faith: So we need to have that focal person, not just one person, but a team, of experts in palliative care to make sure that ahm the country, is adhering to best standards in palliative care, cause you know there're a lot of standards in palliative care, like the African Palliative Care, Association they came up with aah African based, you know, standards in palliative care, that Namibian, Namibia can ah, also learn from.

Rachel: Um

Faith: But they are not being applied because we don't have that commitment, you know, from the [not clear] level, you know to take up palliative care to make sure that we, aah improve the quality of life of, patients within the hospital setting. Because some of the cases, they don't need to, really to be admitted, but they are admitted.

Rachel: Ok. You have made reference to advocacy and lobbying the government ...

Faith: Yaa

Rachel: Maybe in terms of palliative care policies and also in terms of commitment? What do you think are some of the things that can be done get the government commitment?

Faith: Ok. We, we need palliative care champions within the country, NGOs can be a starting point, you know, NGOs that are just committed and specific..., that, that specifically focus on you know, advocating for the rights of you know, patients with life limiting illnesses. So I think we, we need, some, such NGOS that, to push, put pressure, you know, on the government, you know, to, to listen, you know, to the voices of aah,

palliative care patients, and also to commit to improving palliative care services aah in the country, so that palliative care services are not centralised only to Windhoek, because we find palliative care, patients throughout the country, but the services ahm offered in Windhoek, so it doesn't make sense, so we need to decentralise palliative care services throughout the country. So we need to engage the Ministers, you know, we need to engage, you know, the policy makers within the country. Ya.

Rachel: Ok. Uhm, Faith, we have come to the end of our conversation, I would call it, and I would really like to thank you sincerely for taking your time out of your busy schedule to dedicate time for this particular conversation, it was quite informative and educational and we really appreciate your time, so thank you so much.

Faith: Thank you for having me. I'm glad to have given my input to the study. I hope my contributions were meaningful, and that they will go, a long way a-a-a in, he-helping to enrich the knowledge that is available in Namibia in as far as the role of a social worker in palliative care settings is concerned.

Rachel: Uhum.

Faith: Thank you

Rachel: Thank you so much. And I just wanted to remind you that, um, this will be highly confidentially treated, ah I will write it up, transcribe the interviews myself, and should there be a need, eh for further information maybe or clarification from my side, I trust that you will be available. It could be either through, telephonic conversation or an email, or if need be maybe another face to face, interview.

Faith: I'll be available to, assist you with ah any information where you need clarification.

Rachel. Ok

Faith: Ya.

Rachel: Thank you so much. Have a blessed evening!

Faith: Thank you

Rachel: Thank you

Faith: Alright

End of Interview

APPENDIX 7: BIOGRAPHIC PROFILES OF THE PARTICIPANTS

7.1 Catherine

Catherine, who was between 25-35 years of age, is a Damara /Nama speaking Christian woman. She has been employed at a district hospital in Swakopmund for the past 2 years. She had qualified as a social worker and received palliative care training during her undergraduate studies. Although she did not receive any in-service training or continuous education and training on palliative care, she has a keen interest in working with patients in the hospital setting. She also provides counselling to the HIV-positive patients, TB patients and those who have had a miscarriage and are referred by the doctors. Eighty percent of her work focuses on palliative care, providing individual, couple and family counselling to HIV-positive patients who do not want to accept their HIV-status.

7.2 Nanna

Nanna, who was also between 25-35 years of age, is a Damara /Nama speaking Namibian Christian woman. She has been employed at a district hospital in Swakopmund for the past 2 years. She had qualified as a social worker and received palliative care training during her undergraduate studies, but she does not practice or specialize as a palliative case social worker. She is employed as a development social worker, who is responsible for the provision of community work, but stationed at the hospital. She did not receive any in-service training or continuous education and training on palliative care, yet she provides therapeutic counselling to patients with life-limiting illnesses (e.g. cancer, HIV and AIDS) who are referred to a social worker by the doctors, but only at the end-of-life. Despite her efforts of conducting holistic assessments (socially, physically, mentally, emotionally and spiritually) on patients and their families, most of the terminally ill cases are being referred to Windhoek for palliative care intervention.

She provides family therapy involving the patients and the family through educative sessions. She sometimes also involves staff members (such as doctors, nurses, general staff and the cleaners) to provide education on different types of social problems.

7.3 Faith

Faith, who was between 25-35 years of age, is a Shona speaking, Zimbabwean Christian woman. She has been employed at a national referral hospital in Namibia for the past 6 years. She had qualified as a social worker, but her undergraduate social work training did not include a palliative care module. She obtained a postgraduate Diploma in palliative care in 2015. At the time of this study, she was the only social worker employed in the Ministry of Health and Social Services in Namibia who obtained a post-graduate qualification in palliative care. She worked as a medical social worker in the oncology ward where she specialized as a palliative care social worker delivering palliative care to patients in the oncology, cardiac dermatology and other specialized units. She worked within the multi-disciplinary team where her duties as a palliative care social worker included providing psychosocial support and counselling to patients and their families diagnosed with a life-limiting illness (in this case mostly cancer). She offered counselling, psychosocial support, conduct group work and community work to these patients and has a keen interest in working with patients with life-limiting illnesses. At the time of writing up this chapter, she resigned from the Ministry of Health and Social Services.

7.4 Selma

Selma, who was between 25-35 years of age, is a Silosi speaking, Namibian Christian woman. She has been employed at a national referral hospital in Windhoek for the past 4 years. She had qualified as a social worker and received palliative care training during her undergraduate studies. She started working as a specialized palliative care social worker at the Spinal Cord Injury Unit.

Upon graduating from university, she went to Sweden where she received in-service training and continuous education on palliative care. She provides psycho-social counselling and support to patients with complete and incomplete spinal cord injuries (such as quadriplegic, paraplegic and tetraplegic) who are physically challenged to take care of themselves. She works within the multi-disciplinary team, providing rehabilitation to these patients from admission over 8 weeks up to 12 weeks' period. She conducts assessments on the patients' social and family backgrounds, and identifies patients' palliative care needs where after she either assists or links them with the necessary resources. She conducts group therapy and educational sessions for the patients in rehabilitation.

7.5 Linda

Linda, who was between 25-35 years of age, is a Silosi speaking, Namibian Christian woman. She has been employed at a national referral hospital in Windhoek for the past 4 years. She had qualified as a social worker and received palliative care training during her undergraduate studies. She did not receive any in-service training or continuous education on palliative care. She started working as a social worker at the Antiretroviral Treatment Unit dealing with HIV-positive patients where she provides them with psycho-social support, counselling and adherence counselling.

7.6 Si

Si, who was 50+ years of age, is a Damara>Nama speaking, Namibian Christian man who had been employed at an intermediary hospital in Windhoek for the past 30+ years. He started working as an Auxiliary Social Welfare Worker in 1986. He, in later years enrolled at the University of Namibia in order to upgrade his qualification as a registered social worker. During his time of undergraduate training, the social work training curriculum did not cover palliative care as a module. Si attended five-days training on palliative care, which he paid himself.

He is employed as a medical social worker in a senior position for the past ten years, where he provides supervision to the junior social workers in the hospital setting. Eighty to ninety percent of Si's work focuses on palliative care where he mostly deals with cancer patients who need to undergo amputations due to cancer or diabetes. He breaks the bad news to patients and their families (on life-limiting diagnoses, such as cancer, diabetes, etc.) in cases where an amputation needs to be done. He provides the patient and the family with counselling and support and continues with bereavement counselling in cases where death and dying occur. His role as a social worker entails facilitating good communication between the medical staff, the families, spiritual counsellors, e.g. pastors and the patients in order to prepare the patients in the process of dealing with grief, loss and pain (physically, emotionally, psychological and or spiritually). Si is actively involved in discharge planning before the patients are discharged by doing assessments and conducting home visits on the social background and circumstances of the patients. He also involves the family in the discharge planning in decision making regarding the care of the patient through health educational sessions.

7.7 Taywa

Taywa was between 25-35 years of age, is a Shona speaking Zimbabwean Christian man who is employed at a district hospital in Gobabis for the past 12 years. He had qualified as a social worker and received palliative care training during his undergraduate studies. He also attended five-days training on palliative care which he paid himself. He is employed as both a hospital and community based social worker due to the shortage of social workers in Namibia. As a hospital social worker, only 40% of his work focusses on providing palliative care to patients with life-limiting illnesses. He deals with patients in need of counselling, adherence counselling (HIV-positive and TB patients). He conducts ward rounds together with the multi-disciplinary team in the hospital and compiles social background reports where needed. He links the patients with their spiritual leaders where spiritual counselling is needed and makes referrals to either internal (occupational therapists, pharmacists, doctors, dieticians, etc.) and external service providers.

He serves on the home-based care forum for patients with life-limiting illnesses and conducts home visits in order to assess patients' palliative care needs and their social circumstances. He provides suicide prevention counselling at the hospital and within the community. In community based social work, he deals with cases on alcohol and substance abuse, domestic violence, family therapy and conducting programmes focusing on the elderly.

7.8 Edward

Edward, who was 50+ years of age, is a Shona speaking Zimbabwean Christian man who has been employed at a district hospital in Gobabis for the past 17 years. He had qualified as a social worker and received palliative care training during his undergraduate studies. Prior to joining the Ministry of Health and Social Services in Namibia, he used to work with a hospice in Zimbabwe, where he as a palliative care social worker visited cancer and HIV-positive patients for assessments and home-based care services. He later on became a training officer at that hospice where he used to train social workers and nurses on palliative care. He joined the Ministry of Health and Social Services in Namibia as a hospital based social worker, but only 20% of his work focusses on palliative care, due to the shortage of social workers in Namibia. He is working as both a hospital and community based social worker with adults, adolescents and children providing counselling and psycho-social support to patients with life-limiting illnesses (e.g. HIV, cancer). In the 20% of the palliative care provision, he provides counselling to patients with life-limiting illness, helping them to accept the diagnoses. He conducts home visits to patients in order to meet and assess them in their environments. In cases where the patient is approaching death, he as the social worker responsible, conducts family conferences in order to explain, prepare and help the family to deal and cope with the death of a loved one. He provides bereavement counselling, adherence counselling, marriage and divorce counselling. He does community awareness raising and education on different social problems such as alcohol and substance abuse, teenage pregnancies, suicide, etc.

7.9 Richard

Richard was between 25-35 years of age. He is a Shona speaking Zimbabwean Christian man who has been employed at a regional training hospital in Keetmanshoop for the past 2 years. He had qualified as a social worker and received palliative care training during his undergraduate studies. He first started working as a volunteer social worker at a non-governmental organization called King's Daughters, an organization rendering rehabilitation services to commercial sex workers and HIV-positive patients in Okuruangava in Windhoek. At this organization he was conducting group work with the sex workers and the HIV-positive patients. He conducted home visits and compiled assessments on their social circumstances, where after he started with community development programmes on counselling and rehabilitation for the HIV-positive commercial sex workers. He joined the Ministry of Health and Social Services as a medical social worker. Most of his cases are referrals from the doctors where he provides counselling, group work, community work and conducting research with patients with different life-limiting illnesses (such as cancer, diabetes, TB, HIV and AIDS). He has never attended any training or continuous education and training on palliative care.

7.10 Charlotte

Charlotte, who was 50+ years of age, is an Afrikaans speaking coloured Namibian Christian woman who has been employed at a regional training hospital in Keetmanshoop. She had qualified as a social worker at the age of 20 years, but her under-graduate social work studies curriculum did not include palliative care training. She started working for the Association of the Handicapped for one year, where after she continued to work for the Roman Catholic Church as a hospital based social worker conducting case work, group work and child development work. She has 24 years of social work practice experience and although she did not receive any undergraduate; in-service training or continuous education in palliative care, a large proportion of her work as a medical social worker at both the Roman Catholic hospital (RCH) and the

Association of the Handicapped focused on the provision of palliative care to patients with life-limiting illnesses. She worked for the RCH for ten years and moved to Namibia Development Trust (NDT) as a Developmental Social Worker, who was responsible for channelling money to non-governmental organizations (NGOs) in order to address social problems caused by apartheid. She left NDT in 1996, where she continued her post-graduate studies in program planning, assessment, management, monitoring and evaluation in the Netherlands. After completion of her post-graduate studies, she returned to Namibia and continued to work for NDT, where after she exited NDT as a development consultant for the government, NGO's and foreign NGOs. At the time this study was conducted, she joined the Ministry of Health and Social Services as a medical social worker for eight months. During her eight months of service as a medical social worker, she had close encounters with diabetic patients who needed to undergo amputations of their limbs. She became more aware of the need for palliative care social work, as a crucial practice in addressing the palliative care needs of patients with life-limiting illnesses, their families and the caregivers. She became actively involved in the delivery of palliative care social work, where she conducts home visits; assesses patients living circumstances; calls family conferences; breaking bad news to the patient and the family. For example, in a case where a patient has to undergo an amputation, she prepares the patients and the family to accept a life-limiting condition and then encourages them to make the necessary lifestyle adjustments. She links patients with the necessary resources, for example, in cases where patients need artificial limbs, walking aids or hearing aids, etc. She conducts community research and identifies resources within the community through the churches to provide in the palliative care needs of the patients. She provides psycho-social counselling to cases referred to the social work office.

7.11 Shaka

Shaka, who was between 25-35 years of age, is a Shona speaking Zimbabwean Christian man who has been employed at a regional training hospital in Keetmanshoop for the past 4 years.

He had qualified as a social worker and works in a hospital setting. His under-graduate social work training did not include palliative care training and in his four years of service as a hospital based social worker, he never received an opportunity to attend any in-service training or continuous education on palliative care. This limited his abilities and competencies to deliver quality care to patients with life-limiting illnesses. Shaka states, *“although palliative care is such a crucial component in care provision, there is no specific portion of my work that focusses specifically on palliative care. This I attributes to the fact that palliative care social work has not been institutionalized within the Ministry of Health and Social Services in Namibia as a specialized practice. Palliative care social work is not emphasized to the district medical social workers, although there are personal attempts. I find it challenging to deliver palliative care to patients with life-limiting illnesses, because as a hospital-based social worker within the Ministry of Health and Social Services, I did not receive any targeted in-service training or continuous education on palliative care”*. He does not work as a specialized palliative care social worker however he is responsible for providing social work counselling and psychosocial support to the clients in general. He is responsible for planning, organizing and implementing community based activities in relation to social problems, such as alcohol and substance abuse, suicide prevention, marriage and divorce counselling, parenting services within the hospital setting. He provides counselling to HIV-positive patients, TB and cancer patients.

7.12 Gift

Gift, who was between 25-35 years of age, is an Oshiwambo speaking Namibian Christian woman who had been employed at an intermediary hospital in Oshakati for the past 2 years. She had qualified as a social worker, and received palliative care training during her undergraduate studies. She specializes as a palliative care social worker working with patients diagnosed with stage 4 cancer and HIV and AIDS. Gift conducts holistic assessments, looking at the patient in totally (physically, emotionally, mentally, culturally and spiritually). She provides counselling, bereavement counselling, psychosocial support and family therapy to patients and their families facing social problems.

She assesses patients' social circumstances and then links them with the needed resources. She conducts entrepreneurship skills training on basket making and vegetable gardening for mothers of patients with life-limiting illnesses, for example, babies born with the clubfoot condition. The entrepreneurship skills training on basket making and vegetable gardening equip the mothers of these babies with income-generating business skills. The mothers sell the baskets and vegetables to the palliative care multi-disciplinary team of the hospital in order to generate funds to provide formula milk to their babies. She provides bereavement counselling, for example, to mothers who gave birth to severely macerated babies and to mothers whose babies are not born alive. She serves as a broker, linking patients with resources in order to provide in their palliative care needs. For example, in cases of poverty where the patient is on antiretroviral treatment and the patient does not have food at home, this implicates that the person will not be able to adhere to his or her medication. In these cases she links the patients with the office of the regional council to qualify for food parcels. Her services as a social worker also entail adherence counselling and incorporate patient and family health education sessions.

7.13 Lucky

Lucky, who was between 25-35 years of age, is an Oshiwambo speaking, Namibian Christian woman who has been employed at an intermediary hospital Oshakati for the past 6 years. She had qualified as a palliative care social worker, but her undergraduate studies did not include palliative care training, and she never attended any in-service training or continuous education on palliative care. However, she provides acceptance counselling and psychosocial counselling to in-patients with life-limiting illness (e.g. HIV) who are referred by the doctors from the out-patients department.

7.14 Shane

Shane, who was between 25-35 years of age, is an Oshiwambo speaking, Namibian Christian woman who has been employed at an intermediary hospital in Oshakati for

the past 3 years. She had qualified as a social worker and received palliative care training during her undergraduate studies. She did not receive any in-service training or continuous education on palliative care during her 3 years of services. She started working as a specialized palliative care social worker where she provides palliative care services to patients who are coming to the hospital and referred by the doctors. She involves herself in case work, for example, in most of the cases the patient comes alone to the hospital and then she provides counselling to the patient. When she realizes that the services need to be extended, she sometimes calls in the family so that she can also interview or provide them with counselling or information on how to take care of a patient. Since she is based at the hospital, she also provides information on alcohol and drug abuse prevention and healthy living to pregnant mothers who come for antenatal care, especially at primary health care. She serves as an active member on the commemoration of international health days. A big portion of her work focusses on palliative care provision to patients involved in motor vehicle accidents (MVA), becoming paraplegics.

7.15 Aardvark

Aardvark, who was between 25-35 years of age, is a Damara>Nama speaking, Namibian Christian woman who has been employed at a district hospital in Swakopmund for the past 6 years. She had qualified as a social worker, but palliative care was not part of the undergraduate social work curriculum. She works as a Developmental social worker within both the hospital and the community due to the shortage of social workers in the country. Although she did not receive specialized palliative care training during her undergraduate training as a social worker, she received in-service training on psycho-social support for persons with HIV and AIDS. She provides counselling to patients with chronic hypertension, adherence counselling to HIV and TB defaulting cases and trauma counselling to attempted suicidal cases. A big proportion of her caseload consists of the prevention of marital problems, substance abuse and suicide therefore a lot of attention and time is dedicated to marriage counselling, substance abuse

rehabilitation and suicide prevention. She also attends managerial meetings and conducts staff wellness programmes.

7.16 Kay

Kay, who was between 25-35 years of age, is a Silosi speaking, Namibian Christian woman who has been employed at a national referral hospital in Windhoek for the past 2 years. She had qualified as a social worker, and received palliative care training during her undergraduate studies. She started working as a specialized palliative care social worker in the cardiac unit. She is dealing with the reclassification of patients from private to becoming State patients. This is mostly done for patients who suffer from a life-limiting condition, for example, cardiac arrest or cancer and who require extensive treatment. She reclassifies these patients in order for the government of Namibia to assist them in covering their medical expenses, without exhausting their medical aids. She practices group work interventions, for example, where she provides pre – operation counselling, preparing the patients for an operation. She provides post-operation counselling in order to follow up with patients on their well-being and the recovery process. She also offers family therapy in a case, for example, where a person is hit by a stroke and may stay in the hospital for a long time she calls in the family members for counselling. In the case where the family members are from the regions, she as the social worker arranges free transport for the family members to come see the patient. She, together with the doctors, then explains to the patient’s family members the condition of the patient. After the doctors have done their part, she then provides family therapy to the patient and the family. She is also involved in community work, whereby she solicits donations, for example second hand clothes for the patients who stay in the hospital for longer periods. One of the major cases she deals with is to assist parents to obtain national identification and travelling documents in cases where, for example, a baby has to travel to Cape Town, South Africa for treatment. As a member of the multi-disciplinary team, she also participates in the outreach programme to patients conducted by the cardiac team. She also facilitates educational information sessions and distributes information on different heart conditions.

7.17 Alice

Alice, who was between 25-35 years of age, is a Damara>Nama speaking, Namibian Christian woman who has been employed at an intermediary hospital in Oshakati for the past 2 years. She had qualified as a social worker, but she was not present by the time palliative care as a module was presented as part of the undergraduate social work curriculum. She works as a specialized palliative care social worker. In her two years of service, she has been attached to the medical ward, and works mostly with patients with life-limiting illnesses and their families. The scope of her practice covers generally the in-patients that are admitted. Alice gives one-on-one therapeutic counselling; family therapy and do discharge planning in order to ensure that the patients who are discharged in the care of the family, are well taken care of. She provides a lot of psycho-social support, conducts assessments, and makes referrals to external sources regarding the aftercare of the patients. She conducts information-sharing sessions and liaises a lot with the doctors and the nurses on the care of patients. She advocates on behalf of the patient, especially in cases where the patient and his or her family did not get any medical information regarding the patients' medical condition. She focusses on patient's care on a daily basis, but her encounter with patients with life-limiting illnesses, especially regarding palliative care, was when she worked closely with the third year social work students from the University of Namibia during their palliative care clinical attachments. This was when she had her encounter being actively involved in palliative care provision. Alice emphasizes that *“referrals regarding palliative care from doctors and or nurses are going quite slowly, but I cannot blame the doctors for not referring patients that require palliative care, it is a matter of sensitizing and bringing about awareness to the nurses and the doctors that social workers provide palliative care”*.

7.18 Anna

Anna, who was between 25-35 years of age, is an Afrikaans speaking, coloured Namibian Christian woman who has been employed at an intermediary hospital in

Windhoek for the past 4 years. She had qualified as a social worker, and received palliative care education and training during her undergraduate studies. She did not receive any in-service training or continuous education on palliative care and thus does not specialize as a palliative care social worker. However, she works as a medical social worker, who most of the times provides counselling and psychosocial support; conducts assessments on gathering social background information on the patient and the family where she investigates what might be the reasons behind them being admitted and causing them to be treated in the hospital. She refers the patient to the designated palliative care social worker who is a member of the multi-disciplinary team. The designated palliative care social worker then works in close collaboration with the doctors and the nurses upon admission and diagnosis of a patient with a life-limiting illness. Anna states that *“when the doctors find that according to the prognoses of the patients there is actually not much that can be done for the patients, besides treatment, then the social worker is informed or referral is given to the designated palliative care social worker in order to break the bad news to the patient and the family. In such a case the role of the social worker will then be to prepare the patient, explain to the patient and the family about the life-limiting illness or condition and also to link the patient with any other home-based care services in the community, depending on how far the doctors see the patient’s life-limiting illness progressed”*.

7.19 Abel

Abel, who was 50+ years of age, is a Damara>Nama speaking, Namibian Christian man who has been employed at an intermediary hospital in Windhoek for the past 32 years. He had been trained as an Auxiliary Social Welfare worker who did not receive any undergraduate palliative care training or any in-service or continuous education on palliative care. Abel in later years qualified as a social worker from the University of Namibia. He works at the TB ward providing care to the TB patients, where he is responsible for conducting health surveys and home visits to encourage the TB patients’ family members to come and visit the patients in the hospital.

He also assists patients from Angola in the renewal of their passports and medical visas in order for them to receive medical treatment. He also assists multi-drug-resistant (MDR) TB patients who are bedridden in their applications for a disability social grant.

7.20 Ashley

Ashley, who was between 36-44 years of age, is a Shona speaking, Zimbabwean Christian woman who has been employed at a national referral hospital in Windhoek for the past 2 ½ years. She had qualified as a palliative care social worker, but does not practice as specialized palliative care social worker. Most of the cases she deals with are mainly outpatients, who are coming in from home and are being seen by the doctor on a one-day basis and then they go back home. She provides basic counselling to outpatients, diabetic patients, and epileptic patients and in some instances, people who are infected with HIV and attempted suicidal cases. In the cases of the diabetic and HIV-positive patients, she provides more adherence-counselling, because most of them would have defaulted and then the doctors refer them to the social worker to encourage these patients to adhere to the doctor's orders. She conducts home visits and assessments, for example, she assists in cases where a patient needs a wheel chair.

APPENDIX 8: SUMMARY OF THE DEMOGRAPHICS OF THE PARTICIPANTS

Social categories	Demographics	N = Total
Age	Broad age category	25-60
	Average age	41.6
Ethnicity	Damara Nama	6
	Shona	6
	Oshiwambo	3
	Silosi	3
	Coloured	2
Sex	Females	14
	Males	6
Years as social worker	Estimate average years	2-32
	Average years	6.25
Type of hospitals	District Hospital	5
	National Referral Hospital	4
	Intermediary Hospital	8
	Training Hospitals	3
Religious beliefs	Charismatic Christian	6
	Catholic	5
	Adventist	4
	Lutheran	3
	Methodist	1
	Anglican	1

**APPENDIX 9: SUMMARIZED CHARACTERISTICS OF THE
PARTICIPANTS**

No	Pseudonym	Age	Ethnicity	Sex	Religious Belief	Work Exp.	Place	Type of Hospital
1	Catherine	25-35	Damara>Nama (Nam)	F	Christian	2	Swakopmund	District hospital
2	Nanna	25-35	Damara>Nama (Nam)	F	Christian	2	Swakopmund	District hospital
3	Faith	25-35	Shona (Zimbabwean)	F	Christian	6	Windhoek	National Referral (Windhoek Central Hospital)
4	Selma	25-35	Silosi (Nam)	F	7 th Day Adventist	4	Windhoek	National Referral (Windhoek Central Hospital)
5	Linda	25-35	Silosi (Nam)	F	7 th Day Adventist	4	Windhoek	National Referral (Windhoek Central Hospital)
6	Si	50+	Damara>Nama (Nam)	M	Christian	30+	Windhoek	Katutura Intermediary Hospital
7	Taywa	25-35	Shona (Zimbabwean)	M	Christian	12	Gobabis	District hospital
8	Edward	50+	Shona (Zimbabwean)	M	Roman Catholic	17	Gobabis	District hospital
9	Richard	25-35	Shona (Zimbabwean)	M	Christian	2	Keetmanshoop	Regional Training Hospital

10	Charlotte	50+	Coloured (Nam)	F	Roman Catholic	24	Keetmanshoop	Regional Training Hospital
11	Shaka	25- 35	Shona (Zimbabwean)	M	Anglican	4	Keetmanshoop	Regional Training Hospital
12	Gift	25- 35	Oshiwambo (Nam)	F	Evangelic Lutheran	2	Oshakati	Intermediary hospital
13	Lucky	25- 35	Oshiwambo (Nam)	F	Evangelic Lutheran	6	Oshakati	Intermediary hospital
14	Shane	25- 35	Oshiwambo (Nam)	F	Roman Catholic	3	Oshakati	Intermediary hospital
15	Aardvark	25- 35	Damara>Nama (Nam)	F	Roman Catholic	6	Swakopmund	District hospital
16	Kay	25- 35	Silosi (Nam)	F	7 th Day Adventist	2	Windhoek	National Referral (Windhoek Central Hospital)
17	Alice	25- 35	Damara (Nam)	F	African Methodist Epostolic	2	Windhoek	Katutura Intermediary Hospital
18	Anna	25- 35	Coloured (Nam)	F	7 th Day Adventist	4	Windhoek	Katutura Intermediary Hospital
19	Abel	50+	Damara (Nam)	M	Evangelical Lutheran	32	Windhoek	Katutura Intermediary Hospital
20	Ashley	36- 44	Shona (Zimbabwean)	F	Roman Catholic	2 ½	Windhoek	Katutura Intermediary Hospital