

**FACTORS ASSOCIATED WITH HEALTH SEEKING BEHAVIOUR OF PULMONARY
TUBERCULOSIS PATIENTS IN BUTALEJA DISTRICT IN UGANDA**

by

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submitted in accordance with the requirements

for the degree of

MASTER OF PUBLIC HEALTH

at the

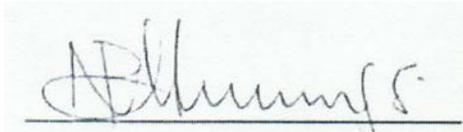
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I declare that **FACTORS ASSOCIATED WITH HEALTH SEEKING BEHAVIOUR OF PULMONARY TUBERCULOSIS PATIENTS IN BUTALEJA DISTRICT IN UGANDA** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

A handwritten signature in black ink on a light blue background. The signature is cursive and appears to read 'PN Mujasi'.

SIGNATURE

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FACTORS ASSOCIATED WITH HEALTH SEEKING BEHAVIOUR OF PULMONARY TUBERCULOSIS PATIENTS IN BUTALEJA DISTRICT IN UGANDA

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ABSTRACT

Pulmonary Tuberculosis (TB) is a significant cause of morbidity in Uganda. TB control in the Ugandan district of Butaleja remains poor, characterised by TB case detection and cure rates below national targets. A qualitative exploratory and descriptive study was conducted to identify factors associated with health-seeking behaviour of TB patients in Butaleja district; with an aim to present recommendations for promoting positive health-seeking behaviour amongst the patients. Data was collected through individual in-depth interviews with seven diagnosed TB patients and analysed using Creswell's (2009:186) analytic spiral steps. The findings revealed three major themes, namely; the nature of health-seeking behaviour, factors associated with the health-seeking behaviour and advice to others experiencing similar symptoms. The health-seeking behaviour of participants was generally poor, characterised by delay in seeking proper medical treatment for TB. Health system, individual and social factors contributed to poor health-seeking behaviour among the participants. The study recommends health system and community interventions targeted at individuals to improve health-seeking behaviour for Pulmonary TB.

Key concepts: Butaleja district; diagnosed Tuberculosis patients; health-seeking behaviour; pulmonary Tuberculosis

ACKNOWLEDGEMENTS

I want to thank the following persons for their respective contributions to this dissertation:

- My wife, Pauline Mujasi, for her unconditional love, support and encouragement.
- A special thank you to my supervisor, Dr MC Matlakala, for her guidance, support and encouragement.
- My colleagues in the MPH course, especially D Mwima Gerald, for their support, help and encouragement.
- The late Dr Kanan Mweru, the former District Health Officer, Butaleja district, for his support and help in making the data collection for this study possible.
- The Butaleja District Health Office, for granting me permission to conduct the study.
- The staff of Nabiganda health centre, especially Mr Moses Wabala, for helping with organising the data collection interviews.
- My colleague and good friend, D Kenneth Ofosu-Barko, for providing me with the support needed to acquire the required research text books to assist me plan and execute the study.
- The participants in the study who were all too willing to participate in the study and freely shared their experiences.
- M Pauline Kalule Nabunya, for editing the manuscript.

Dedication

To my wife Mrs Pauline Mujasi

To my dear parents, Mr & Mrs Mwima

TABLE OF CONTENTS

CHAPTER 1

ORIENTATION OF THE STUDY

1.1	INTRODUCTION.....	1
1.3	RESEARCH PROBLEM	3
1.4	PURPOSE AND OBJECTIVES OF THE STUDY	6
1.4.1	Research purpose	6
1.4.2	Research objectives	6
1.5	FOUNDATIONS OF THE STUDY	6
1.5.1	Assumptions underlying the study	6
1.5.2	Meta-theoretical assumptions.....	7
1.5.3	Ontological assumptions	8
1.5.4	Methodological assumptions	8
1.6	SIGNIFICANCE OF THE STUDY	9
1.7	DEFINITION OF KEY CONCEPTS	9
1.7.1	Diagnosed TB patients	9
1.7.2	Factors associated	10
1.7.3	Pulmonary Tuberculosis	10
1.7.4	Health-seeking behaviour	10
1.7.5	Treatment compliance	11
1.8	RESEARCH DESIGN AND METHODS.....	11
1.8.1	Setting.....	12
1.8.2	Population and sample	12
1.8.3	Sampling method and sample size	12
1.9	DATA COLLECTION.....	13
1.10	ETHICAL CONSIDERATIONS	13
1.11	DATA ANALYSIS	15

1.12	MEASURES TO ENSURE TRUSTWORTHINESS.....	15
1.13	STRUCTURE OF THE DISSERTATION.....	15
1.14	CONCLUSION	16

CHAPTER 2

LITERATURE REVIEW

2.1	INTRODUCTION.....	17
2.2	TUBERCULOSIS	17
2.2.1	Incidence and prevalence of Tuberculosis.....	17
2.2.2	Risk factors for Tuberculosis	19
2.2.3	Transmission of Tuberculosis	20
2.2.4	Pathological process of Tuberculosis	21
2.2.5	Signs and symptoms of Tuberculosis	23
2.2.6	Diagnosis of Tuberculosis	23
2.2.7	Management of Tuberculosis	25
2.2.7.1	Public prevention strategies	25
2.2.7.2	Tuberculosis prevention in health care settings	26
2.2.7.3	Pharmacological treatment.....	30
2.3	THE RESEARCH CONTEXT	31
2.3.1	Country profile of Uganda.....	31
2.3.1.1	Location and geographical information	31
2.3.1.2	Demographic profile	31
2.3.1.3	The economy of Uganda	32
2.3.2	The rural district of Butaleja.....	33
2.3.2.1	Location and geography of Butaleja	34
2.3.2.2	Demographic information	34
2.3.2.3	Economic information.....	35
2.3.2.4	Burden of disease and health services	35
2.4	THE UGANDA HEALTH CARE SYSTEM.....	35

2.4.1	Central level institutions and functions.....	36
2.4.2	General, regional and national Hospitals	36
2.4.3	District Health Systems	37
2.4.3.1	Health Sub-district Systems (HC IV).....	38
2.4.3.2	Health Centres IIIs, II and Village Health Teams (HC I)	38
2.4.4	Delivery of health services.....	39
2.4.4.1	The Public Health Care Delivery System	39
2.4.4.2	The Private Sector Health Care Delivery System	40
2.4.5	Burden of disease in Uganda	41
2.5	TUBERCULOSIS AS A PUBLIC HEALTH PROBLEM.....	42
2.5.1	TB as a global public health problem.....	42
2.5.1.1	Global TB mortality.....	42
2.5.1.2	Multi-drug resistant TB	43
2.5.1.3	MDR TB in Uganda	43
2.5.2	TB control in Uganda.....	43
2.5.2.1	The Directly Observed Treatment Short-course (DOTS) Strategy	44
2.5.2.2	Goals and performance of the national TB and Leprosy programme	45
2.6	HEALTH-SEEKING BEHAVIOUR	46
2.6.1	Definition of health-seeking behaviour	46
2.6.2	Health-seeking behaviour theories and models	47
2.6.2.1	The Health Belief Model (HBM)	47
2.6.2.2	The Theory of Planned Behaviour (TPB).....	48
2.6.2.3	The Health Care Utilisation Model	48
2.6.2.4	The “four As” Model.....	49
2.6.2.5	The Pathways Model.....	49
2.6.3	Approaches to studying health-seeking behaviour.....	50
2.6.3.1	Health care seeking behaviour as utilisation of the system.....	50
2.6.3.2	Health-seeking behaviour as the process of illness response.....	51

2.6.4	Methods used in health-seeking behaviour studies	51
2.6.4.1	Household surveys.....	51
2.6.4.2	Facility-based surveys	52
2.6.4.3	Other quantitative studies.....	52
2.6.4.4	Qualitative surveys, ethnographic and narrative studies	52
2.6.4.5	Mixed-methods surveys.....	52
2.6.5	Issues in health-seeking behaviour studies	53
2.7	HEALTH-SEEKING BEHAVIOUR FOR TUBERCULOSIS	53
2.7.1	Causes of delayed TB diagnosis	54
2.7.2	Duration of delayed TB diagnosis.....	54
2.7.3	Impact of delayed TB diagnosis.....	55
2.7.4	The problem of non-compliance to TB treatment.....	55
2.7.5	Causes of non-compliance to TB treatment.....	56
2.7.6	Impact of non-compliance to TB treatment	56
2.8	CONCLUSION	57

CHAPTER 3

RESEARCH DESIGN AND METHODS

3.1	INTRODUCTION.....	58
3.2	RESEARCH DESIGN.....	58
3.2.1	Qualitative research	58
3.2.2	Exploratory research	59
3.2.3	Descriptive research.....	59
3.3	RESEARCH METHODS.....	60
3.3.1	Population	60
3.3.2	Setting.....	60
3.3.3	Sample and sampling method	61
3.3.4	Eligibility criteria.....	62
3.3.4.1	Inclusion criteria	62

3.3.4.1	Exclusion criteria	62
3.4	DATA COLLECTION.....	62
3.4.1	Data collection method.....	63
3.4.2	Data collection instrument	63
3.4.3	Data collection approach.....	63
3.4.4	Data management.....	64
3.5	DATA ANALYSIS	65
3.6	MEASURES TO ENSURE TRUSTWORTHINESS.....	65
3.6.1	Credibility	66
3.6.2	Dependability	67
3.6.3	Conformability	67
3.6.4	Transferability.....	67
3.7	ETHICAL CONSIDERATIONS	68
3.7.1	Permission to conduct the study.....	68
3.7.2	Maintaining confidentiality and privacy	68
3.7.3	Beneficence	68
3.7.4	Autonomy and respect for persons.....	69
3.7.5	Provision of debriefing, counselling and additional information.....	69
3.7.6	Act on findings and publishing.....	69
3.8	CONCLUSION	69

CHAPTER 4

ANALYSIS, PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

4.1	INTRODUCTION.....	70
4.2	DATA COLLECTION PROCESS.....	70
4.2.1	Challenges encountered during interviews	72
4.3	DATA ANALYSIS AND PRESENTATION	72
4.4	DATA FINDINGS.....	72

4.4.1	Biographical information of the participants	72
4.4.2	Themes and categories	73
4.5	INTERPRETATION OF DATA	73
4.5.1	Theme 1: Nature of health-seeking behaviour	73
4.5.1.1	Category 1.1: Institutions and health providers visited	74
4.5.1.2	Category 1.2: Interventions and treatment received	76
4.5.1.3	Category 1.3: Compliance to treatment	77
4.5.2	Theme 2. Factors associated with the health-seeking behaviour	79
4.5.2.1	Category 2.1: Health system factors	79
4.5.2.2	Category 2.2: Personal factors	82
4.5.2.3	Category 2.3: Social factors	86
4.5.3	Theme 3: Advice to others experiencing similar symptoms	89
4.5.3.1	Category 3.1: Seeking health care	89
4.6	DISCUSSION OF THE FINDINGS	91
4.6.1	Theme 1: Nature of health-seeking behaviour	91
4.6.2	Theme 2: Factors associated with the health-seeking behaviour	93
4.6.3	Theme 3: Advice to others experiencing similar symptoms	95
4.7	CONTEXTUALISATION OF THE RESEARCH FINDINGS WITHIN THE HEALTH BELIEF MODEL	95
4.8	CONCLUSION	96

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1	INTRODUCTION	97
5.2	RESEARCH METHOD AND DESIGN	97
5.3	CONCLUSIONS	98
5.3.1	Nature of health-seeking behaviour	98
5.3.2	Factors associated with health-seeking behaviour	98
5.4	GENERAL CONCLUSIONS	100

5.5	RECOMMENDATIONS	101
5.5.1	Health system level interventions	101
5.5.1.1	Update health workers' skills in TB diagnosis and management.....	101
5.5.1.2	Provide information about health facilities in the district that offer TB services	102
5.5.1.3	Ensure an un-interrupted supply of TB medicines	102
5.5.1.4	Strengthen the ability of private providers to identify and refer potential TB patients .	102
5.5.1.5	Establish partnerships between the government health facilities and the private sector for management of pulmonary Tuberculosis	103
5.5.2	Community level interventions.....	103
5.5.2.1	Design and implement a comprehensive community based health education programme to improve community attitudes on pulmonary Tuberculosis.....	103
5.5.2.2	Strengthen community based DOTS especially use of treatment supporters to improve treatment adherence.....	104
5.5.3	Individual level Interventions	104
5.5.3.1	Improve individual knowledge about pulmonary Tuberculosis	104
5.5.3.2	Provide adequate counselling to individuals diagnosed with pulmonary Tuberculosis	105
5.5.4	Recommendations for further research	105
5.6	CONTRIBUTIONS OF THE STUDY	105
5.7	LIMITATIONS OF THE STUDY	106
5.8	CONCLUDING REMARKS.....	106
	LIST OF SOURCES.....	Error! Bookmark not defined.

LIST OF FIGURES

Figure 2.1: Map of Uganda, showing Study area.....	33
Figure 2.2: Trends in NTLP performance 1999-2010	45
Figure 3.1: Map of study area	61

LIST OF TABLES

Table 1.1: Quarterly performance (Case Detection Rate) of the Tuberculosis Programme in Butaleja district, 2008-2011.....	5
Table 4.1: Summary of findings using classification by theme and category	73

LIST OF ABBREVIATIONS

ACSM	Advocacy, communication and social mobilisation
AFB	Acid Fast Bacillus
AIDS	Acquired Immunodeficiency Syndrome
BCG	Bacillus Calmette-Guérin
CB-DOTS	Community Based Directly Observed Treatment Short course
CDR	Case Detection Rate
CVs	Community volunteers
DOTS	Directly Observed Treatment Short Course
GDP	Gross Domestic Product
HBM	Health Belief Model
HC	Health Centre
HIV	Human Immunodeficiency Virus
HSD	Health Sub district
ICD	International Classification of Diseases
ICN	International Council of Nurses
IMR	Infant Mortality Rate
IUATLD	International Union Against Tuberculosis and Lung Disease
KAP	Knowledge Attitude and Practices
MDGs	Millennium Development Goals
MDR-TB	Multi Drug Resistant Tuberculosis
MOH	Ministry of Health
MOLG	Ministry of Local Government
NCD	Non Communicable Disease
NRH	National Referral Hospital
NTLP	National TB and Leprosy Programme
OPD	Out Patient Department
PHP	Private Health Practitioners

PNFP	Private Not for Profit
RRH	Regional Referral Hospitals
SCHWs	Sub county health workers
STD	Sexually Transmitted Disease
TB	Tuberculosis
TCMP	Traditional and Complementary Medicine Practitioners
TPB	Theory of Planned Behaviour
TRA	Theory of Reasoned Action
TSR	Treatment Success Rate
UAC	Uganda AIDS Commission
UBOS	Uganda Bureau of Statistics
UNHRO	Uganda National Health Research Organisation
Unisa	University of South Africa
VHT	Village Health Teams
WHO	World Health Organization
XDR-TB	Extensively drug-resistant Tuberculosis

LIST OF ANNEXURES

Annexure A	Approval from the University
Annexure B	Approval from the Uganda Council of Science and Technology
Annexure C	Letter seeking consent from the Butaleja District Health Office and Approval
Annexure D	Participant consent form
Annexure E	Interview schedule

CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

According to the World Health Organization (WHO), globally in 2009, there were an estimated 14 million prevalent cases of Tuberculosis (TB); 9.4 million incident cases and an estimated 1.3 million deaths due to TB. Uganda is one of the 22 high TB burdened countries. These countries together accounted for 81% of all estimated TB cases worldwide in 2009 (WHO 2010a:5).

Tuberculosis is a major cause of morbidity and mortality in Uganda. According to the Ministry of Health of Uganda (MOH), TB was among the top five causes of hospital deaths in Uganda during the period July 2010 to June 2011; accounting for 3.9% of all reported deaths. The other causes were Malaria (20%) AIDS (9.4%); Pneumonia (7.8%) and Anaemia (7.5%) (MOH 2011:9). According to the WHO (2010a:72), 9,400 people (range 4,000-18,000) are estimated to have died of TB in Uganda in 2009.

The number of reported TB cases in Uganda is increasing as indicated in the MOH 2010/2011 annual health sector performance report. According to the report, during the period July 2010 to June 2011, a total of 45,546 TB cases were notified to the MOH; a 5% increase from 43,335 cases that were notified to MOH in the same period from July 2009 to June 2010 (MOH 2011:14).

The Global Stop TB strategy was launched in 2006 with the goal of reducing the global burden of TB by 50% (compared to the 1990 baseline) by 2015 in line with the Millennium Development Goals (MDGs) and the Stop TB Partnership targets. Prior to that, in 1994 the internationally recommended TB control strategy, later named Directly Observed Treatment Short course (DOTS) was launched (WHO 1994).

Uganda adopted Community Based-TB care which includes offering every TB patient DOTS by a community volunteer (CB-DOTS) as a national policy in 2000. The CB-

DOTS strategy was aimed at achieving the national and global targets for TB control, namely, a detection of 70% of new smear positive cases; meaning 70% case detection rate (CDR) and cure of 85% of such cases; that is, 85% treatment success rate (TSR). However, reports from MOH indicate that Uganda is yet to achieve these targets.

1.2 BACKGROUND TO THE STUDY

According to Buregyeya, Kulane, Colebunders, Waija, Kiguli, Mayanja, Musoke, Pariyo and Mitchell (2011:938), TB patients in Uganda are perceived to seek care at a late of the disease process or to avoid care. In their study, Buregyeya et al (2011:940) found that combining care from traditional healers and biomedical system was common; and that the length of TB treatment negatively affected health-seeking behaviour.

The MOH in Uganda established a National Tuberculosis and Leprosy Control Programme (NTLP) with the mandate of performing the core functions for providing TB and leprosy control services. The NTLP emphasises the Directly Observed Treatment Short course (DOTS) strategy for TB control, with a component of Community Based-TB care. This includes community sensitisation and mobilisation, as well as offering every TB patient DOTS by community volunteers. This approach is also referred to as CB-DOTS (MOH 2010a:12-13).

The current goals of the Uganda MOH for TB control are to achieve 85% treatment success rate (TSR) and 70% case detection rate (CDR), these being the global targets (MOH 2010a:71). For these targets to be met, the WHO recommends that countries pursue high quality DOTS expansion and enhancement (WHO 2006a:6). In line with this recommendation, decentralised TB care, called CB-DOTS has been expanded to all districts in Uganda (MOH 2010b:70).

Uganda still falls short of attaining the global TB targets. Over the past 10 years, the case detection rate (CDR) has generally stagnated around 50% while the treatment success rate (TSR) has shown an increase from about 50% to 70%. In 2010, the CDR declined to 53.9% from 55.9% in 2009. The TSR improved from 67.3% in 2009 to 70.3% in 2010. These rates are below Uganda's (and global) targets of 70% CDR and 85% TSR.

The Banyole, a Bantu tribe, whose language is called Lunyole are the predominant ethnicity in Butaleja district, accounting to 85%. Just like most tribes in Uganda, the Banyole have an indigenous health care system which involves use of herbs and consultation of traditional healers for various health problems (Whyte 1997:98). However, as the Banyole is a small tribe, there is limited knowledge about their practices with regard to health-seeking behaviour in relation to the treatment of TB.

According to Mosby's Medical Dictionary (2009), health-seeking behaviours are personal actions to promote optimal wellness, recovery, and rehabilitation. There are several factors which affect the health-seeking behaviour of TB patients, which include amongst others fear of stigma, long term treatment and inability to access TB health care services. The barriers to people in rural areas to access health care could be cultural barriers, lack of health facilities or even lack of transport. Wentzel and Voce (2012:78) indicate that these barriers could delay seeking health care, reaching health facilities or even receiving adequate health care.

1.3 RESEARCH PROBLEM

A research problem is a situation in need of a solution, improvement or alteration; a discrepancy between the way things are and the way they ought to be. It is an area of concern where there is a gap in the knowledge base needed for professional practice (Burns & Grove 2005:70; Polit & Beck 2008:765). These problematic situations stimulate research. Pulmonary TB is a significant cause of morbidity in Uganda. Whereas efforts have been made to control TB through the CB-DOTS strategy that involves communities in the care for TB patients, success still remains limited in achieving national case detection and cure rates.

The 2010 WHO Global TB Report ranked Uganda 16th among the 22 TB high burden countries. The WHO estimates that in 2009, there were an estimated 96 000 (range 78 000 to 120 000) incident cases of TB in Uganda. This figures are equivalent to 293 cases (range 238 to 353) per 100 000 population. More than half, which is about 56% (range 39% to 73%) of these incident cases are estimated to have been HIV positive (WHO 2010a:76). The WHO further estimates that in Uganda, there were an estimated 91 000 prevalent cases (range, 39 000-170 000) of TB in 2009 equivalent to 277 (range 119-527) cases per 100 000 population (WHO 2010a:72).

According to the WHO, in 2009, a total of 41,703 new and relapse TB cases were notified in Uganda. Of these cases, 40,321 cases (97%) were new cases and 1,382 (3%) were relapses (WHO 2010a:76). Of the new cases, 35,428 cases (88%) were pulmonary TB cases and the remaining 4,893 (12%) were extra pulmonary TB cases. Of the pulmonary TB cases, 65% were smear positive and 35% were smear negative (WHO 2010a:80). Among the new smear positive pulmonary cases, 63% of the cases were male while 37% of the cases were female. The male to female ratio was 1.7 (WHO 2010a:93). This statistics, although not scientifically proven, suggests that in Uganda, males are disproportionately more affected by pulmonary TB than women. According to data from the WHO in 2009, 88% of the positive pulmonary new TB cases notified in Uganda were in the economically productive age group of 15 to 54 years (WHO 2010a:93).

The number of reported TB cases in Uganda is increasing, with reports that during the period July 2010 to June 2011, a total of 45,546 TB cases were notified to the MOH. This is a 5% increase from 43,335 cases that were notified to MOH in the same period from July 2009 to June 2010 (MOH 2011). A number of factors may be fuelling this increase, including the high prevalence of HIV and AIDS in the country, the country's poor health infrastructure and hospital coverage, a lack of awareness of the disease among the public, and poor sanitation in the slum areas of urban centres, where most cases have been recorded (Wasswa 2006:872).

The MOH indicates that in 2010, Butaleja achieved a TB cure rate of below 70%; which was below the national average for that year of 77% and below the national target of 85% (MOH 2011:212). Also, Butaleja district has consistently had a low case detection rate, far below the national target of 70%. The number of treatment defaulters has also increased over the years. Table 1.1 below summarises performance of the TB control programme in Butaleja district for the period 2008-2011.

Table 1.1: Quarterly performance (case detection rate) of the Tuberculosis programme in Butaleja district, 2008-2011

Year	Estimated total district population	Estimated # of new cases to be detected	Number of new cases detected				Total annual new cases detected	Case detection rate
			Jan-Mar	Apr-June	Jul-Sept	Oct-Dec		
2008	191,400	249	14	32	29	19	94	38%
2009	197,700	254	0	12	18	14	44	17%
2010	204,300	266	10	18	11	11	50	19%
2011	211,120	274	24	25	29	26	104	38%

(Extracted from Butaleja District Health Data Bank 2011)

It can be deduced from the statistics in table 1.1 that performance of the TB control programme in Butaleja district is poor and is characterised by a low case detection rate below the national target of 70%. Factors contributing to the poor performance of the TB programme in Butaleja could include delayed diagnosis of TB; which could contribute to the low case detection rate and non-compliance to TB treatment; thus leading to the low treatment success rate and an increased number of defaulters.

Delayed TB diagnosis leads to delayed initiation of treatment and consequently a prolonged period of infectivity in the community (Harling, Ehrlich & Myer 2008:493). The adverse effects of delayed TB diagnosis and poor compliance with treatment by TB patients underscore the importance of health workers to acquire a comprehensive and holistic understanding of barriers to, and facilitators of proper TB treatment by patients in terms of seeking early diagnosis and complying with treatment (Weiguo, Wei, Yang, Limei, Hongbing & Jianming 2009:169).

There is limited knowledge among health professionals, of the health-seeking behaviours of pulmonary TB patients in Butaleja district, and the factors that are associated with their health-seeking behaviour. This results in health professionals not understanding the low utilisation of the established health care system for early TB

diagnosis. This led to the question of whether there are specific factors affecting the health-seeking behaviour of the Banyole tribe, amongst patients diagnosed with TB in Butaleja district, Uganda.

1.4 PURPOSE AND OBJECTIVES OF THE STUDY

1.4.1 Research purpose

The purpose of this study was to identify the factors associated with health-seeking behaviour of TB patients in the Butaleja district of Uganda, with an aim to develop recommendations to promote positive health-seeking behaviour amongst TB patients.

1.4.2 Research objectives

The objectives of the study were to

- explore the health-seeking behaviour of the pulmonary TB patients in Butaleja district
- describe the factors that influence the health-seeking behaviour of patients diagnosed with pulmonary TB
- provide recommendations for promoting positive health-seeking behaviour amongst patients diagnosed with TB

1.5 FOUNDATIONS OF THE STUDY

The philosophical foundation underlying this study was naturalistic, interpretive and humanistic; and was concerned with the understanding of the meaning of social interactions by those involved; that is, TB patients.

1.5.1 Assumptions underlying the study

Assumptions are basic principles that are accepted as true on the basis of logic or reasoning without proof or verification (Polit & Beck 2008:528). In research, the assumptions are embedded in the philosophical base of the framework or study. These assumptions influence the development and implementation of the research process.

Their recognition leads to the development of a more rigorous study (Burns & Grove 2007:146).

Assumptions are not intended to be empirically tested, but are underlying propositions, which can be challenged meta-theoretically. With regard to paradigmatic assumptions, the process of research, principles and ideas which researchers base their procedures on is referred to as the methodological assumptions. Creswell (2009:5) suggests some fundamental interrelated questions that the inquirer should ask in order to understand the assumptions of each paradigm. These questions are:

- What is the nature of reality?
- How can the researcher go about finding out whatever he/she believes can be known?

Within the context of this study, the researcher selected certain assumptions from the naturalistic perspective in response to his interaction with the phenomenon, in order to answer the questions indicated. These assumptions included the meta-theoretical, ontological and methodological assumptions.

1.5.2 Meta-theoretical assumptions

The term “meta-theory” refers to critical reflection on the nature of scientific inquiry. Meta-theoretical reflection typically addresses issues such as the nature and the structure of scientific theories, the nature of scientific growth, the meaning of truth, explanations and objectivity (Mouton 2008:104). Meta-theoretical assumptions are interrelated sets of concepts, beliefs, commitments and propositions that constitute the study. Their origin is philosophical in nature, and therefore not meant to be tested. Meta-theoretical assumptions denote commitment to the truth of the theories and laws of a particular paradigm. Creswell (2009:11) postulates that qualitative research focuses on the process occurring as well as the product.

The assumptions that were made about the health-seeking behaviour of TB patients in Butaleja, which are intricately linked to nursing practice, were related to their worldview, prevailing cultural and social structure dimensions and the participants’ environmental context. The assumptions for this study were as follows:

- **Worldview:** the way individual TB patients looked out and understood their world and their perspective about life influenced their health-seeking behaviour.
- **Cultural and social structure dimensions:** the dynamic, holistic and interrelated patterns of the Banyole culture, including religion (or spirituality), kinship, social, political, economic, education, technology, cultural values and philosophy influenced the health-seeking behaviour of Banyole TB patients.
- **Environmental context:** the environment, which includes the physical, geographic and socio-cultural situations and experiences of Banyole people guided their behaviour and decisions regarding seeking health for TB.

1.5.3 Ontological assumptions

The ontological assumptions deal with the nature of reality as an object of inquiry. According to the naturalistic philosophy, truth or reality is both dynamic and complex. Reality is multiple and subjective, mentally constructed by individuals. Humans are perceived to continuously construct, develop and change their everyday interpretations of their worlds in order to make sense of their lives (Burns & Grove 2005:14).

The reality in this study was the health-seeking behaviour of pulmonary TB patients. The ontological assumption was that individual realities are subjectively constructed and are self created. The realities were the experiences and health-seeking behaviour of the individual TB patients including the factors that influenced this behaviour. In this regard it could be assumed that the reality of health-seeking for pulmonary TB could only be understood within the context of the experiences of each participant.

1.5.4 Methodological assumptions

The methodological assumptions relate to how the inquirer should obtain knowledge (Burns & Grove 2005:13). The naturalistic philosophy relies on a methodological approach concerned with studying the subjective reality from an insider perspective, namely the perspective of the research participants. Qualitative research reports faithfully on these realities and on the voices and interpretations of participants (Creswell 2009:6). Therefore, knowledge is obtained through an inductive process with

emphasis on the entirety of the phenomenon of interest in a holistic way. During the inquiry process, there are emerging interpretations grounded in the participants' experiences.

A flexible study design is used with no control over the context of the study. Emphasis is on narrative information which is analysed qualitatively. Through the study, patterns, and not generalisations are sought. In this study the assumptions were related to the health-seeking behaviour of pulmonary TB patients in Butaleja district. Qualitative data collection and analysis was meant to capture the health-seeking behaviour of individual TB patients and the factors that influenced this behaviour.

1.6 SIGNIFICANCE OF THE STUDY

The findings of this study may contribute towards TB control efforts in the rural district of Butaleja by providing a better understanding and appreciation of the factors associated with health-seeking behaviour for TB. This may help health care planners and providers in designing congruent TB control programmes, including health education that will lead to increased effectiveness of TB control efforts. The recommendations from this study may be used to educate the Banyole tribe on TB and assist them in developing positive and prompt health-seeking behaviour whenever they suspect TB or any other disease.

1.7 DEFINITION OF KEY CONCEPTS

A concept is an abstraction based on observations of behaviours or characteristics (Polit & Beck 2004:714). Concepts are described as general ideas derived or inferred from specific instances or occurrences. The following concepts are defined in the context of this study:

1.7.1 Diagnosed TB patients

According to the Uganda MOH, a diagnosed TB patient is one in who TB has been bacteriologically confirmed through one (1) sputum smear positive or culture; or determined by a clinician (MOH 2010a:23).

For purposes of this study, diagnosed TB patients are those who were confirmed by means of the prescribed diagnostic tests such as sputum microscopy in one of the diagnostic centres in Butaleja district to be infected with the germs that cause TB in their lungs. The patients in this study were those registered at Nabiganda health centre for treatment of pulmonary TB, with sputum smear positive for AFB or sputum smear negative, but chest x-ray suggestive of pulmonary TB.

1.7.2 Factors associated

According to the Oxford Dictionary (2012), the term factor refers to “an event which may be a significant element in the outcome of a larger situation”. The associated factors in this study are those factors that affect the patients’ decision to seek medical care and also the practices, beliefs and knowledge of the patients regarding the treatment of TB.

1.7.3 Pulmonary Tuberculosis

Pulmonary TB refers to a contagious disease caused by Tubercle Bacillus affecting the lungs (WHO 2010b).

1.7.4 Health-seeking behaviour

Health-seeking behaviours are personal actions to promote optimal wellness, recovery, and rehabilitation (Mosby's Medical Dictionary 2009). Thus, health-seeking behaviour entails any course of action by an individual in searching for a condition of soundness of the body, a condition in which the body’s functions are duly and efficiently discharged.

In this study, health-seeking behaviour encompasses the participants’ pathway to utilisation of the formal health system for diagnosis and treatment of pulmonary TB; including the institutions visited, health care providers consulted, diagnostic and treatment process, in addition to use of any other treatments before and during utilisation of the formal health care system.

1.7.5 Treatment compliance

Treatment compliance is the following of a recommended course of treatment by taking all prescribed medications for the length of time necessary (McGraw-Hill Concise Dictionary of Modern Medicine 2002).

For purposes of this study, treatment compliance is the action of a patient with pulmonary TB in accordance with the direction provided by the health care provider regarding application of remedies, medical or surgical applications or services for purposes of curing the pulmonary TB.

1.8 RESEARCH DESIGN AND METHODS

A research design is a blue print for conducting a study that maximises control over the factors that could interfere with the validity of the findings (Burns & Grove 2005:734). It is the overall plan for addressing a research question including specifications for enhancing the study's integrity (Polit & Beck 2008:765). A qualitative exploratory and descriptive study was conducted to identify factors associated with health-seeking behaviour of TB patients in Uganda. The study was carried out in Butaleja district, Eastern Uganda.

Qualitative research is the investigation of phenomena, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a flexible research design (Polit & Beck 2008:765). Qualitative researchers attempt to study human action from the perspective of the social actors themselves. The primary goal is describing and understanding, rather than explaining human behaviour (Babbie & Mouton 2004:53). The purpose of qualitative research is to discover the essences, patterns, symbols, attributes and meanings of human and related phenomena under study with informants in their natural or familiar environments (Leininger & Mc Farland 2002:86).

By utilising a qualitative approach, an attempt was made to understand the health-seeking behaviour of pulmonary TB patients and the factors that influence this behaviour from the subjective perspective of the pulmonary TB patients themselves.

The patient's health-seeking behaviour and the factors influencing this behaviour were explored and described.

1.8.1 Setting

Setting is defined as a quiet environment that provides privacy, is comfortable, non threatening and easily accessible to facilitate the interview process (De Vos, Strydom, Fouché & Delpont 2007:294-295). The setting was the health facility, this being the area where participants first came to learn about their diagnosis of pulmonary TB and where they received their medical treatment.

1.8.2 Population and sample

A population is the entire set of individuals having some common characteristic (Polit & Beck 2008:727). It is defined as a group of target units in a specified area that clearly manifests the condition of concern to the programme (De Vos et al 2007:372). The universal population was pulmonary TB patients in Butaleja district. The target population was pulmonary TB patients attending Nabiganda health centre. The accessible population comprised the individuals who conformed to the eligibility criteria (refer to chapter 3) and were available for this study (Burns & Grove 2005:342).

A sample is a subset of a population, selected to participate in a study (Polit & Beck 2008:731). Sampling is the process of selecting a portion of the population to represent the entire population (Brink, Van Der Walt & Van Rensburg 2011:214). The sample was selected from registered pulmonary TB patients at the Nabiganda health centre who were willing to come to the health centre for the interview or who could be contacted by phone to set up an interview.

1.8.3 Sampling method and sample size

Sampling method refers to the approach used to obtain a sample (Brink et al 2011:134); and a sample size refers to the number included in such a subset of the population and used for the study (Brink et al 2011:141). Convenience sampling was used to select the sample based on established eligibility criteria. Convenience sampling involved the

selection of the most readily available persons as participants in the study (Polit & Beck 2008:715). The researcher chose convenience sampling because it was an easy and economical way of identifying participants. Whereas this may have resulted in a non-representative sample, this was not a concern because the aim of the study was not to generalise findings but to get an in-depth understanding regarding health-seeking behaviour for TB from the selected participants. A total of seven participants were included in the study and the sample size depended on the saturation of information during data collection.

1.9 DATA COLLECTION

Data collection refers to the precise, systematic gathering of information relevant to the research purpose or the specific objectives of a study (Burns & Grove 2005:732). It is the gathering of information to address a research problem. Data may be gathered by a variety of data collection methods which correspond with data sources (Mouton 2008:104).

Unstructured individual interviews were used to collect data. The researcher used unstructured interviews in order to gain a detailed understanding of the participants' health-seeking behaviour and the factors that influenced this behaviour. The method gave both researcher and participants more flexibility. It also enabled the researcher to follow up particular interesting avenues that emerged in the interview; enabling the participants to give more information (De Vos 2007:296). The process of data collection is described in detail in chapter 3.

1.10 ETHICAL CONSIDERATIONS

Research ethics involves protecting the rights of the respondents and the institutions in which research is done, and maintaining scientific integrity (Burns & Grove 2005:181; Polit & Beck 2004:141). Ethical considerations were adhered to by obtaining ethical clearance from the academic institution, by requesting permission to conduct the study from the relevant authorities at the Butaleja district health office and the study site; and by adhering to the ethical principles that guided the researcher. The fundamental ethical principles as outlined by Burns and Grove (2005:180-181) were adhered to as follows, in order to protect the participants in this study:

Permission to conduct the study: Permission to conduct the study was sought from the Higher Degrees Committee of the Department of Health Studies, UNISA, the Uganda Council of Science and Technology and the relevant health authorities responsible for Butaleja district and Nabiganda health centre where the study was conducted (see annexures A, B, and C). Informed consent to participate in the study was also obtained from the individual participants.

Autonomy and respect for persons: Participation in the study was voluntary and the participants were assured that they could withdraw from the study at any time if they so wished, without penalty.

Maintaining confidentiality and privacy: Confidentiality and privacy was ensured by using a password, restricted access computer to store and manage the collected data; and anonymity was guaranteed by assigning interviewees codes instead of using their names.

Beneficence: Beneficence will be ensured by making the research results known to the Butaleja district health office and other interested parties who by gaining a better understanding and appreciation of factors associated with delayed TB diagnosis and non-compliance with treatment may be able to design better interventions to promote positive health-seeking behaviour; thereby benefiting people with TB.

Provision of debriefing, counseling and additional information: Participants were provided with a brief background to the study prior to the commencement of interviews. Any false hopes or expectations that the interview might have caused were respected and talked through to prevent emotional or any other risk.

Act on findings and publishing: The work of others has been acknowledged and negative and positive findings have been reported. The findings of this study will be disseminated in the form of publications in accredited journals and presentation at the relevant gatherings such as conferences and workshops (Katzellenbogen 2007:27-34).

1.11 DATA ANALYSIS

The researcher used a computer analysis software ATLAS/ti 7 to aid in the management of textual data, for storage and retrieval of information more quickly and accurately. Data analysis was done using open coding. The analysis involved breaking up the data into manageable themes, patterns, trends and relationships. The aim of analysis was to understand the various constitutive elements of the collected data through inspection of the relationships between concepts, constructs or variables and to see whether there were any patterns or trends that could be identified or isolated to establish themes in the data (Mouton 2008:108). Content analysis was done to explore in detail for common themes and these were then established into units of meaning or codes (Mouton 2008:198). Data analysis will be described in detail in chapter 3.

1.12 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness refers to the confidence qualitative researchers have in their data. This is assessed using criteria of credibility, transferability, dependability and conformability (Polit & Beck 2008:511). In this study, member checking was done by having the research participants' review, validate and verify the researcher's interpretations and conclusion (Brink et al 2011:124). There was also prolonged engagement with the participants; the researcher invested sufficient time collecting data to have an in depth understanding of the participants under study and to test for misinformation and distortions (Polit & Beck 2008:430). The researcher spent as much time as was necessary interacting with the participants during data collection.

1.13 STRUCTURE OF THE DISSERTATION

Chapter 1: Introduction and overview

Chapter 2: Literature review

Chapter 3: Research design and methods

Chapter 4: Analysis, presentation and description of the research findings

Chapter 5: Conclusions and recommendations

1.14 CONCLUSION

In this chapter the introduction, purpose of the study, research problem, objectives and significance of research was outlined. Key concepts were defined and an overview of research methodology presented. In the next chapter a detailed review of research literature is presented.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

A literature review is a written summary of the state of evidence on a research problem. The purpose of the review is to familiarise the researcher with the scope of the field of study (Polit & Beck 2008:137). This chapter contains the literature review on TB, the research context and health-seeking behaviour. The process of reviewing the literature was undertaken to search for and identify pertinent literature that would add value to and improve the understanding of the phenomenon under study, which was health-seeking behaviour of patients diagnosed with TB. Several sources were consulted, including medical textbooks, medical and research journals, and the WHO policy documents. Sources were obtained from the library and the Internet.

The researcher acknowledges the fact that there are certain criticisms of the usefulness of a literature review in a qualitative study. However, the literature was reviewed to orientate the reader in relation to the context of the phenomenon. The literature review focused on TB, the research context and health-seeking behaviour.

2.2 TUBERCULOSIS

Tuberculosis (TB) is an infectious, communicable disease caused by bacteria called *Mycobacterium Tuberculosis*, which primarily affects the lung parenchyma. As a communicable disease, TB can be transmitted directly or indirectly from one person to another (Smeltzer, Bare, Hinkle & Cheever 2008:643; Van den Berg & Viljoen 2005:111).

2.2.1 Incidence and prevalence of Tuberculosis

Tuberculosis remains a major cause of morbidity and mortality in many countries and a significant public health problem worldwide due to its high incidence. It is estimated that

of all those who are infected with mycobacterium Tuberculosis, about 5% will develop active TB disease within five years of primary infection; the other 95% will develop a latent infection that may later progress to cause disease, depending on the status of the immune system of the individual. The WHO estimates that, on average, one infectious source who does not receive treatment infects 20 others with mycobacterium Tuberculosis over an average period of two years before death. Thus, a population of 100 000 people with 50 new cases of smear-positive TB occurring every year would produce 100 infectious cases in the population at any given time, leading to 1 000 new infections annually, that is, 1% of the population becoming infected every year (WHO 2008c:16-17).

It is further indicated that in the absence of infection with HIV and without anti-TB treatment, about 65% of cases who remain smear-positive will die, most within two years, while only 10-15% of cases who remain smear-negative are expected to die. Even with treatment, more than 10% of patients may die in settings where adherence to treatment is low or where rates of HIV infection or drug resistance are high. In places where treatment is good and HIV is absent, less than 2% of smear-positive patients die while on treatment (WHO 2008c:16-17).

The absolute number of TB cases globally continues to increase slightly from year to year, as slow reductions in incidence rates per capita continue to be outweighed by increases in population. Women account for an estimated 3.3 million cases (range 3.1 million-3.5 million), equivalent to 35% of all cases. Most of the estimated number of cases in 2009 occurred in Asia (55%) and Africa (30%). Smaller proportions of cases occurred in the Eastern Mediterranean Region (7%), the European Region (4%) and the Region of the Americas (3%) (WHO 2010a:5).

The 22 high burden countries among which Uganda is included account for 81% of all estimated cases worldwide. The five countries with the largest number of incident cases in 2009 were India (1.6-2.4 million), China (1.1-1.5 million), South Africa (0.40-0.59 million), Nigeria (0.37-0.55 million) and Indonesia (0.35-0.52 million). India alone accounts for an estimated one fifth (21%) of all TB cases worldwide, and China and India combined account for 35% (WHO 2010a:7).

2.2.2 Risk factors for Tuberculosis

According to literature (WHO 2008c:17, 73, 87; Van den Berg & Viljoen 2005:32; Smeltzer et al 2008:643; Nhlema, Benson, Salaniponi, Theobald, Squire & Kemp 2007:65), there are a number of risk factors associated with development of TB by individuals, including the presence of HIV infection; underlying health conditions such as diabetes mellitus and cancer; close contact with TB infected individuals; age (with the young and elderly being particularly vulnerable); alcoholism and poverty.

HIV infection exacerbates the TB epidemic through its impact on susceptibility to mycobacterium Tuberculosis infections and progression from infection to active disease. HIV infection increases the rate at which mycobacterium infections are acquired and increases the likelihood that people who are already infected will develop active TB disease (WHO 2008b:17).

People suffering from conditions such as diabetes mellitus, cancer, leukaemia or Hodgkin's disease are prone to lowered resistance against infections. Chronic illnesses of the kidney, liver and gastro-intestinal tract lead to a negative nitrogen balance, which in turn leads to lowered resistance, since proteins are necessary for producing leucocytes and antibodies. Chronic neurological illnesses related to taking medication over a long period can also lower a person's resistance and make them susceptible to contracting TB (Van den Berg & Viljoen 2005:32).

Individuals receiving certain medical treatments such as cancer chemotherapy or transplant anti-rejection medication are at risk because corticosteroids suppress the inflammatory reaction as well as the cell-mediated immune response (Van den Berg & Viljoen 2005:32). People who have been in close contact with someone who has infectious TB, including health care practitioners with HIV-associated immune-suppression, are particularly vulnerable to developing TB disease if they become infected with mycobacterium Tuberculosis as a result of the exposure.

Health care practitioners are at a much higher risk of TB infection and disease than the general population, especially if they work in high-risk settings such as TB wards. Laboratories carrying out mycobacterium Tuberculosis culture procedures are also high-

risk areas. Other high-risk settings include institutions such as jails, prisons, detention centres and drug rehabilitation centres (WHO 2008c:73-74). Close contact with someone who has active TB in high-risk setting results in inhalation of airborne nuclei from the infected person that is proportional to the amount of time spent in the same air space, the proximity of the person and the degree of ventilation (Smeltzer et al 2008:643).

Very young children and the elderly are more susceptible to communicable diseases than adults. Young children are susceptible due to the immaturity of their immunological system, which negatively influences the ability of the lymphoid system to react to foreign antigens. The activity of the immune system of an elderly person usually slows down, causing the general resistance of the body to be lowered (Van den Berg & Viljoen 2005:33).

People who are diagnosed with alcohol abuse or are alcohol dependent are particularly at risk of TB disease. This risk increase might be explained by their specific social mixing patterns and living conditions, which lead to an increased risk of infection. These people may have compromised immunity as a result of the toxic effects of the alcohol or medical conditions caused by alcohol (WHO 2008c:87).

Poverty is associated with vulnerability to TB infection and the development of the disease because poor people are likely to live in crowded conditions. Overcrowding poses extensive economic barriers to access to health services due to opportunity and financial costs that are exacerbated by geographical and health system-related barriers to care seeking (Nhlema et al 2007:65). If patients with TB cannot access health services due to financial constraints, this could result in the patient being infectious for a longer period of time than necessary before receiving treatment; and this increases the risk of transmission to close contacts.

2.2.3 Transmission of Tuberculosis

The causative organism of TB is mycobacterium Tuberculosis, which is an acid-fast aerobic rod that grows slowly and is sensitive to heat and ultraviolet light (Smeltzer et al 2008:643). The tubercle bacillus has a capsule composed of waxes and fatty

substances, which makes it more resistant to destruction than many other organisms (Crowley 2004:389). Transmission of tubercle bacilli occurs when a patient who suffers from pulmonary TB coughs and produces droplets in the air containing the bacilli. The liquid in the droplets evaporates leaving the droplet nuclei containing the bacilli. The droplet nuclei are small enough to be inhaled into the lungs and deposited into the alveoli.

Transmission is easier in a closed environment where ventilation is poor. Close contact over a prolonged period with a pulmonary TB sputum smear-positive patient who is not yet on treatment increases the chance of becoming infected with *Mycobacterium Tuberculosis* (MOH 2010a:20). The TB bacilli can live for up to six months in dust after having been coughed up. When the dust is disturbed, for example by sweeping with a broom, the wind blowing or children playing on soil, the infected dust is inhaled by the susceptible person (Van den Berg & Viljoen 2005:266).

Transmission generally occurs indoors, where droplet nuclei can stay in the air for a long time. An infected person releases droplet nuclei that are usually 1 to 5µm in diameter. Larger droplets settle, while smaller droplets remain suspended in the air and are inhaled by a susceptible person. The two main factors that determine an individual's risk of exposure are the concentration of droplet nuclei in contaminated air and the length of time over which the person breathes that air. Droplet nuclei may also be produced in the laboratory where aerosol-producing investigations such as sputum induction and bronchoscopy are conducted. Transmission also occurs through the manipulation of lesions, and the processing of tissues or secretions in the laboratory.

2.2.4 Pathological process of Tuberculosis

TB begins when a susceptible person inhales *mycobacterium Tuberculosis* and becomes infected. The bacteria are transmitted through the airways to the alveoli, where they are deposited and begin to multiply. The body's immune system responds by initiating an inflammatory reaction. Phagocytes (macrophages and neutrophils) engulf many of the bacteria, and TB-specific lymphocytes destroy the bacilli and normal tissue. The tissue reaction results in the accumulation of exudates in the alveoli,

causing bronchopneumonia. The initial infection usually occurs two to ten weeks after exposure (Smeltzer et al 2008:644).

Granulomas, which are new tissue masses of live and dead bacilli surrounded by a protective wall of macrophages, are also formed as part of the pathological process. They are later transformed to a fibrous tissue mass, the central portion of which is called a Ghon tubercle. The material (bacteria and macrophages) becomes necrotic, forming a cheesy mass. This mass may become calcified and form a collagenous scar. At this point, the bacteria become dormant and there is no further progression of active disease (Smeltzer et al 2008:644). As soon as fibrosis (sterilisation of lesions) sets in, recovery takes place. To a great extent the person's health depends on the formation of these lesions (Van den Berg & Viljoen 2005:270).

The following are the different stages of TB:

- *Latent TB*

People who are infected with the TB bacteria do not necessarily develop active TB because the body is able to fight the bacteria to stop them from growing. The bacteria become inactive, but they remain alive in the body and can become active later. This is called latent TB infection. People with latent TB infection have no symptoms of TB and do not feel sick. They do not spread TB to others but may develop TB later (Unite against TB 2009:32). People with latent TB infection usually have positive tuberculin skin tests (International Council of Nurses (ICN) 2008:14).

- *Active TB*

Active TB disease can either develop when a person is first exposed to the TB bacteria, especially if his or her immune system is weak, or it can develop as reactivation disease in people who have been previously infected (Unite against TB 2009:32). With active TB, the Ghon tubercle ulcerates, releasing the cheesy material into the bronchi. The bacteria then become airborne, resulting in further spread of the disease (Smeltzer et al 2008:644).

- *Chronic TB*

Tuberculosis can become chronic when dormant tubercle bacilli persist in tissues after primary infection and start to multiply, often in response to a trigger such as a weakening of the immune system. Unless the process is arrested, it spreads slowly downwards to the hilum of the lungs and later extends to adjacent lobes. The process may be prolonged and is characterised by long remissions when the disease is arrested, followed by periods of renewed activity (Smeltzer et al 2008:644).

2.2.5 Signs and symptoms of Tuberculosis

Tuberculosis presents with a variety of symptoms. Persistent coughing for more than two weeks is the most common symptom of pulmonary TB. Early in the course of the illness, the cough may be non-productive, but subsequently becomes productive. The cough may start out dry but later produces sputum or blood (haemoptysis). Therefore, any patient presenting with a cough of longer than three weeks' duration should be investigated for TB (Van den Berg & Viljoen 2005:272).

Other symptoms include chest pain, which is usually a sharp pleuritic pain although it may also present as a dull ache; and dyspnea (difficulty in breathing) which is a symptom that is caused by the pathology of the disease. Pyrexia (elevated body temperature) is usually present, and may be intermittent or recurring. Anorexia (loss of appetite) and loss of weight are important early signs, and in the progressive stage may lead to emaciation. Night sweats are usually also present as a result of the toxemia that develops (Van den Berg & Viljoen 2005:272). A patient showing these signs and symptoms who is or was in contact with a person with infectious TB, may more likely be suffering from TB.

2.2.6 Diagnosis of Tuberculosis

A complete history, physical examination, tuberculin skin test, chest X-ray, acid-fast bacillus (AFB) smears and sputum culture are used to diagnose TB. During history taking, the patient may reveal contact with someone who suffered from TB disease. The nurse or doctor needs to take a full medical history including the duration of symptoms,

other prevailing medical conditions, previous health-seeking behaviour and the outcomes thereof (ICN 2008:62). A chest X-ray of a person infected with TB may reveal lesions in the upper lobes of the lungs; and the AFB smear contains mycobacterium (Smeltzer et al 2008:645).

The tuberculin test measures the delayed hypersensitivity response to an injection of purified protein derivative by producing a local skin reaction within 48 to 72 hours of being injected into the skin of an infected person. The tuberculin skin test has great diagnostic value as a screening test for TB and can be done on a large scale in children younger than 16 years. A strong positive skin reaction indicates the presence of viable tubercle bacilli in the body. A variety of tuberculin tests are available but the Mantoux test is considered the most reliable (Van den Berg & Viljoen 2005:275).

Radiography of the lungs is frequently performed for screening purposes. Chest radiography is useful to evaluate persons who have negative sputum smears in order to attempt to find evidence for pulmonary TB and to identify other abnormalities that may be responsible for the symptoms. With regard to TB, radiographic examination is most useful when applied as part of a systematic approach in the evaluation of persons whose symptoms and/or findings suggest TB but who have negative sputum smears (WHO 2006b:22).

Sputum specimens are taken for microscopy for rapid diagnosis and culture. Smears are taken to check for acid-fast bacilli. Acid-fast bacteria have a waxy capsule, which is stained with difficulty by means of certain red dyes (Crowley 2004:113). When sputum containing tubercle bacilli is stained with certain dyes and examined under the microscope, the bacilli look red. This is because they are acid-fast, that is, they have kept the dye even after being washed with acid and alcohol (WHO 2004:24). If acid-fast bacilli are seen on microscopy, the specimen should be cultured to confirm the identity of the bacilli (ICN 2008:27). Culture examination is more accurate than microscopy but it takes much longer to obtain results, usually about six weeks (WHO 2006b:22).

2.2.7 Management of Tuberculosis

Management of TB includes preventive measures that are intended to reduce the pool of infected persons and protect people against infection. Management is as follows:

2.2.7.1 Public prevention strategies

According to the Uganda MOH guidelines, public prevention strategies begin at birth. A single dose of the Bacillus Calmette-Guérin (BCG) vaccine should be given to all infants as soon as possible after birth (MOH 2010a:42). BCG is a vaccine that has the ability to stimulate the production of antibodies against TB (ICN 2008:9). Primary cell-mediated immunity is elicited by immunisation with the BCG vaccine. Nurses should educate community members on the importance of BCG immunisation and the early signs and symptoms of TB disease (Van den Berg & Viljoen 2005:280).

Living conditions in private dwellings and in various residential institutions can have an important impact on the transmission of TB. Factors that promote the spread of TB, such as overcrowding and unhygienic conditions, should be eliminated by improving socio-economic conditions. The general standard of living must be improved by means of creating more jobs for people. In addition to this, measures should be implemented to upgrade housing. People living in informal settlements have to be assisted in building their houses so that cross ventilation is prevented (Van den Berg & Viljoen 2005:279).

Aspects which lead to diminished immunity, such as stress, alcoholism and malnutrition, should be addressed through health education. Considerable stigma is attached to the disease and this may interfere with adherence to therapy. The provision of emotional support to patients may increase the likelihood of adherence to therapy. When patients feel stressed, they should seek support. This support could be organised in the form of support groups or one-to-one counseling by trained providers. Informal support can also be provided by physicians, nurses, DOTS supporters and family members (WHO 2006b:90).

While good nutrition increases the general resistance of a person, malnutrition may be linked to an increased risk for TB disease through immune deficiency caused by

deficiencies in protein, energy, vitamins and minerals (WHO 2008b:86). Malnutrition renders the person susceptible to infections. Any shortage of vitamins also lowers the general resistance of a person (Van den Berg & Viljoen 2005:32). It is thus necessary to implement community feeding schemes, encourage breastfeeding and provide health education regarding good nutrition and a balanced diet.

Effective community and patient involvement yields positive results, such as improved case finding and treatment outcomes, raised awareness concerning the nature of the disease and effective utilisation of the available treatment, which is often free of charge. To be successful, community and patient involvement should be designed and implemented with community members involved as equal partners (WHO 2008b:175).

Education about TB is important because having the necessary knowledge can safeguard community members and their families against the threat of TB infection. Such information will motivate those who are considered at risk to participate in TB screening programmes. Nurses are in a good position to educate people, given the broad contacts they have with clients most vulnerable to TB, such as those nurses working in schools with diverse immigrant populations and in emergency-room settings. Avenues for the broad dissemination of health educational information on TB include the media, public health departments, school systems and occupational health offices (Ailinger, Lasus & Margaret 2003:211).

2.2.7.2 Tuberculosis prevention in health care settings

The three levels of TB infection control are workplace and administrative (managerial) control measures, environmental control measures and personal control measures (respiratory protection). Each level operates at a different point in the transmission process and is discussed as follows:

- *Workplace and administrative control measures*

Workplace and administrative control measures have the greatest impact on preventing TB transmission. They serve as the first line of defense for preventing the spread of TB in health care settings. There are five components of good workplace and administrative

control, namely, an infection control plan, administrative support, training of staff, education of patients, and co-ordination and communication with the TB control programme (WHO 2008b:74).

Each facility should have a written TB infection prevention and control plan with a designated infection prevention and control officer who is responsible for overseeing the implementation of infection-control measures. The plan should include screening of patients to identify persons with symptoms of TB disease, placing TB suspects and cases in separate waiting areas and sending patients for diagnostic investigations of TB. Staff should also be investigated for TB free of charge if they have had a cough for two weeks or longer. The infection-control plan should list designated staff members to be contacted to initiate confidential TB investigations.

Each institution establishes a multidisciplinary infection prevention and control committee to monitor and evaluate the infection prevention and control plan (WHO 2008b:75). All staff should understand the importance of infection prevention and control policies through training, and should receive instruction specific to their job category. Training should be conducted before staff members are initially assigned to their posts, and continuing education should be provided to all employees and volunteers annually (WHO 2008b:75). Training should cover the basic concepts of TB, including transmission, pathogenesis, signs and symptoms of TB, the risk of transmission to health care practitioners and other staff members, and measures by means of which they can protect themselves and patients against TB. The training should also cover the importance of the infection prevention and control plan and the responsibility of each staff member with regard to the implementation of the plan. Health care practitioners and other staff members must be reminded that they can develop TB, regardless of previous infection status or BCG vaccination (WHO 2008b:75).

Patients must be educated on how to recognise the signs and symptoms of TB. Infected patients should receive instruction on how to protect others from exposure to TB by simple cough hygiene measures, personal hygiene, good nutrition and medication compliance. Educational materials that are culturally and linguistically appropriate for the patient must be used. HIV fuels the TB epidemic in populations where there is an overlap between those infected with HIV and those infected with TB. Intense

transmission of mycobacterium Tuberculosis increases the pool of HIV-infected people exposed to, and subsequently infected with TB (WHO 2004:14). Co-ordination and communication between HIV/AIDS and TB programmes must therefore be prioritised. Each facility without an integrated system that provides care for both TB and HIV should establish a referral mechanism for HIV patients suspected of having TB to be investigated in a TB diagnostic centre and commenced on treatment, if indicated. There must be a monitoring mechanism that provides feedback to the referring facility to evaluate both the linkage with TB diagnostic services and the appropriateness of referrals as indicated by the proportion of suspects actually confirmed as having TB disease (MOH 2010a:60).

- *Environmental control measures*

Environmental controls include ventilation (natural and mechanical), filtration and ultraviolet germicidal irradiation. Controlled natural ventilation considerably reduces the risk of spreading mycobacterium Tuberculosis. Designing waiting areas and examination rooms to maximise natural ventilation can significantly reduce the spread of TB. In warm climates, open-air shelters with a roof to protect patients from sun and rain are appropriate. Natural ventilation relies on open doors and windows to bring in air from the outside. When fresh air enters a room, it dilutes the concentration of particles in room air, such as droplet nuclei containing mycobacterium Tuberculosis. Controlled ventilation includes checks to ensure that doors and windows are maintained in an open position that enhances ventilation. Fans may also assist in distributing the air. However, the use of ceiling fans is only justified if there is free air flow out from the room through open windows (WHO 2008b:75).

In small rooms with a limited number of patients or in other small enclosed areas, room air cleaners with high-efficiency particulate air filters may be a useful alternative to mechanical ventilation that requires structural changes. These room air cleaners may be free standing or may be permanently attached to floors or ceilings to minimise tampering. Correct maintenance of the filter is essential (WHO 2008b:76). Negative-pressure ventilation is another method used to prevent contaminated air from flowing out of the room into adjacent areas in laboratories or health care facilities, by maintaining an air pressure difference between the two areas. Air is drawn into the room

from adjacent areas and exhausted directly to the outside, removing and diluting any infectious particles. This may be the method of choice in some settings, depending on various factors that include climatic conditions and available resources. The necessary equipment requires continued maintenance and the air exchange rate may be lower than that achieved by well-designed natural ventilation (WHO 2008b:76).

When patients provide sputum smear specimens for TB diagnosis, they should do so outside, in the open air, away from other people. When this is not possible because of climatic constraints, it should be done in an adequately ventilated booth and not in small rooms such as toilets or other enclosed areas (WHO 2008b:76). Mycobacterium Tuberculosis is killed if the organisms are exposed to sufficient ultraviolet germicidal irradiation. However, effectiveness depends on close contact with the ultraviolet light source and may be limited if humidity is high to over 60% and where dust levels are high. Ultraviolet lights should be directed to the ceiling, accompanied with adequate air flow and must be regularly maintained. The major concerns about inadequately installed and maintained ultraviolet germicidal irradiation units have been reactions resulting from overexposure, such as acute and chronic skin and eye changes. For these reasons and because of the inability to assess for effectiveness in field conditions, ultraviolet germicidal irradiation is not generally recommended as a method to disinfect room air in patient wards (WHO 2008b:76).

- *Personal protective measures (respiratory protection)*

A face mask, such as a surgical mask made of cloth or paper, serves as a physical barrier between the mouth, nose and the environment. Use of face masks is not generally recommended for health care staff because they do not protect against TB transmission by aerosol. A certified N95 or greater respirator is the mask of choice (WHO 2008b:77). N95 masks are called particulate respirators because they filter particles, such as droplets of respiratory secretions emitted by a person infected with TB.

2.2.7.3 Pharmacological treatment

Treatment of TB includes pharmacological treatment. For the treatment of new cases of pulmonary TB, the WHO (2008b:39) recommends a standardised regimen consisting of two phases. The initial intensive phase uses four drugs, namely, rifampicin, isoniazid, pyrazinamide and ethambutol administered for two months. This initial intensive treatment phase is aimed at rapidly killing the tubercle bacilli. These four drugs are called first-line drugs as they are the most potent and best tolerated anti-TB drugs (WHO 2006b:42).

The first-line regimen is followed by a continuation phase with two drugs namely, rifampicin and isoniazid for four months or, exceptionally, with isoniazid and ethambutol for six months when adherence to treatment with rifampicin cannot be ensured (WHO 2008b:39). Rifampicin is a semi-synthetic broad-spectrum bactericidal antibiotic. Isoniazid is a synthetic, antitubercular agent which is bacteriostatic for semi-dormant bacilli and bactericidal against actively dividing mycobacteria. Pyrazinamide is an antimycobacterial agent, which may be bacteriostatic or bactericidal depending on its concentration and the susceptibility of the organism. It is effective against persisting tubercle bacilli within the acidic intracellular environment of the macrophages. All agents are readily absorbed following oral administration with wide distribution to most tissues and fluids, including cerebrospinal fluid (WHO 2008b:39)

TB treatment in Uganda occurs by means of fixed-dose combination formulas (MOH 2010a:32). The use of fixed-dose combination treatment has several advantages over individual drugs. Prescription errors are likely to be less frequent as dosage recommendations are straightforward and adjustment of doses according to patients' weight is relatively easy. Compared with individual drugs, the number of tablets to be taken is fewer and patients cannot be selective in the choice of drugs to ingest, thus reducing non-compliance with the drug regimen and the potential for acquiring drug resistance. The need for direct observation of treatment is however not obviated with the use of fixed-dose combination treatment (WHO 2008c:38).

Application of DOTS is required to ensure treatment adherence. It helps reinforce patients' motivation to continue with their treatment and counters the tendency of some

to interrupt the treatment. DOTS also ensure the accountability of health care practitioners to ensure that patients take their TB treatment and helps prevent the emergence of drug resistance. It is therefore important to note that DOTS is recommended for the entire period of treatment.

2.3 THE RESEARCH CONTEXT

The research context describes in detail the country profile of Uganda and the rural area of Butaleja as follows:

2.3.1 Country profile of Uganda

Uganda is a land locked country in East-Central Africa, often referred to as the pearl of Africa. It lies on the Equator with geographical coordinates 1 00 N, 32 00 E.

2.3.1.1 Location and geographical information

Uganda is bordered by Sudan to the North; Kenya to the East; the Democratic Republic of Congo to the West; and Rwanda and Tanzania in the south. Uganda shares Lake Victoria with Kenya and Tanzania (CIA World Fact Book 2012). Uganda has an area of 240,038 Km² of which 197,323 km² is covered by land. It is generally a raised plateau. It has a tropical climate which is warm and wet throughout the year. The vegetation includes tropical forests near the equator, but most of the country is generally tropical savannah grassland (CIA World Fact Book 2012). Although most of the country is physically accessible, there are some areas whose geographical landscape presents a challenge in terms of access, in particular the mountainous areas and the islands of Lake Victoria. Administratively, Uganda is divided into districts which are further subdivided into lower administrative units, namely counties, sub-counties and parishes.

2.3.1.2 Demographic profile

The Population census conducted in 2002 puts the total population of Uganda at 24.7 million persons while the projected 2011 midyear Ugandan population by the Uganda Bureau of Statistics (UBOS) is 32.9 million. Uganda has one of the highest population

growth rates in the world standing at a rate of 3.2% per annum and higher than the Sub Saharan Africa average of 2.4% (MOH 2010c:9). The population comprises of majorly ethnic Africans (99.0%) with Asians, Europeans and Arabs making up the remaining 1.0%. It is estimated that 49% of Uganda's population constitutes of persons under the age of 15. About 48.5% of the population are male while 51.5% are female; with 88% of the population resident in rural areas (UBOS 2002).

There has been a general improvement in mortality levels in Uganda. The Infant Mortality Rate (IMR) declined from 97 to 76 deaths per 1,000 live births between 1995 and 2006 while the under five mortality declined from 162 to 137 deaths per 1,000 live births over the same period. Life expectancy in Uganda is estimated at 50.4 (UBOS 2011).

2.3.1.3 *The economy of Uganda*

Uganda is classified as a low income country in the sub-Sahara African region (World Bank 2011). It is classified as a developing country with poor infrastructure. The economy is largely based on small scale agriculture. Uganda's average gross domestic product (GDP) growth is estimated at 7.1% (World Bank 2011). This means that the country's economy is small, stable and steadily growing. However, it is estimated that 35.0% of the population lived below the poverty line in 2001 (CIA World Fact Book 2011). Uganda has substantial natural resources, including fertile soils, regular rainfall, small deposits of copper, gold, and other minerals, and recently discovered oil. Agriculture is the most important sector of the economy, employing over 80% of the work force, but contributing only about 23.6% of GDP. Coffee accounts for the bulk of export revenues. The labour force distribution by occupation is agriculture 82.0%; industry 5.0%; and services 13.0%. This means that agriculture is a mass employer but contributing modestly to the economy since most people are subsistence farmers (CIA World Fact Book 2011). The CIA World Fact Book (2012) puts Uganda's GDP at \$ 1,300 (2011 estimate).

2.3.2 The rural district of Butaleja

The research was conducted in the rural district of Butaleja in Eastern Uganda. Figure 2.1 shows location of the district.

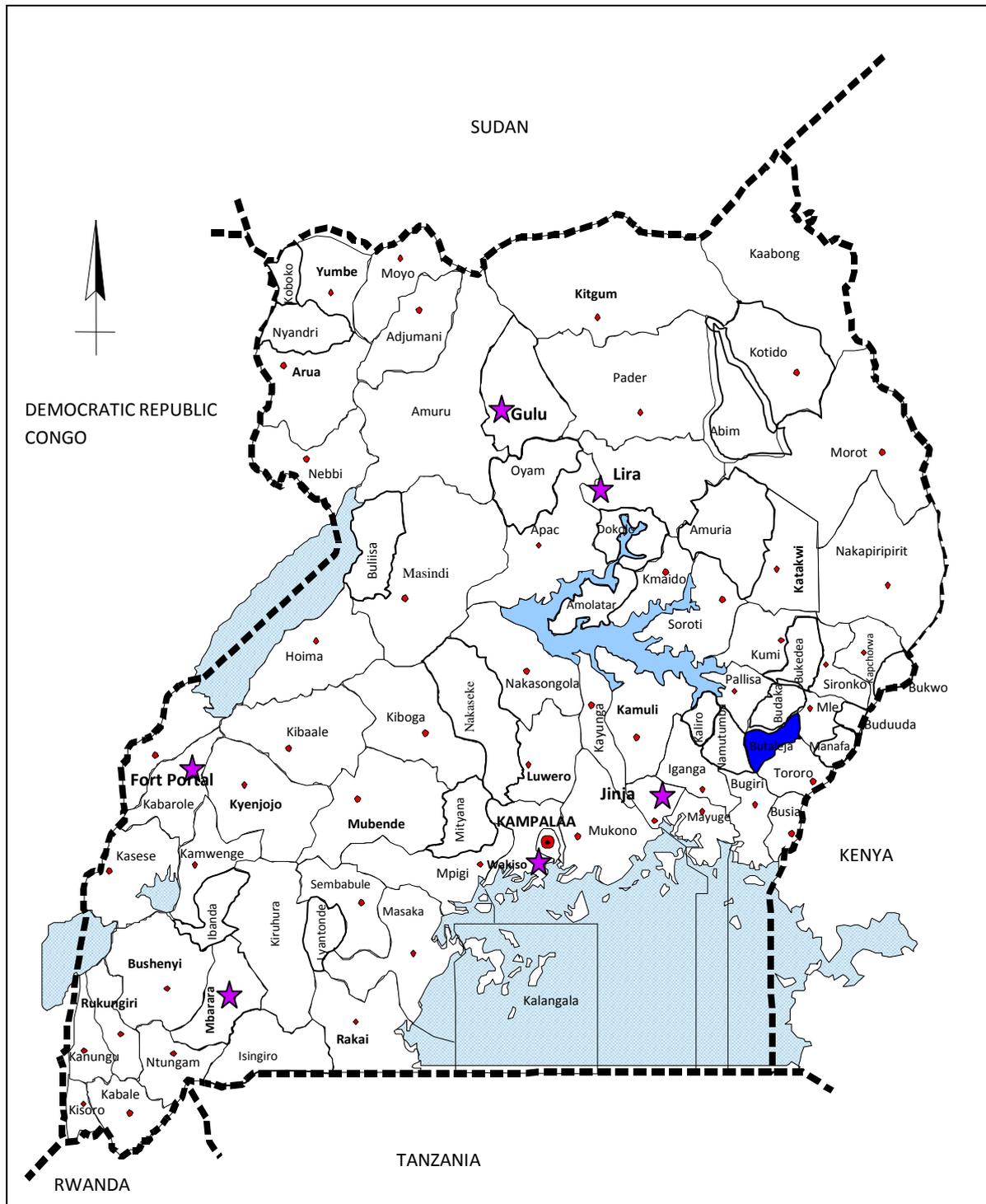


Figure 2.1: Map of Uganda, showing study area
(Adapted from Butaleja District Council 2011)

2.3.2.1 Location and geography of Butaleja

Butaleja District is a district in Eastern Uganda. It is named after its 'chief town', Butaleja, where the district headquarters are located. The district was created by an Act of the Ugandan parliament and became operational on 01 July 2005. Prior to that, the district was known as Bunyole County and was part of Tororo district (MOLG 2010). Butaleja district is bordered by Budaka district to the north, Mbale district to the east, Tororo district to the southeast, Bugiri district to the south and Namutumba district to the west. The district headquarters at Butaleja, are located approximately 38 kilometres (24 miles), by road, southwest of Mbale, the nearest large city. The coordinates of the district are 00 56N, 33 57E. The district covers a total land area of 644 square kilometres (sq kms) most of which is flat and suitable for agriculture (MOLG 2010).

The district is comprised of seven sub-counties, namely Budumba, Busaba, Busolwe, Butaleja, Kachonga, Nawanjofu and Mazimasa. There are two municipalities in the district; Butaleja where the district headquarters are located and Busolwe, the location of Busolwe hospital a 120 bed public hospital that belongs to the Uganda Ministry of Health. The district has 64 parishes and 423 villages (Ministry of Local Government (MOLG) (2010).

2.3.2.2 Demographic information

The district has a total population estimate (2010) of 206,200 of which 99,600 (48%) are males and 106,600 (52%) females. The population growth rate is estimated at 3.3% per annum. The district has a population of 57.4 % below 18 years of age and 6% aged 65 and above. This means that the district has a mainly young population. Life expectancy is 47 years. The literacy rate is estimated at 50.6% (MOLG 2010). The predominant ethnicity in the district (85%) is Banyole, a Bantu tribe whose language is called Lunyole. Other ethnicities in the district (15%) include the Jopadhola, the Bagisu, the Basoga, the Iteso, the Karimojong and the Bagwere (online http://en.wikipedia.org/wiki/Butaleja_District 2011).

2.3.2.3 Economic information

Butaleja is a generally poor district with an estimated 58% of the population living on less than a dollar per day as of 2007. The district is lacking in infrastructure. There are no tarmac roads. Water is obtained from streams and public boreholes (MOLG 2010). Like most of Uganda's districts, subsistence agriculture is the backbone of the district's economy. About 78% of the population is engaged in agriculture. Butaleja District is the home to Doho, Uganda's most famous paddy rice scheme. Other crops grown besides rice include millet, maize, sweet potatoes, beans, bananas, matooke, cotton, groundnuts, cassava and sorghum. Livestock kept by the population include: cattle, goats, sheep, rabbits, pigs, chicken, turkeys, ducks, pigeons and guinea fowl (GabriellazPoint 2011).

2.3.2.4 Burden of disease and health services

Over 80% of the top ten causes of ill health among the population of Butaleja district are preventable. They are Malaria which accounts for 46% of out-patients department (OPD) attendance and 23% of admissions; Acute Respiratory Infections (ARI); Diarrhoeal diseases; Intestinal worms; HIV/AIDS; Malnutrition; Trauma; Pregnancy related diseases; Eye conditions; and Skin diseases (Butaleja District Council 2010). The district has 24 health units of which two are general hospitals (HCIV), 10 are HCIIIs and 12 are HCIIIIs (MOLG 2010).

2.4 THE UGANDA HEALTH CARE SYSTEM

The National Health System in Uganda is made up of the public and private sectors. The public sector includes all Government of Uganda health facilities under the Ministry of Health, health services of the Ministries of Defence (Army), Education, Internal Affairs (Police and Prisons) and Ministry of Local Government. The private health delivery system consists of Private Not for Profit (PNFPs) providers, Private Health Practitioners (PHPs) and the Traditional and Complementary Medicine Practitioners (TCMPS) (MOH 2010b:3).

The provision of public sector health services in Uganda is decentralised with districts and health sub districts (HSDs) playing a key role in the delivery and management of health services at those levels. The health services are structured into National Referral Hospitals (NRHS) and Regional Referral Hospitals (RRHS), General Hospitals, Health Centre (HC) IVs, HC IIIs, HC IIs and Village Health Teams (HC Is) (MOH 2010b:3).

2.4.1 Central level institutions and functions

At the Central level, the Ministry of Health headquarters perform the following core functions: policy analysis, formulation and dialogue; strategic planning; setting standards and quality assurance; resource mobilisation; advising other ministries, departments and agencies on health-related matters; capacity development and technical support supervision; provision of nationally coordinated services including health emergency preparedness and response; and epidemic prevention and control; in addition to coordination of health research and monitoring and evaluation of the overall health sector performance (MOH 2009:2).

Several functions have been delegated to national autonomous institutions including Uganda Cancer Institute, Uganda Heart Institute, Uganda Blood Transfusion Services, Uganda Virus Research Institute, National Medical Stores, Central Public Health Laboratories, Professional Councils, National Drug Authority and Research institutions. The Uganda National Health Research Organisation (UNHRO) coordinates the national health research agenda, whilst research is carried out by several institutions including the Uganda National Chemotherapeutic Research Laboratory. The Health Service Commission is responsible for the recruitment and deployment of human resources for health at the Central and Regional Referral hospital levels. In the districts, this function is carried out by the District Service Commission. The Uganda AIDS Commission (UAC) coordinates the multi sectoral response to the HIV/AIDS epidemic (MOH 2010b:4).

2.4.2 General, regional and national Hospitals

The National Hospital Policy (2005) spells out the role and functions of hospitals at different levels in the National Health System. Hospitals provide technical back up for referral and support functions to the district health services. Hospital services are

provided by the public, private health providers and private not for profits providers. The public hospitals are divided into three groups, namely General Hospitals, Regional Referral hospitals and National Referral hospitals (MOH 2010b:4).

General hospitals provide preventive, promotive, curative, maternity, in-patient health services, surgery, blood transfusion, laboratory and medical imaging services. These hospitals also provide in-service training, consultation and operational research in support of the community based health care programmes. Regional Referral Hospitals offer specialist clinical services such as psychiatry, Ear, Nose and Throat services, Ophthalmology, higher level surgical and medical services and clinical support services (Laboratory, Medical Imaging and Pathology). This is in addition to services provided by general hospitals. They are also involved in teaching and research. National Referral hospitals provide comprehensive specialist services and are involved in health research and teaching in addition to services offered by general hospitals and regional referral hospitals (MOH 2010b:4).

All hospitals are supposed to provide support supervision to lower levels and to maintain linkages with communities through their community health departments. Currently there are 65 public hospitals, two National Referral Hospitals, 11 Regional Referral Hospitals and 52 General Hospitals. There are 56 Private not for Profit Hospitals and nine Private Health Provider hospitals. With decentralisation, the public general hospitals are managed by local governments. The Regional Referral Hospitals have been granted self accounting status and remain under the Ministry of Health oversight. The two National Referral Hospitals, namely Mulago and Butabika are semi-autonomous. All private-not-for-Profit Hospitals are autonomous as granted by their respective legal proprietors (MOH 2010b:5).

2.4.3 District Health Systems

The constitution of Uganda (1995) and the Local Government Act (1997) mandate the Local Governments to plan, budget and implement health policies and health sector plans. They have responsibility for recruitment, deployment, development and management of human resources for district health services, development and passing of health related by-laws and monitoring of overall health sector performance in their

districts. Local governments manage public general hospitals and health centres and also supervise and monitor all health activities (including those in the private sector) in their respective areas of responsibility (MOH 2010b:5).

2.4.3.1 Health Sub-district Systems (HC IV)

The Health Sub-districts, administratively corresponding to the County level are mandated with planning, organising, budgeting and management of health services at the sub-district and lower health centre levels. Health sub-districts carry out an oversight function of overseeing all curative, preventive, promotive and rehabilitative health services including those carried out by private not for profit and private for profit service providers in the health sub-district. The headquarters of a health sub-district are a Health Centre (HC) IV or a selected general hospital (MOH 2010b:5). Staff responsible for rendering health care at the HC IV includes a medical officer, two medical clinical officers, one anaesthetic officer, two midwives, three nurses, and one public dental officer. There is also one records officer, a driver and two support staff members (MOH 2010b:5).

2.4.3.2 Health Centres IIIs, II and Village Health Teams (HC I)

Health Centre IIIs are found at the sub-county level and provide basic preventive, promotive and curative care. They also provide support supervision of the community and Health Centre IIs under their jurisdiction. There are provisions for laboratory services for diagnosis, maternity care and first referral cover for the sub-county. The workforce at this level includes one medical clinical officer, a laboratory assistant, two nurses, a midwife and a nursing assistant. This health care facility is headed by the medical clinical officer (MOH 2010b:5).

The HC IIs located at the parish level provide the first level of interaction between the formal health sector and the communities. Health Centre IIs only provide out patient care, immunisation services, community outreach services and linkages with Village Health Teams (VHTs). Staff at this level of care includes a nurse, midwife and two nursing assistants. The health facility is headed by the nurse (MOH 2010b:5). Village

Health Teams (VHTs) facilitate health promotion, service delivery, community participation and empowerment in access to and utilisation of health services.

The Village Health Teams are responsible for identifying the community's health needs and taking appropriate measures; mobilising community resources and monitoring utilisation of all resources for their health; mobilising communities for health interventions such as immunisation, malaria control, sanitation and promoting health-seeking behaviour; maintaining a register of members of households and their health status; maintaining birth and death registration; Serving as the first link between the community and formal health providers; community based management of common childhood illnesses including Malaria, Diarrhoea and Pneumonia; and management and distribution of any health commodities availed from time to time (MOH 2010b:5).

2.4.4 Delivery of health services

The delivery of health services in Uganda is by both public and private sectors with Government of Uganda owning most of the facilities. The government of Uganda owns about half of the health facilities in Uganda followed by the Private not for profit sector (MOH 2010b:5).

2.4.4.1 *The Public Health Care Delivery System*

Public Health services in Uganda are delivered through Village Health Teams, Health Centre IIs, HC IIIs, HC IVs, general hospitals, Regional Referral hospitals and National Referral hospitals. Other players in service provision and promotion include the media, Civil Society Organisations and community structures such as the Village Health Teams (MOH 2010b:5-6). The range of health services delivered varies with the level of care. In all public health facilities, curative, preventive, rehabilitative and promotive health services are free, user fees having been abolished in 2001. However, private wings of public hospitals still charge user fees for their services (MOH 2010b:6). Although 72% of the households in Uganda live within 5 km from a health facility (public or private), utilisation is still limited due to poor infrastructure, lack of medicines and other health supplies. Shortage of human resources in the public sector, low salaries, lack of

accommodation at health facilities and other factors further constrain access to quality service delivery (MOH 2010b:6).

2.4.4.2 The Private Sector Health Care Delivery System

The private sector plays an important role in the delivery of health services in Uganda covering about 50% of the reported outputs. The private health care system comprises of the Private not for profit organisations, Private Health practitioners and the Traditional and Complementary Medicine practitioners (MOH 2010b:6). The Private not for profit sector is more structured and prominently present in rural areas. The private for profit sector is fast growing but most facilities are concentrated in urban areas. Traditional and Complementary Medicine providers are present in both rural and urban centres, but services provided are not consistent and vary from traditional practices in rural areas to imported alternative medicines, mostly in urban areas. The contribution of each sub-sector to the overall health output varies widely. The government of Uganda recognises the importance of the private sector by subsidising the Private not for profit providers, a few private hospitals and the Private not for Profit training institutions (MOH 2010b:6-7).

- *Private not for profit sub-sector*

The private not for profit sub-sector is divided into two categories, namely Facility based and Non facility based. The Facility based private not for profit providers provide both curative and preventive services, while the non facility based private not for profit providers mainly provide preventive, palliative and rehabilitative services. The facility based Private not for profit providers account for 41% of the hospitals and 22% of lower level facilities complementing government facilities especially in the rural areas (MOH 2010b:6). The non facility based Private not for profit subsector is diverse and less structured comprising of hundreds of non-governmental organisations and community based organisations that mainly provide preventive health services which include health education, counselling, health promotion and support to community health workers (MOH 2010b:6).

- *Private health care practitioners*

As of 2010, it is estimated that private health care practitioners constituted 22.5% of health care providers. Dual employment is however common with 54% of doctors working in the private sector also working in the government sector (MOH 2010b:7). The private health practitioners have a large urban and peri-urban presence. More than 80% of the doctors employed in the private sector are employed in the central region and the major municipalities nationwide. The private health care providers offer a wide range of services mainly in primary and secondary care. Few Private health providers provide tertiary care. Curative services are widely offered, but preventive services are more limited with exception of family planning services. Majority (over 90%) of Private health facilities offer Malaria and STD treatment, but only a few (about 22%) offer immunisation services. About 40% of private health facilities provide maternity, post abortion care and adolescent reproductive health services (MOH 2010b:7).

- *Traditional and complementary medicine practitioners*

Approximately 60% of Uganda's population seeks care from Traditional and Complementary Medicine Practitioners such as Herbalists, traditional bone setters, traditional birth attendants, hydro-therapists, spiritualists and traditional dentists before and after visiting the formal sector. The traditional and complementary medicine practitioners practice in both urban and rural areas with varying and inconsistent service provision. Many traditional healers remain unaffiliated and unregulated (MOH 2010b:7). Most traditional and complementary health practitioners have no functional relationship with public and private health providers. This results into late referrals, poor management of various medical, surgical, obstetric conditions and high morbidities and mortalities. Non-indigenous traditional or complementary practitioners such as the practitioners of Chinese and Ayurvedic medicine have emerged in recent years (MOH 2010b:8).

2.4.5 Burden of disease in Uganda

In Uganda, Malaria, HIV and AIDS, and TB remain the leading causes of morbidity and mortality. Seventy percent of overall child mortality is due to malaria, ARIs, diarrhoea

and malnutrition. Non Communicable Diseases (NCDs) are an emerging problem and these include hypertension, cardiovascular diseases, diabetes, chronic respiratory diseases, mental illness and injuries (MOH 2009:2). According to the Ugandan demographic and health survey report the major causes of disease in Uganda were peri-natal and maternal conditions (20.4%); malaria (15.4%); respiratory tract infections (10.5%); AIDS (9.4%) and diarrhoeal diseases (8.4%)(UBOS 2006:2). Communicable diseases account for 54% of the total burden of disease in Uganda with HIV/AIDS, TB and Malaria being the leading causes of ill health (MOH 2010:14). The burden of TB in Uganda is high and its ranked 16th by the WHO among the 22 high TB burden countries (WHO 2010a).

2.5 TUBERCULOSIS AS A PUBLIC HEALTH PROBLEM

2.5.1 TB as a global public health problem

In 1999, the World Health Organization ranked TB among the most serious health threats to the world. Renewed efforts to promote TB control were launched with the development of the Global Stop TB strategy (WHO 2006a:4). Unfortunately, the wide distribution of the infection and its complex epidemiology and natural history, coupled with insufficient resources to adequately respond to the epidemic mean that TB will be a serious public health problem for many more years.

2.5.1.1 *Global TB mortality*

According to WHO (WHO 2010a:7), in 2009, an estimated 1.3 million deaths (range, 1.2 million-1.5 million) occurred among HIV-negative cases of TB; including 0.38 million deaths (range, 0.3 million-0.5 million) among women. This is equivalent to 20 deaths per 100 000 population. In addition, there were an estimated 0.4 million deaths (range, 0.32 million-0.45 million) among incident TB cases that were HIV-positive; these deaths are classified as HIV deaths in the 10th revision of the International Classification of Diseases (ICD-10). Thus in total, approximately 1.7 million people died of TB in 2009. The number of TB deaths per 100 000 population among HIV-negative people plus the estimated number of TB deaths among HIV-positive people equates to a best estimate of 26 deaths per 100 000 populations (WHO 2010a:7).

2.5.1.2 Multi-drug resistant TB

According to WHO, there were an estimated 440 000 cases of multi-drug resistant TB (MDR-TB) in 2008 (range, 390 000-510 000). The 27 countries (15 in the European Region) that account for 86% of all such cases have been termed the 27 high MDR-TB burden countries. The four countries that had the largest number of estimated cases of MDR-TB in absolute terms in 2008 were China (100 000; range, 79 000-120 000), India (99 000; range, 79 000-120 000), the Russian Federation (38 000; range, 30 000-45 000) and South Africa (13 000; range 10 000-16 000). By July 2010, 58 countries and territories had reported at least one case of extensively drug-resistant TB (XDR-TB) (WHO 2010a:7).

2.5.1.3 MDR TB in Uganda

The actual Drug resistant TB burden in Uganda is not exactly known but a drug resistance survey carried out by MOH puts MDR TB prevalence in new cases at 1.3% and in previously treated cases at 12.1% (IUATLD 2011:13). Whereas the WHO estimated that there are 870 MDR-TB cases per year (2010), Uganda recorded 226 MDR-TB cases from March 2008 up to October, 2011. These cases were notified to the Ministry of Health from several districts in the country. Very few previously treated TB patients receive drug sensitivity testing (9%). This could be the reason of very low detection rate of MDR-TB (IUATLD 2011:13).

2.5.2 TB control in Uganda

The Ministry of Health in Uganda established the National Tuberculosis and Leprosy Control programme (NTLP) with the mission of providing quality diagnosis and patient centred care for TB and Leprosy patients. Its core functions include establishing countrywide quality diagnosis and treatment services for TB and Leprosy; coordinating implementation of TB and Leprosy activities; and preventing and managing leprosy-related disabilities (MOH 2010a:4). Currently the National Tuberculosis and Leprosy control programme in Uganda emphasises the DOTS strategy for TB control (MOH 2010a:12).

2.5.2.1 The Directly Observed Treatment Short-course (DOTS) Strategy

Directly Observed Treatment Short Course (DOTS) is the internationally recommended strategy for TB control and has been recognised as a highly efficient and cost-effective strategy. DOTS comprises five components: Sustained political and financial commitment; Diagnosis by quality ensured sputum-smear microscopy; Standardised short course anti TB treatment given under direct and supportive observation; a regular uninterrupted supply of high quality anti-TB drugs; and standardised recording and reporting (WHO 2006a:9).

2.5.2.1.1 The Uganda community based DOTS model (CB-DOTS)

Uganda adopted community based-TB care as a national policy in 2000. This national TB control policy includes community sensitisation and mobilisation, as well as offering every TB patient DOTS by a community volunteer (CB-DOTS). This community-based-care approach builds on the strength of the DOTS package, including securing drug supply, monitoring and evaluation, and staff training. The approach adds significant effort in community mobilisation, partnership, and attention to various local cultural, economic, and institutional conditions across Uganda. The objectives of CB-DOTS include improving ease of access to treatment for patients, increasing TB control effectiveness, increasing efficient use of limited health sector resources, relieving overcrowded hospitals, and enhancing the community's active role in DOTS and public health. The CB-DOTS model shifts treatment from hospitals to ambulatory care with direct observation by volunteers selected by their communities (Management Sciences for Health 2003).

Under the CB-DOTS model, TB patients are initially treated in a health centre by a health worker for two weeks before they are sent back to their communities to continue treatment, under supervision of a community volunteer. The community volunteers are responsible for administering, directly observing therapy and referring the TB patients to health centre for follow-up sputum testing and clinical reviews (MOH 2010c:12-13). The community volunteers are overseen by sub county health workers (SCHWs) who conduct community mobilisation, facilitate communities through their leaders to select

community volunteers (CVs), train the selected community volunteers (CVs), supervise them and replenish their TB drugs fortnightly (MOH 2010a:8-10).

2.5.2.2 Goals and performance of the national TB and Leprosy programme

The current goals of the Uganda MOH for TB control are to achieve 70% case detection rate (CDR) and 85% treatment success rate (TSR), these being the global targets (MOH 2010b:71). For these targets to be met, the WHO recommends that countries pursue high quality DOTS expansion and enhancement (WHO 2006a:6). In Uganda, decentralised TB care, called Community based DOTS has been expanded to all districts (MOH 2010b:70). Figure 2.2 below, shows trends in NTLP Performance (TSR and CDR) for the period 1999-2010.

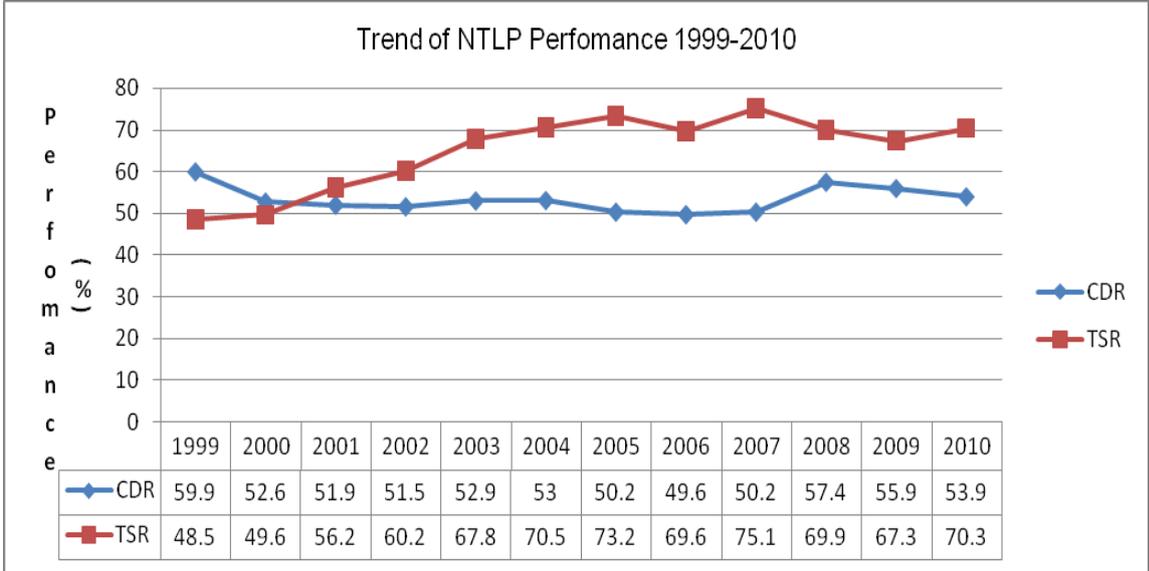


Figure 2.2: Trends in NTLP performance 1999-2010
(Adapted from NTLP Annual Surveillance Report 2011)

The figure indicates that Uganda still falls short of attaining the global TB targets. Over the past 10 years, the Case Detection Rate (CDR) has generally stagnated while the Treatment Success Rate (TSR) has shown an increase. In 2010, the Case Detection Rate declined to 53.9% from 55.9% in 2009. The Treatment Success Rate improved from 67.3% in 2009 to 70.3% in 2010. These rates are below Uganda’s (and Global) targets of 70% CDR and 85% TSR. Underperformance is due to a combination of factors including poor access to TB diagnostic and treatment services; shortage of human resources especially laboratory staff; poor quality of DOTS services including

poor recording and reporting, stock outs due to weak logistics management capacity, inadequate facilitation to sub county health workers (SCHWs) leading to inappropriate implementation of the CB-DOTS strategy; high HIV prevalence, low community awareness and a weak advocacy, communication and social mobilisation (ACSM) strategy among others (MOH 2010b:16). These factors contribute to two particular challenges that make it difficult for the National TB and Leprosy Programme to attain the case detection and treatment success targets: diagnosis delay and non-compliance to TB treatment by diagnosed patients. These reflect poor health-seeking behaviour by TB patients.

2.6 HEALTH-SEEKING BEHAVIOUR

Understanding of health-seeking behaviour could reduce delay to diagnosis, improve treatment compliance and improve health promotion strategies in a variety of contexts (MacKian 2001:3). Thus there is growing acknowledgement that health care seeking behaviour and local knowledge need to be taken seriously in programmes and interventions to promote health in a variety of contexts (MacKian 2001:6). The purpose of this study was to determine the factors associated with health-seeking behaviour of TB patients in the Butaleja district of Uganda, with one of the research objectives being to use the gained local knowledge to develop recommendations to promote positive health-seeking behaviour amongst patients diagnosed with TB.

2.6.1 Definition of health-seeking behaviour

According to Mosby's Medical Dictionary (2009), health-seeking behaviours are personal actions to promote optimal wellness, recovery and rehabilitation. Thus, health-seeking behaviour can be defined as any activity undertaken by individuals who perceive themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy. Literature distinguishes health-seeking behaviour from the broader concept of health behaviour, which refers to any activity undertaken by individuals who see themselves as healthy for the purpose of preventing disease or detecting it in an asymptomatic stage (Ward, Mertens & Thomas 1997:21). In this study, health-seeking behaviour refers to the course of action by an individual in searching for a condition of soundness of the body, a condition in which the body's functions are duly and efficiently discharged.

2.6.2 Health-seeking behaviour theories and models

Health- and treatment-seeking behaviour models from social psychology, medical sociology and medical anthropology allow for considerable examination of the determinant factors for behaviour observed in health-seeking behaviour studies (Hausmann-Muela, Ribera & Nyamongo 2003:9). In public health, the most utilised models from social psychology are the Health Belief Model, the Theory of Reasoned Action and its later development to the Theory of Planned Behaviour. Most known from medical sociology and medical anthropology are, respectively, the Health Care Utilisation or Socio-Behavioural Model and the Decision Making Model. All models contain associations of variables which are considered relevant for explaining or predicting health-seeking behaviours (Hausmann-Muela et al 2003:9).

2.6.2.1 *The Health Belief Model (HBM)*

According to a version of the model as presented by Sheeran and Abraham (1995) action in the HBM is guided by:

- Beliefs about the impact of illness and its consequences (threat perception) which depend on perceived susceptibility, or the beliefs about how vulnerable a person considers him- or herself in relation to a certain illness or health problem; and perceived severity of illness or health problems and its consequences.
- Health motivation or readiness to be concerned about health matters.
- Beliefs about the consequences of health practices and about the possibilities and the effort to put them into practice. The behavioural evaluation depends on perceived benefits of preventive or therapeutic health practices; perceived barriers, both material and psychological (for example 'will-power'), with regard to a certain health practice.
- Cues to action, which includes different internal and external factors that influence action. For example, the nature and intensity (organic and symbolic) of illness symptoms, mass media campaigns, advice from relevant other (family, friends, health staff, etc.).

- Beliefs and health motivation are conditioned by socio-demographic variables (class, age, gender, religion, etc.) and by the psychological characteristics of the interviewed person (personality, peer group pressure etc) (Hausmann-Muela et al 2003:9).

2.6.2.2 The Theory of Planned Behaviour (TPB)

The Theory of Planned Behaviour (TPB) (Ajzen 1988) is an extension of the earlier Theory of Reasoned Action (TRA) (Fishbein & Ajzen 1975; Ajzen & Fishbein 1980). Both theories centre on factors which lead to a specific intention to act, or Behavioural Intention. In the TPB, Behavioural Intention is determined by:

- Attitudes towards behaviour, determined by the belief that a specific behaviour will have a concrete consequence and the evaluation of this consequence.
- Subjective norms or the belief in whether other relevant persons will approve one's behaviour, plus the personal motivation to fulfill with the expectations of others.
- Perceived behavioural control, determined by the belief about access to the resources needed in order to act successfully, plus the perceived success of these resources (information, abilities, skills, dependence or independence from others, barriers, opportunities, etc.).
- Socio-demographic variables and personality traits which condition attitudes, subjective norms and perceived behavioural control. These are the same as in the HBM. An outstanding aspect of the TPB is the central role of social network support (Hausmann-Muela et al 2003:9).

2.6.2.3 The Health Care Utilisation Model

The socio-behavioural or Andersen model (Andersen & Newman 1973) groups in a logic sequence three clusters or categories of factors (predisposing, enabling and need factors) which can influence health behaviour. The model was specifically developed to investigate the use of biomedical health services. Later versions have extended the model to include other health care sectors, that is, traditional medicine and domestic treatments (Hausmann-Muela et al 2003:12).

2.6.2.4 The “four As” Model

It has become popular among researchers to use different categories which group key factors for health-seeking behaviour. The best known is the grouping into the “four As”:

- Availability, which refers to the geographic distribution of health facilities, pharmaceutical products etc.
- Accessibility which includes transport, roads, etc.
- Affordability which includes treatment costs for the individual, household or family. A distinction is made between direct, indirect and opportunity costs.
- Acceptability which relates to cultural and social distance. This mainly refers to the characteristics of the health providers, such as health workers’ behaviour, gender aspects (non acceptance of being treated by the opposite sex, in particular women who refuse to be seen by male nurses/doctors) and excessive bureaucracy.

The ‘model’ of the “four As” has been widely used by medical geographers, anthropologists and epidemiologists who mainly emphasised distance (both social and geographical) and economic aspects as key factors for access to treatment. The advantage of the “four As” is the easy identification of key potential ‘barriers’ for adequate treatment (Hausmann-Muela et al 2003:14).

2.6.2.5 The Pathways Model

Starting with recognition of symptoms, pathways models centre on the path that people follow until they use different health services (home treatment, traditional healer, biomedical facility). One of the variables studied in these models is the influence of significant others. Significant others are part of the ‘therapy managing group’, and are key for understanding decision making in therapeutic processes. This idea of therapy managing group challenges the strong emphasis on the individual and stresses the pivotal role of extended groups of relatives and friends in illness negotiation and management. In the course of the illness episode, the involvement of support groups in illness management can successively change. Pathway models acknowledge these

dynamics of illness and decision-making. Most of the studies which use pathway models investigate the path until the first contact with a health facility (Hausmann-Muela et al 2003:15).

2.6.3 Approaches to studying health-seeking behaviour

Researchers have long been interested in what facilitates the use of health services, and what influences people to behave differently in relation to their health and several studies have been conducted. There are studies which emphasise the 'end point' which is utilisation of the formal system, or health care seeking behaviour; secondly, there are those which emphasise the 'process' which is illness response, or health-seeking behaviour (MacKian 2001:4). This study combined both approaches. In this study, health-seeking behaviour encompasses the participants' pathway to utilisation of the formal health system for diagnosis and treatment of pulmonary TB including the institutions visited, health care providers consulted, diagnostic and treatment process, in addition to use of any other treatments before and during utilisation of the formal health care system.

2.6.3.1 Health care seeking behaviour as utilisation of the system

Studies of this nature focus specifically on the act of seeking 'health care' as defined officially in a particular context. Although data are also gathered on self care, visits to more traditional healers and unofficial medical channels, these are often seen largely as something which should be prevented, with the emphasis on encouraging people to opt first for the official channels (Ahmed et al 2001:104). The view is often that the desired health care seeking behaviour is for an individual to respond to an illness episode by seeking first and foremost help from a trained allopathic doctor, in a formally recognised health care setting. However, a consistent finding in many studies is that, for some illnesses, people will choose traditional healers, village homeopaths, or untrained allopathic doctors above formally trained practitioners or government health facilities (Ahmed et al 2001:100).

Under this approach, there are studies which categorise the types of barriers or determinants which lie between patients and services. Again, there are as many

categorisations and variations in terminology as there are studies, but they tend to fall under the divisions of geographical (e.g. distance and physical access), social (e.g. age and sex), economic (e.g. cost of care), cultural (e.g. status of women in the community) and organisational factors (e.g. perceived quality of service). There are also studies that attempt to categorise the type of processes or pathways at work. Such studies develop pathways to care models identifying stages where decisions are made, and delay may be introduced, towards adoption of 'modern care'. This approach offers an opportunity to identify key junctions where there may be a delay in seeking competent care, and is therefore of potential practical relevance for policy development.

2.6.3.2 Health-seeking behaviour as the process of illness response

The second approach, rooted especially in psychology, looks at health-seeking behaviour more generally; drawing out the factors which enable or prevent people from making 'healthy choices', in either their lifestyle behaviour or their use of medical care and treatment. While in the first approach health care seeking behaviour is conceptualised as a 'sequence of remedial actions' taken to rectify 'perceived ill-health' in the second approach a wider perspective on affirmative, health promoting behaviour is adopted (Mackian 2001:7).

2.6.4 Methods used in health-seeking behaviour studies

The various methods that follow in the next discussion have been used in both health-seeking behaviour and health care seeking behaviour studies.

2.6.4.1 Household surveys

Household surveys are the most common method of health-seeking behaviour study, generally under the names of knowledge, attitude and practice (KAP) studies, treatment (care) seeking behaviour or health-seeking behaviour. Most are disease specific (Grundy & Annear 2010:2).

2.6.4.2 Facility-based surveys

These come mostly in the form of patient surveys and are often disease specific in areas such as TB or neonatal care. Clients are recruited at facilities and followed up using either qualitative or quantitative methods. Conclusions drawn from facility or household surveys may appear mundane or obvious, albeit important. For example, the findings of one study concluded that ‘to be more effective, TB control efforts need to be better accessible to the economically and socially vulnerable’ (Grundy & Annear 2010:3).

2.6.4.3 Other quantitative studies

Quantitative techniques may be used to analyse contextual influences on health care seeking and outcomes. For example, a study in Nigeria analysed the individual and social background characteristics of families with children with protein energy malnutrition. Predictably, the study found that social characteristics (wealth index) were associated with health care seeking and outcomes (Uthman 2009:114).

2.6.4.4 Qualitative surveys, ethnographic and narrative studies

Qualitative surveys provide more opportunity to investigate motivations for different health-seeking behaviour and may also uncover contextual influences on understanding of disease causation and care-seeking behaviour, for example between different ethnic groups. A variety of methods are applied in qualitative surveys including ethnography and in-depth semi-structured interviews. Qualitative methods often research treatment pathways (Grundy & Annear 2010:4).

2.6.4.5 Mixed-methods surveys

Some surveys use mixed methods. In one study of the attitudes of mothers to maternal care-seeking behaviour in Bangladesh, in-depth interviews were conducted with a smaller sample followed by a larger sample of structured quantitative interviews. The qualitative interviews were used to identify the main care-seeking patterns, after which

the quantitative survey determined the frequencies with the health-seeking behaviour pattern (Grundy & Annear 2010:4).

2.6.5 Issues in health-seeking behaviour studies

The literature provides a thoughtful critique of Health-seeking behaviour studies. One common criticism is that health-seeking behaviour studies often describe patterns of behaviour without elucidating causes for the behaviour. For example, the knowledge, attitudes and practices (KAP) survey technique, though providing highly descriptive data, does not provide an explanation of why people do what they do. KAP studies are also based on the underlying assumption that there is a direct relationship between knowledge and action (Grundy & Annear 2010:9).

Analysts recognise the very weak relationship between health knowledge and health-seeking behaviour and therefore proceed by analysing individual or household decision making within a social context. The very fact that health-seeking behaviour is patterned is suggestive of the role of social influence or sociocultural factors in determining or influencing decisions. Traditional health-seeking behaviour theories (for example, the health belief model or notions of 'locus of control') essentially base the determinants of health-seeking behaviour within the individual or the household. However, health-seeking behaviour actually extends beyond personal and household factors, to include community and health system factors. Analysing this patterning of health-seeking behaviour is a more balanced approach from the standpoint of the individual within the society. (Grundy & Annear 2010:9).

2.7 HEALTH-SEEKING BEHAVIOUR FOR TUBERCULOSIS

The DOTS strategy, recommended by the World Health Organization (WHO) for the prevention and control of TB and adopted by Uganda, relies on passive case finding by sputum smear microscopy (WHO 2004:179). Tuberculosis suspects are therefore expected to be able to recognise TB symptoms, have positive attitudes towards TB being managed by formal health services and seek early care from the formal health services. In Uganda for example, any patient with cough lasting more than 3 weeks is advised to visit a health centre for assessment of TB. The formal health services are expected to promptly diagnose suspects and put them on treatment to reduce morbidity

and spread of TB in the community (MOH 2010a:20-26). However, various studies document poor health-seeking behaviour for TB leading to delayed TB diagnosis and non-compliance to treatment by diagnosed TB patients.

2.7.1 Causes of delayed TB diagnosis

Various studies have found the causes of delays in diagnosis of TB, such as, duration from symptom onset to diagnosis, or from first consultation to diagnosis to be associated with poor perception of the health services (Godfrey-Faussett, Kaunda, Kamanga, Van Beers, Van Cleeff, Kumwenda-Phiri & Tihont 2002:798); access to health services, and the expertise of the health personnel (Harling, Ehrlich & Myer 2008:503); fear of stigmatisation (Abebe, Deribew, Apers, Woldemichael, Shiffa, Tesfaye, Abdissa, Deribie, Jira, Bezabih, Aseffa, Duchateau & Colebunders 2010:4); and the individual's perception of disease, the severity of the disease, lack of knowledge about TB and traditional beliefs (Shetty, Shemko & Abbas 2004:79). These causes of TB diagnostic delays can be categorised into patient factors which includes cultural factors, lack of knowledge and beliefs about the severity of the disease; and health system factors which include poor knowledge of providers about TB, lack of diagnostic services and seeking treatment from other providers other than health care providers.

2.7.2 Duration of delayed TB diagnosis

Delays in diagnosis of TB have been reported in both industrialised and developing countries and vary considerably, from 6.2 weeks in Australia to 12 weeks in Botswana (Steen & Mazonde 1998:629); and 16 weeks in Ghana (Lawn, Afful & Acheampong 1998:636). Similar delays have been found in studies carried out in Uganda. In a cross-sectional survey of 231 newly diagnosed smear-positive TB patients conducted in Mulago National referral Hospital from January to May 2002; aimed at determining the time taken for patients later confirmed as having TB to present with symptoms to the first health provider (patient delay) and the time taken between the first health care visit and initiation of TB treatment (health service delay); the median total delay to treatment initiation was 12 weeks (Kiwuwa, Karamagi & Mayanja 2005:122).

2.7.3 Impact of delayed TB diagnosis

Delayed TB diagnosis leads to delayed initiation of treatment and this leads to a prolonged period of infectivity in the community. Left untreated, each person with active TB disease will infect on average between 10 and 15 people every year (WHO 2010b). Strategies aiming to reduce the time between the onset of symptoms and the initiation of effective chemotherapy may impact the infectious duration in the community and thereby reduce the number of new infections.

Besides contributing to continued infectiousness in the community; at the individual patient level, delay in diagnosis and initiation of treatment leads to advancement of the disease process with consequent increase in acute morbidity, late sequelae and mortality. In a cross sectional study carried out in Uganda on patient and health service delay in pulmonary TB patients attending a referral hospital, illness severity as measured by chest radiography and sputum smear grades was found to be associated with the duration of delay to treatment (Kiwuwa et al 2005:122). Advanced TB disease has also been found to correlate with mortality and chronic morbidity (Lawn et al 1998:635).

2.7.4 The problem of non-compliance to TB treatment

Treatment compliance is one of the potential factors to increase the cure rate in TB patients. The WHO recommends DOT, adapted to patient needs and the availability of trained health workers, as the best method of avoiding treatment interruption in order to improve compliance to and completion of TB treatment (WHO 2006a:6). Non-compliance to TB treatment is a major constraint to eradicating the disease. According to Volmink and Garner (2004:2), between 20% and 50% of people with TB do not complete treatment within a 24 month period. This can lead to prolonged infectiousness, drug resistance, relapse of TB, or even death. Incomplete treatment thus poses a serious risk for the individual as well as the community.

2.7.5 Causes of non-compliance to TB treatment

In a synthesis of qualitative evidence derived from multiple international studies eight major themes were identified across the studies regarding patient adherence to TB treatment, namely, organisation of treatment and care; interpretations of illness and wellness; the financial burden of treatment; knowledge, attitudes, and beliefs about treatment; law and immigration; personal characteristics and adherence behaviour; side effects; and family, community, and household support (Munro, Lewin, Smith, Engel, Fretheim & Volmink 2007:238).

In a household-based survey conducted in six randomly selected catchment areas of Ndola district in Zambia, with the aim of investigating factors contributing to treatment non-adherence and knowledge of TB transmission from patients receiving TB treatment within a six months; it was found that overall the patients stopped taking their medication. The factors leading to non-compliance included patients beginning to feel better, lack of knowledge on the benefits of completing the course of treatment, running out of drugs at home and TB drugs being too strong (Kaona, Tuba, Siziya & Sikaona 2004:68).

2.7.6 Impact of non-compliance to TB treatment

Non-compliance to TB treatment by TB patients through interrupting or defaulting on treatment contributes to prolonged infectiousness, drug resistance, relapse and death. It contributes to emergency of Drug Resistant strains of TB which are harder to treat and require more expensive and toxic drugs administered for a longer duration (Volmink & Garner 2006:2). Besides the initial size of the bacillary population in a TB patient (presence of pulmonary cavities), the drug regimen prescribed, non-compliance to an otherwise adequate regimen is one of the factors associated with the development of multi drug resistant TB while on treatment (Blumberg, Burman, Chaisson, Daley, Etkind, Friedman, Fujiwara, Grzemska, Hopewell, Iseman, Jasmer, Koppaka, Menzies, O'Brien, Reves, Reichman, Simone, Starke & Vernon 2003:642).

2.8 CONCLUSION

The literature review presented in this chapter has included causes, risk factors, pathogenesis, transmission, symptoms, diagnosis and management of TB globally and in the Ugandan context. Additionally the research context including the Uganda health system was reviewed. The chapter also reviewed health-seeking behaviour broadly including the various theories of health-seeking behaviour, and the various approaches to studying health-seeking behaviour. The chapter ended with a review of the literature related to health-seeking behaviour for TB.

CHAPTER 3

RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

The purpose of the study was to determine the factors associated with health-seeking behaviour of diagnosed pulmonary TB patients in Butaleja district in Uganda, with the aim of developing recommendations to promote positive health-seeking behaviour amongst patients diagnosed with TB in Butaleja district.

This chapter describes the research design, sample, and techniques for data collection and analysis used for the study. The process that was used to gain permission to conduct the study is outlined. Ethical considerations and issues pertaining to the rigor and trustworthiness of the study are discussed, as well as the strengths and weaknesses inherent in the study design.

3.2 RESEARCH DESIGN

A research design is a plan for collecting and utilising data or blueprint of how the researcher intends to conduct the research (De Vos et al 2007:132). It is a blue print for conducting a study that maximises control over the factors that could interfere with the validity of the findings (Burns & Grove 2005:734). It is the overall plan for addressing a research question including specifications for enhancing the study's integrity (Polit & Beck 2008:765). A qualitative approach, with exploratory and descriptive design was used.

3.2.1 Qualitative research

Qualitative research is the investigation of phenomena, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a flexible research design (Polit & Beck 2008:729). It is a systematic, interactive, subjective approach used to describe life experiences and give them meaning (Burns & Grove

2005:747). The purpose of qualitative research is to discover the essences, patterns, symbols, attributes and meanings of human and related phenomena under study with informants in their natural or familiar environments (Leininger & Mc Farland 2002:86). Qualitative research`s hallmark is the richness of information and the types of settings that are modified to enrich understanding (Mouton 2008:75).

In this qualitative study, the researcher attempted to understand people in terms of their own definition of the world. By utilising a qualitative approach, an attempt was made to understand the health-seeking behaviour of the diagnosed pulmonary TB patients from the subjective perspective of the TB patients. The complexity, richness and diversity of their health-seeking behaviour could only be captured by describing what really goes on during their health-seeking for pulmonary TB, incorporating the context in which they practiced this health-seeking behaviour as well as their frame of reference (Mouton 2008:195)

3.2.2 Exploratory research

Exploratory research is conducted to gain insight into a situation, phenomenon, community or individual. Generally exploratory research has a basic research goal and researchers frequently use qualitative data (De Vos et al 2007:106). In this study, the researcher attempted to gain insight into health-seeking behaviour for TB as a phenomenon by asking participants the factors that influence their decision to seek health care when they are sick.

3.2.3 Descriptive research

Descriptive research presents a picture of the specific details of a situation, social setting or relationships. A descriptive study is more likely to refer to a more intensive examination of a phenomenon and the deeper meanings thus leading to a thicker description (De Vos et al 2007:106). In this study the researcher attempted to get a deeper meaning of the health-seeking behaviour for TB by describing the answers given by the participants.

3.3 RESEARCH METHODS

Research methods refer to the techniques used to structure a study and to gather and analyse information in a systematic fashion. The control provided by the design increases the probability that the study results are accurate reflections of reality (Burns & Grove 2005:211).

3.3.1 Population

The population is the entire set of individuals having some common characteristic (Polit & Beck 2008:727). The accessible population comprises the individuals who conform to the eligibility criteria and are available for a particular study (De Vos et al 2007:198, Polit & Beck 2008:338). The universal population for this study was pulmonary TB patients in Butaleja district. The target population was pulmonary TB patients attending Nabiganda health centre. The accessible population was the newly registered pulmonary TB patients at the health centre who were willing to come to the health centre for the interview or could be contacted by phone to set up an interview.

3.3.2 Setting

Setting is defined as a quiet environment that provides privacy is comfortable, non-threatening and easily accessible to facilitate the interview process (De Vos et al 2007:294-295). The setting was Nabiganda health facility, this being the area where participants first came to learn about their diagnosis of pulmonary TB and where they received their treatment. Figure 3.1 is a map that shows the health centers in Butaleja district and Nabiganda health Centre, which was the study site.

sample was used because it was an easy and economical way of indentifying participants who were willing to participate in the study. Whereas this may have resulted in a non-representative sample, it was not a concern in this study because the aim of the study was not to generalise the findings, but to get an in-depth understanding regarding health-seeking for TB from those participants selected. The sample size depended on the saturation of information during data collection.

3.3.4 Eligibility criteria

The term eligibility criteria refers to criteria used by a researcher to designate the specific attributes of the target population, and by which subjects are included or excluded from participation in a study (Burns & Grove 2005:342; Polit & Beck 2008:290). Specific inclusion and exclusion criteria were used to decide whether an individual would or would not participate in the study (Brink et al 2011:133). The eligibility criteria were as follows:

3.3.4.1 Inclusion criteria

- Adult pulmonary TB patients (18 years and above) both male and female
- Diagnosed at, and attending treatment at Nabiganda health centre (study site).
- Newly diagnosed as determined from the health centre records and attending the health centre for no more than 4 weeks.
- Munyole by tribe (indigenous tribe).
- Resident in Butaleja district.

3.3.4.1 Exclusion criteria

- Those not willing to come to the health centre for the interview.

3.4 DATA COLLECTION

Data collection refers to the precise, systematic gathering of information relevant to the research purpose or the specific objectives, questions or hypotheses of a study (Burns & Grove 2005:732). It is the gathering of information to address a research problem

(Polit & Beck 2004:716). Data collection method corresponded with data sources (Mouton 2008:104) as follows in 3.4.1.

3.4.1 Data collection method

Unstructured individual, face-to-face interviews were used to collect data. An unstructured interview is an oral self report in which the researcher asks the respondent questions without having a predetermined plan regarding the content or flow of information being gathered (Streubert & Carpenter 2011:34). In this study questions were not asked in a predetermined sequence, but the researcher ensured that all relevant topics were covered and that the research focus was kept in mind (Tjale & De Villiers 2004:243). The researcher used unstructured interviews in order to gain a detailed understanding of the participants' health-seeking behaviour and the factors that influenced this behaviour. The method gave both researcher and participant more flexibility of providing information. It also enabled the researcher to follow up particular interesting avenues that emerged in the interview enabling the participant to give more information (De Vos 2007:296).

3.4.2 Data collection instrument

The researcher used an interview schedule to guide the dialogue (see annexure E). The interview schedule was based on one central question, followed by prompts from the researcher. The central research question was "***What are the factors that influence your decision to seek health care when you are sick?***" This question was followed by probing questions based on the initial response from the participant. The questions in the interview schedule were translated into the local language (Lunyole).

3.4.3 Data collection approach

The interviews took place at the Nabiganda health centre in Butaleja district. The interviews were audio recorded with the permission of the participants (Katzellenbogen 2007:177). The audio recorder was placed with the participant's permission on a nearby surface such as a desk to record the interview. Notes were written down on the interview schedule during the interview and same included during the transcription to capture the researcher's own observations. The observations made during data

collection assisted the researcher during data analysis in providing additional insight into emergent themes and subthemes.

3.4.3.1 Advantages and disadvantages of interview

Advantages

The advantages of face-to-face interview were that:

- It offered flexibility which enabled the researcher to elicit more in-depth responses.
- In-depth interviews provided much more detailed information.
- The face-to-face element meant the researcher was certain of who would answer the questions (Hayden, Thompson & Levy 2007:204).

Disadvantages

- Interruptions, such as telephone calls, participant disruptions caused by recording the interview, verbose participants and some participants who tended to wander of the subject.
- On the researcher's part they proved costly in terms of time and transport costs.

3.4.4 Data management

The researcher used a computer analysis tool ATLAS/ti 7 to aid in the management of textual data, for storage and retrieval of information more quickly and accurately. The researcher's observations were noted at the back of the interview schedule. Each audio recorded interview was typed by the researcher in the form of a verbatim transcript. The researcher typed the transcripts within two days of the interview and completed the transcripts of one day's interview before the next day of interviews.

3.5 DATA ANALYSIS

Audio recorded data was transcribed verbatim and the resulting texts analysed. A computer analysis software ATLAS/ti 7 was used to aid in the management of textual data, for storage and retrieval of information more quickly and accurately. Data analysis was done using open coding. The analysis involved breaking up the data into manageable themes, patterns, trends and relationships. The aim of analysis was to understand the various constitutive elements of the collected data through inspection of the relationships between concepts, constructs or variables and to see whether there were any patterns or trends that can be identified or isolated to establish themes in the data (Mouton 2008:108).

Content analysis was done to explore in detail for common themes and these were then established into units of meaning or codes (Mouton 2008:198). The advantages were that these were descriptions of real situations and the information gained was rich. The disadvantage was that transcribing and data analysis was time consuming.

Creswell's (2009:186) analytic spiral was utilised to analyse data as follows:

- Planning for recording of data.
- Data collection and preliminary analysis.
- Managing or organising data.
- Reading and writing memos.
- Generating categories, themes and patterns.
- Coding the data.
- Testing the emergent understandings.
- Searching for alternative explanations.
- Representing, visualising (i.e. writing report).

3.6 MEASURES TO ENSURE TRUSTWORTHINESS

Trustworthiness refers to the confidence qualitative researchers have in their data. This was assessed using the criteria of credibility, transferability, dependability and conformability (Polit & Beck 2008:540).

3.6.1 Credibility

Credibility is a criterion for evaluating data quality in qualitative studies, referring to confidence in the truth of the data (Polit & Beck 2008:542). The following strategies were used to enhance credibility of the study:

Member checking: During the face to face interviews with the participants in the process of data collection, member checking was carried out by the researcher occasionally rephrasing the participants' responses to check if the responses had been interpreted correctly by the researcher. Participants were encouraged to provide critical feedback about factual or interpretive errors or inadequacies.

Prolonged engagement was achieved through investment of sufficient time collecting data to have an in depth understanding of the participants under study and to test for misinformation and distortions (Polit & Beck 2008:539). The researcher spent as much time as was necessary interacting with the participants during data collection.

Reflexivity: During the process of conducting interviews, the researcher was aware of the interaction between self and the data. Acknowledgement and analysis of this process is termed reflexivity (Lietz, Langer & Furman 2006:1).

Peer debriefing and examination: This involved a session with the clinical officer in charge of the health centre for peer review and to explore various aspects of the inquiry (Polit & Beck 2008:539). A senior doctor with a background in Public Health, working with the MOH in Uganda with the National TB programme was requested to review and comment on the researcher's understanding of the health-seeking behaviour of the pulmonary TB patients interviewed. Throughout the phase of data collection and data analysis, the researcher worked in close collaboration with the supervisor referring samples of interview transcripts and coded analysis for comments and guidance. This further enhanced the credibility of the research.

3.6.2 Dependability

Dependability is a criterion for evaluating data quality in qualitative data, referring to the stability of data over time and over conditions (Polit & Beck 2008:539). Dependability was enhanced by taking steps to ensure that the findings would be consistent if the study is replicated with the same informants or in a similar context. In this research, dependability was achieved by applying strategies to enhance the credibility of the study and by establishing an audit trail. Lietz, Langer and Furman (2006:11) describe audit trail as keeping track of the decisions which led to the choice of particular steps in the research procedure. Reasons for the choice of research design, sampling type and sample size and methods of data collection and analysis were described in this chapter. This provides others who intend to replicate the research project in another context with the necessary methodological information.

3.6.3 Conformability

Confirmability is a criterion for evaluating data quality by referring to the objectivity or neutrality of the data (Polit & Beck 2008:539). It refers to documented verbatim statements and direct observational evidence from participants, situations and other people who firmly and knowingly confirm and substantiate the data or findings (Leininger & Mc Farland 2002:88). Confirmability was enhanced through member checking whereby, during the data collection, confirmation was sought from the participants that the data collected was truly a reflection of their narratives regarding health-seeking behaviour for pulmonary TB. An audit trail was created that could be used independently to establish both the dependability and confirmability of the data. This was done through a systematic collection of materials and documentation that could allow an independent auditor to come to conclusions about the data. The materials included the raw data including field notes; interview transcripts and the data reduction and analysis products.

3.6.4 Transferability

Transferability refers to the extent to which findings can be transferred to other settings or groups (Polit & Beck 2008:539). It refers to whether the findings from a completed study have similar, though not necessarily identical meanings and relevance to be

transferred to another similar situation, context or culture (Leininger & Mc Farland 2002:88). Data from this study is transferable to their sources only, which was pulmonary TB patients attending treatment at the Nabiganda health centre in Butaleja district of Uganda.

3.7 ETHICAL CONSIDERATIONS

Ethics is a system of moral values that is concerned with the degree to which research procedures adhere to professional, legal and social obligations to the research participants (Polit & Beck 2008:717). Research ethics involves protecting the rights of the participants and the institutions in which research is done, and maintaining scientific integrity (Burns & Grove 2005:181; Polit & Beck 2008:141).

3.7.1 Permission to conduct the study

Permission to conduct the study was sought from the Higher Degrees Committee of the Department of Health Studies, UNISA (see annexure A), the Uganda Council of Science and Technology (see annexure B) and the relevant health authorities responsible for district and health centre where the study was conducted (see annexure C). Informed consent to participate in the study was obtained from the individual participants using a consent form (see annexure D).

3.7.2 Maintaining confidentiality and privacy

Confidentiality and privacy was ensured by using a password, restricted access computer for storage and management of the data; and anonymity was guaranteed by assigning interviewees codes instead of names.

3.7.3 Beneficence

Beneficence will be ensured by making the research results known to the Butaleja district health office and other interested parties, who by gaining a better understanding and appreciation of factors associated with delayed TB diagnosis and non-compliance

with treatment, will be able to design better interventions to encourage appropriate health-seeking behaviour thereby benefiting people with TB.

3.7.4 Autonomy and respect for persons

Participation in the study was voluntary and the participants were assured that they could withdraw from the study at any time if they so wished, without penalty.

3.7.5 Provision of debriefing, counselling and additional information

Participants were provided with a brief background to the study prior to the commencement of interviews. Any false hopes or expectations that the interview might have caused were respected and talked through to prevent emotional or any other risk to the participants.

3.7.6 Act on findings and publishing

The work of others was acknowledged and negative and positive findings were reported. The participants were informed that the findings of this study would be disseminated in the form of publications in accredited journals and presentation at the relevant gatherings such as conferences and workshops (Katzellenbogen 2007:27).

3.8 CONCLUSION

This chapter discussed the research design and methodology for the study. The data collection method and data analysis were explained. The next chapter will present the data analysis and findings of the study.

CHAPTER 4

ANALYSIS, PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

4.1 INTRODUCTION

In this chapter the research findings are discussed. This chapter begins with a description of how the interviews were arranged and conducted. The procedures that were used for managing and analysing the data are described. The final section addresses the important themes and categories which emerged from analysis of the interview data. The findings are then discussed with reference to the research objectives.

The purpose of this study was to determine the factors associated with health-seeking behaviour of diagnosed pulmonary TB patients in Butaleja district in Uganda, with the aim of promoting positive health-seeking behaviour amongst patients in Butaleja district.

The objectives of the study were to

- explore the health-seeking behaviour of the pulmonary TB patients in Butaleja district
- describe the factors that influence the health-seeking behaviour of patients diagnosed with pulmonary TB
- provide recommendations to promote positive health-seeking behaviour amongst patients diagnosed with TB

4.2 DATA COLLECTION PROCESS

Data was collected through individual in-depth unstructured interviews. Seven individual in-depth interviews were held with participants who met the eligibility criteria as explained in chapter three of this study. The participants were pulmonary TB patients

who were receiving their treatment for TB at Nabiganda health centre. The interview dates and times were arranged ahead of time by working with the person in-charge of Nabiganda health centre, who also helped to contact the participants by phone and to set up appointments for the interviews.

The interviews took place at Nabiganda health centre, which was the health facility at which the participants were receiving treatment for TB. Some of the interviews were held under a tree at the health centre and others were conducted in the treatment room. Each interview began with a brief introduction given by the researcher stating the purpose and objectives of the study. The participants were asked if an audio recorder could be used to record the interviews and all the participants agreed to be audio recorded. Written consent to participate in the study was provided by the participants signing or placing their thumb prints on a written consent form.

The consent form was prepared by the researcher before the study and the contents of the form were read to the participants to seek their consent. As part of assuring autonomy from the patients whilst seeking consent for the study, the researcher informed participants that they were free to withdraw their participation at any time of the interview since participation was voluntary. Pseudonyms and interview codes were used to refer to the participants in order to promote confidentiality and anonymity. The central question for the interview was “***What are the factors that influence your decision to seek health care when you are sick?***” followed by probing questions in response to the initial response to the central question.

During each interview, the researcher’s observations were noted on a blank sheet of paper and notes were also taken. The researcher transcribed the verbatim reports within a few days of the interview. Based on each participant’s response to the central question, the following questions were used to probe the participants:

- How did the sickness start?
- What did you think was causing the sickness?
- What did you do/what type of help did you seek from the time the sickness started up to when you came to the health centre?
- Why did you choose to seek the type of help you did when the sickness started?

- What treatment/help were you given?
- What challenges/problems did you have taking your treatment?
- What advice would you give people who would have similar symptoms like the ones you had when your sickness started? Why?

Interviews were conducted with the recruited participants until data saturation occurred. Data saturation occurred at the seventh interview during which no new information was provided compared to what had already been provided by earlier participants.

4.2.1 Challenges encountered during interviews

Most of the interviews went as planned. However, in one of the interviews, the participant's child kept crying and causing interruption of the interview. The participant was given time to calm the baby before the interview could continue.

4.3 DATA ANALYSIS AND PRESENTATION

A computer analysis software ATLAS/ti 7 was used to aid in the management of textual data, for storage and retrieval of information more quickly and accurately. The interviews were audio recorded. Each audio recorded interview was listened to and written down by the researcher in the form of a verbatim transcript which was later analysed. The transcribed data was broken into manageable themes and categories of information. Data analysis was done according to Creswell's (2009:168), analytic spiral method which includes the steps as explained in chapter three of this study.

4.4 DATA FINDINGS

Data findings are presented as biographical information of the participants and the themes and categories that emerged from the interview analysis.

4.4.1 Biographical information of the participants

Seven individual in-depth interviews were conducted. The participants comprised of three females and four males who met the eligibility criteria of the study. The ages of the

participants ranged from 32 to 60 years. Three of the participants reported having had some primary education; one reported had secondary education, whilst three reported never having had any formal education. Apart from one participant who was a retired civil servant, all the six participants reported farming as their occupation. However, two participants reported that they were currently not able to tend their farms due to the effects of the pulmonary TB that they were suffering from.

4.4.2 Themes and categories

Three themes emerged from the findings as presented in table 4.1.

Table 4.1: Summary of findings using classification by theme and category

Theme	Categories	Meaning unit
1 Nature of health-seeking behaviour	1.1 Institutions and health providers visited 1.2 Interventions and treatment received 1.3 Compliance to treatment	<ul style="list-style-type: none"> • Delay in diagnosis and initiation of proper treatment for TB • Causes of symptoms experienced by the participants • Interventions/treatments offered by the health providers attended
2 Factors associated with the health-seeking behaviour	2.1 Health system factors 2.2 Personal factors 2.3 Social factors	<ul style="list-style-type: none"> • Poor access to health services • Altered perceptions of quality of health services • Missed opportunities for early diagnosis and treatment of TB patients • Lack of knowledge about TB • Lack of funds to enable to seek health care • Health Beliefs affecting the decisions to seek health • Social influence: fear of social stigma related to TB diagnosis
3 Advice to others experiencing similar symptoms	3.1 Seeking health care	<ul style="list-style-type: none"> • Advice on when and where to seek care • Reasons for the given advice

4.5 INTERPRETATION OF DATA

4.5.1 Theme 1: Nature of health-seeking behaviour

The nature of health-seeking behaviour was related to the beginning and perceived causes of the participants' TB symptoms. This theme relates to the individual

participants' pathway to utilisation of the formal health system for diagnosis and treatment of their illness (pulmonary TB) including the institutions visited, health care providers consulted, diagnostic and treatment process, in addition to use of any other treatments before and during utilisation of the formal health care system.

The participants reported significant delay from the time when the first symptoms appeared, mainly cough, chest pain and fever; to the time when a definitive diagnosis of pulmonary TB was made and treatment started. One participant mentioned that:

"I used to have chest pain. I would feel pain whenever I would carry something and it went on worsening. Time came when I could not even carry anything. Then I spent a whole year and begun coughing seriously for a whole year. But I was taking tablets, taking this, doing that. But there was no improvement".

The other categories that emerged from this theme included interventions and treatments received prior to consultation at the health care centres and compliance to interventions and treatments offered by the formal health care centres.

4.5.1.1 Category 1.1: Institutions and health providers visited

The findings indicate that there was a delay in diagnosis and initiation of proper treatment for pulmonary TB. The participants indicated that they visited various institutions and health providers to seek health care. These visits contributed to the delay in diagnosis as the participants ended up late in a formal government health facilities such as government hospital or government health centre where their illness was eventually diagnosed as pulmonary TB. The pathway for individual participants to eventual use of the formal government health facilities varied as indicated in the following statement:

"I went to Musoga's clinics here in Nabiganda. When I didn't get better, I came to the government hospital here, but still no change. Then I went to a clinic in Mbale, and I came back here, but still there was no improvement. I then went to the traditional healer, but I did not go deep into them. When I realised it wasn't helping, I stuck on the hospital".

Institutions visited before eventual use of the formal government health facilities included local private health clinics, chemists and traditional healers. The private clinics

and chemists were manned by trained health care workers who charged patients a fee in order to make a profit. This was in contrast to the government health facilities where services are offered free of charge to the patients.

Whilst some participants reported only visiting the private clinics or chemists, which are part of the formal health system (public plus private health providers) some patients reported visiting both the private health providers and the traditional healers. However, once the participants ended up in the government health clinics and their illness correctly diagnosed and started on treatment, they all continued receiving treatment in the formal health centre and did not revert to the traditional healers or even private health providers. This was because they noticed improvement in their symptoms that they had not noticed while using the other health providers.

The multiple health-seeking behaviour, which is referred to as *treatment shopping* observed in this study is similar to what was observed in a study done in Nigeria, in which multiple health care seeking was found to be common, especially among TB patients with unscientific theories of TB such as witchcraft. Chemists were the first point of call for most of the patients (Okeibunor et al 2007:96).

Significant to note is that some of the patients had initially visited the government health facility several times before they were eventually diagnosed with TB. For some of them, they had even gone ahead to visit private clinics and chemists before starting another round of visits to the government health facility during which the diagnosis for pulmonary TB was made. Delay in diagnosing led to delay in initiating proper treatment for TB. Also by the time the diagnosis was made, the health condition of some of the patients had deteriorated. One participant indicated that:

“I was very badly off. I first came here to the health centre and got some treatment, but I wasn’t getting any better. So I decided to go to Mbale in a clinic. They gave me some treatment and I came back; but the sickness was becoming worse. Then I went to Bugwere and I went to the government hospital in Sapiri; but no change. Then I went to Budaka, they treated me, giving me tablets but there was no improvement. Generally the condition was not good, it was too bad. In fact to be brought here, they just carried me because I was almost lifeless”.

The findings corroborate those of a study on TB knowledge, attitudes and health-seeking behaviour in rural Uganda involving parents of infants and adolescents,

community leaders, traditional healers and patients with TB, in which the results suggested that TB patients tend to seek care late, when they are bedridden, coughing blood or too weak to do their normal duties and need encouragement to seek care (Buregyeya, Kulane, Colebunders, Wajja, Kigule, Mayanja, Musoke, Pariyo & Mitchell 2011:942). Reasons cited by respondents for delay in seeking TB care included use of self-medication, lack of money and the fear of being labelled as sick; and in particular being assumed to be co-infected with HIV (Buregyeya et al 2011:941).

4.5.1.2 Category 1.2: Interventions and treatment received

The participants received different treatments depending on which provider they visited. As earlier noted, a number of participants reported visiting a private clinic or chemist at some point in their health-seeking pathway. Medicines offered in the private clinics or chemists were mainly for treatment of the symptoms of TB, specifically the cough and chest pain. Some participants reported being given analgesics, cough syrups and antibiotics, whilst others received injections and intravenous (IV) fluids. One participant mentioned the following:

“The situation was bad. I was feeling heavy. They took me to Musoga’s clinic and they gave me drip. They took me back later and Musoga said he wouldn’t inject me or else I would die”.

Patients who reported consulting the traditional healers were reluctant to divulge the kind of treatment they received. One participant however reported being given herbs that he was required to drink regularly, as indicated in the following statement:

“For the local herbs the seller was vending it in the trading centre and someone brought him home. You know me I was at home and could not walk, so they told me to take some of the medicines saying it would enable me to walk. I took it for only two days. They would mix for me in a mug”.

None of the participants who visited the private health clinics or traditional healers mentioned undergoing any kind of diagnostic procedure to determine the actual illness before receiving prescribed treatment. One participant however mentioned that one of the private health providers requested her to go to the government health facility for the condition to be determined and later come back for treatment. The participant mentioned the following:

“So he told them to bring me here to the health centre to be diagnosed and then may be taken back to him to treat me”.

In the government health facilities, the interviewees reported undergoing several diagnostic tests including X-rays and sputum smears. Once pulmonary TB was diagnosed, the patients received tablets, and others reported receiving injections as well.

4.5.1.3 Category 1.3: Compliance to treatment

For purposes of this study, treatment compliance is the acting of a patient with pulmonary TB in accordance with the direction provided by the health care provider regarding application of remedies, medical or surgical applications or services for purposes of curing the pulmonary TB. Reports from the participants indicated that compliance to treatments received from the private clinics and traditional healers was poor as most patients reported discontinuing treatment. The reported reason for discontinuation of treatment was lack of improvement in their symptoms as indicated in the following statements:

“The problem I had with the treatment from the clinic is that I did not get well. I took the medicines but the situation was worsening”.

“I was taking the medicine but I was not getting any better. The chest was still paining me and becoming heavy, like they had put a stone on it. The condition was just becoming worse. I was not getting improvement from the medicines from the clinic so I stopped”.

Another participant who reported using herbs stated that:

“There was one of these people who “walk around” and he said that he knew the medicine for coughing and chest pain. So he gave me some of those herbs, but still there was no improvement and I stopped. The treatment I was given here (at the health centre) for the 8 months is the one that has made the difference”.

Some participants reported that they experienced side effects during the use of the treatment provided by the private clinics and chemists as indicated as follows:

“The tablets from the clinic were giving me side effects. The tablets would make me swell. They then had to begin treating the swelling. They told me my nutrition was not good and yet I was on treatment and this may have been causing the swelling”.

Reported compliance for medicines received in the government health facilities was good, and this was mainly because of significant improvement in symptoms observed by patients when taking the medicines. The patients mentioned experiencing some side effects when on the anti-TB medications received which included headache, feeling hot and sweaty (*olumbujju*), and change in the colour of urine, extreme weakness and dizziness. However, these were not reported to be a barrier to continuing treatment since the patients seemed to be seeing the value of the treatment in terms of improvements in symptoms. Some participants indicated the following:

“The treatment I got in the health centre was very great. I had even stopped digging but now am able to dig. Here in the health centre I got tablets and I continued using the tablets as per the instructions. I saw the situation was improving though slowly. You also know about sickness”.

“The problem I got with the tablets is that they would make me feel hot and sweaty (Olumbujju). I wanted to preserve my life and get back to normal, so I persisted taking the medicines and am still doing so”.

The many pill burden and long duration of taking treatment also appeared not to have been a barrier to compliance to many of the participants due to the improvement in symptoms while on treatment as one participant said:

“I was not bothered with the number of pills. You see I was going to die and here I was taking some medications and seeing some improvement, so I was really motivated to take my medications and am taking them without any problems”.

However, one participant mentioned having trouble in taking the prescribed tablets leading to interruption of treatment as indicated in the following statement:

“At the hospital, I was given tablets, but they were difficult to swallow. One had to be strong to manage. They were hard to swallow. So one of my nephews called my children and said, the medications want to kill the old woman, they are difficult to take. I swallowed for two months and I stopped”.

Current anti-TB therapy consists of a cocktail of drugs taken over a period of at least 6 months for new patients and 8 months for re-treatment patients. According to Weiguo, Wei, Yang, Limei, Hongbing and Jianming (2009:169), because of the long duration of therapy, there is a risk of non-compliance to treatment through treatment interruption or default. However, some participants in this study did not see the pill burden as a barrier to treatment compliance due to rapid symptomatic relief received from the treatment.

4.5.2 Theme 2. Factors associated with the health-seeking behaviour

Associated factors in this study refer those factors that affect the patient's decision to seek medical care and also the practices of the patients for the treatment of TB prior to and after seeking proper medical care. The following categories describe the various factors that may have led to the earlier described health-seeking behaviour by the various participants:

4.5.2.1 Category 2.1: Health system factors

This category relates to the combination of resources, organisation, financing and management that culminate in the delivery of TB services to the population. Poor access to health services was indicated and related to whether patients were aware of services and able to reach them within an acceptable time.

From the findings, it would seem that private health services were more available than the public health services. This may explain the reason for the participants who initially went to the private clinics or chemists. However, because the initial health services visited did not have TB diagnostic services or because the providers were not well trained, this led to improper treatment and delayed diagnosis. One participant indicated that:

"I chose to go to the clinic here, because us in the village, first treatment is sought from the clinic and if you don't get cured, then you look for further treatment".

This initial preference for clinics is most likely to be related to the wide availability and initial access to private clinics. For example, as Nabiganda health centre was the only government health centre in the area, there were several private clinics and chemists

observed in the area. Knowledge about availability of TB services was another factor that might have negatively influenced health-seeking behaviour. Whilst TB treatment and diagnostic services had always been available at the study site, which was Nabiganda health centre, information provided indicated that not everyone was aware of the availability of the services, as one of the participants indicated that:

“I was unfortunate that they had not yet put TB services at this health centre here, and I could not go to Mbale because it is far and I didn’t have transport and I couldn’t walk”.

Poor perceptions of quality of health services were evident, and this related to the confidence of the client in the ability of the health care provider or health care facility to meet their health care needs according to their expectations. The perceptions acted as either a motivator or a barrier to service utilisation. Quality health services demand that providers are well trained and have the required equipment and supplies to render the required services and to treat clients in a courteous and respectful manner. A key factor that seemed to influence choice of provider was the confidence that the participants had in health providers and in the ability of the provider to address their health problems. Some participants particularly declared their preference of one private health provider, namely, Musoga and this seemed to indicate his popularity and the confidence the participants had in him, as one participant mentioned that:

“I went to the clinic because that Musoga is my life. Had he not referred me here, I would be dead. That man is my life”.

Another factor that seemed to influence health-seeking behaviour was perceived or actual unavailability of medicines in the government health facilities. The participants indicated that availability of medicines in government health facilities was poor and so they did not see the need to go to the health facilities when sick. Some participants indicated the following:

“I go to the clinic first because sometimes there is no medicine here (at the government health centre) and they tell you to go and buy; which is what is supposed to happen in the clinic. So there is no need to come here (health centre) where they say treatment is free and yet there is usually no medicine”.

“They say the hospital never has medicines. So we never come thinking there are no medicines”.

One patient particularly mentioned that at some point during their treatment, they missed their treatment due to medicine being out of stock at the health facility as indicated in the following statement:

“I haven’t had much trouble with the hospital treatment. Only once I came to pick medications and I didn’t find them. They told me to return the following day. I came back but did not still find the medicines. So I had to miss treatment for 5 days”.

Perceived or actual non-availability of TB medicines led to loss of confidence in the public sector health services. However, some participants emphasised their confidence in the public health facilities, preferring to go there even if they knew they would not get the required medicines. It was indicated that whilst there were no medicines, they could at least have their condition diagnosed and the right treatment prescribed. One participant indicated the following:

“Me I don’t go there (private clinic or traditional healer). I come here because this is the hospital they gave us for all sick people. But when I come here and they write for me a prescription, I then go to the clinic and buy instead of going to the ‘hinansi’ (traditional healers)”.

Credibility and confidence in the public health facilities was further strengthened as patients began receiving the much needed relief that they were not getting from the other health providers. This helped improve compliance to treatment as one participant mentioned that:

“You see, I was going to die and here I was taking some medications and seeing some improvement, so I was really motivated to take my medications and am taking them without any problems”.

As mentioned by participants in this study, rapid symptomatic improvement could be both a barrier and an enabler to treatment completion, with patients either interpreting the improvement as meaning they were cured, and thus stopping treatment; or knowing they were getting better and wanting to complete the treatment until they were cured (Martins & Kelly 2008:534).

The findings further indicated missed opportunities for early diagnosis and treatment of TB patients. From the narratives of the patients, some of the patients had visited the

government health centre at least once before their TB was finally diagnosed and proper treatment initiated. Not surprising, for some of them the treatment provided before the diagnosis was not effective which compelled the participants to seek alternative care from the private sector. It was only on their return to the government hospital that TB was diagnosed. One participant mentioned that:

“I thought the sickness was minor. I used to come here (health centre) and they would give me antimalarials and panadol but I wasn’t getting better. And I used to come here often, in fact I have a lot of medical forms from here that I wanted to bring here with me, but my son said it was not necessary”.

The narrative above points to missed opportunities for early diagnosis and treatment of TB patients. This may be due to the low index of suspicion of TB by health workers or a large patient load at the health centre due to limited number of staff which made it difficult for health workers to thoroughly evaluate and screen patients who may have symptoms suggestive of pulmonary TB. This resulted in delayed diagnosis and initiation of treatment for some patients.

Literature has documented a number of system factors that contribute to poor health-seeking behaviour for TB and missed opportunities for early detection and treatment of TB patients. For example, a qualitative study that examined factors affecting the treatment pathway for TB patients in Nepal identified specific health services factors such as perceived quality, costs and service level and lack of provider-initiated referral as contributing to poor health-seeking behaviour (Asbroek, Bijlsma, Malla, Shrestha & Delnoij 2008:7). In Uganda only public health facilities and a few designated private facilities provide TB treatment; this may increase the health service delay among patients who prefer private providers. A study carried out in the urban referral hospital in Uganda showed that an estimated 76% of the TB patients initially presented to chemists (Kiwuwa, Karamagi & Mayanja 2005:122).

4.5.2.2 Category 2.2: Personal factors

Personal factors related to the individual’s feelings, knowledge, experiences and the individual’s unique circumstances that might have influenced health-seeking behaviour. Lack of knowledge about TB was evident, because from the interviews, it would seem that a number of participants were not aware of TB and its symptoms and so might not

have suspected that their symptoms were suggestive of TB. One participant indicated that:

“I did not know about the need to test for TB. I had never heard of it and it was not on my mind. I used to come because of the fever and they would give me medications for fever and I would just go away”.

This lack of knowledge coupled with the low index of suspicion among health workers may have led to a delay in the diagnosis and initiation of TB treatment in this particular participant. However, knowledge that one has an underlying health condition that predisposes them to other health conditions such as HIV, and for which they were already receiving medical treatment; made some of the participants seek early treatment for their symptoms, and to use the health facility since they were already receiving treatment from the hospital for their other underlying health condition. This led to early diagnosis and prompt initiation of treatment. One participant said that:

“You know if you have one disease, it’s the one that calls the others telling them... come here we have gotten a victim. Based on my condition, always coughing, I suspected that I had TB”.

Lack of means to enable health care seeking included lack of funds to travel to the health centres and the state or condition of health the patients were in as indicated by participants who said that:

“I was unfortunate that they had not yet put TB services at this health centre here, and I could not go to Mbale because it is far and I didn’t have transport and I couldn’t walk”.

“I first came to the government hospital here, they treated me here and sent me to Mbale, but there I did not go to the hospital but clinic since I did not have money. So I came back here without improving”.

Besides implying lack of geographical access to TB services, also implied from the narrative is lack of funds for transportation by some participants that might have inhibited their ability to seek care for their symptoms, either on their own initiative or when referred to other health facilities. However, some participants indicated travelling to other towns or even other districts to have pulmonary TB diagnosed and treated. For some participants, this was because they had been advised by their peers to do so, or

because they did not know that such services were available at the study site. It was assumed that some participants did not have confidence in the ability of the health centre to manage their symptoms since they had already visited the health centre before. However, the participants reported later having asked to be referred back to the study site which was nearer and more accessible, and so they would not need to spend a lot of money on transportation.

“I told them the hospital was far and I was failing to get money for transport to take me to Iganga. I asked them to refer me here to Nabiganda and that’s where am now getting my medicines”.

Health beliefs emerged as one of the personal factors affecting health-seeking behaviour of TB patients. Health beliefs were related to participants beliefs that helped explain what caused illness, how it could be cured or treated, and who should be involved in the process. Thus health beliefs provided the participants a rationale for health-seeking behaviour. The widespread resort to ineffective, costly and apparently irrational health-seeking behaviour was set in the context of traditional belief systems about the causes of the disease and how one got well.

From the findings of this study, it would seem that some participants distinguished between diseases they thought were best treated in the formal health sector, which could be regarded as sickness for the hospital; and those that required a different form of treatment. This influenced their choice of health provider between traditional healers or formal health care provider. One participant who mentioned that they did not seek care from a traditional healer commented that:

“I did not go to the traditional healer. I decided to be strong and convince myself that this was sickness for the hospital. I have never gone to the traditional healer or even used traditional medicine”.

It would seem that diseases that were to be treated by the traditional healers were those thought to be caused by witchcraft or for which the patients could not explain the cause. This was supported by the following statements by some of the participants who mentioned visiting the traditional healers:

“Before I discovered it was TB, when I came here (health centre) they used to think it was mere fever. Then I begun having difficulty in breathing and coughing, then I really thought they had bewitched me. I was convinced it was witchcraft”.

“I did not know, I was just guessing ... is it ancestors, is it witchcraft, was I bewitched through tea or? And fever would come, and I would really cough. And I thought I had been bewitched since I had been moving around the village asking for tea. Suspicion is what made me go to the traditional healers. I thought as you know I was asking myself, what could I have done? What have they done to me?”

Other illnesses that were to be treated by traditional healers were those for which the cause was unknown or could not be explained. A participant who reported visiting a traditional healer said:

“I didn’t know anything. But I would just feel pain; and was wondering what was happening to me. I hadn’t fallen down; I hadn’t been beaten, so I was really wondering what was causing the pain. I didn’t think it was the work. I just thought ‘something’ had just come”.

However, the participants reported later returning to seek care either from the private clinics or government health centre when they failed to have their symptoms cured or when the symptoms worsened, as one participant indicated:

“The pain was becoming worse, so even if I had gone to the traditional healers, I decided to go to the clinic”.

Perceived severity of disease influenced how soon the patient sought treatment and where they sought treatment. Some participants indicated that they received initial treatment from the private sector because they perceived their conditions to be minor:

“I chose to go to the clinic because I did not know what it was that I was suffering from. I thought it was a simple fever, and thought if I took the medicines from clinic they would help me. I knew that it was minor. I did not know it would take long”.

For some, they thought the symptoms they had were minor having been caused by exposure to coldness and would quickly resolve. One participant indicated that:

“I thought it was just simple fever that was also blocking my throat. I had just come from the swamp having harvested (the rice)... then I thought I was sick because I had been in the cold looking after the rice. So I went to the clinic knowing it was a simple fever”.

It was either once they did not get the expected improvement or after the symptoms became severe, such as when they began to cough out blood that they would finally go to the public health facility, as one participant said that:

“Initially since I thought it was mere fever, I would buy some tablets and syrup in the clinics or chemists but there was no improvement. So I came and got registered here and got treatment”.

For some patients who suspected that their condition may have been TB, they still delayed seeking proper medical care if they were not coughing blood, which would have been an indication that the sickness was severe and that one needed to visit the government health facility.

4.5.2.3 Category 2.3: Social factors

This category relates to the social values and or behaviour of the groups such as family and friends, to which an individual belonged and their influences on individual's behaviour, for example through peer pressure. Social influence emerged as it related to effects of significant peer's opinions, suggestions and behaviour on an individual's health-seeking behaviour. Suggestions and encouragement seemed to be crucial in encouraging some of the participants to seek initial health care for their symptoms or to seek alternative health care when the current treatment was not working. These suggestions or encouragement could be from relatives, health care providers, peers and friends. One participant commented that:

“You never know the cause, so you wonder and so you stay home and it is someone at home who gives you advice to go for treatment”.

The suggestions were also based on the peers' or friends' own experiences or knowledge; and depending on how accurate the knowledge was, this would promote or hinder proper health-seeking behaviour. One participant said that:

“People in my village who had had similar symptoms were telling me that that must be TB and that I needed to go for treatment”.

Another participant who received helpful advice from the provider they were visiting in the private sector when the treatment they were receiving was not helping indicated that:

“One health worker told me that for the period you have taken tablets, you must by now have taken 4 basin-full of tablets, with no change. Go to the hospital and they will give you a referral for an X-ray”.

Provided suggestions would lead to poor health-seeking behaviour when the friend suggested use of health care that is not effective, for example use of herbs on the suggestion of one’s friends. Social influence in terms of advice from relevant others acted as a cue to action for health care seeking.

Social support was reported as support from others, both financial and otherwise. Social support also seemed to have influenced health-seeking behaviour. Some participants reported not being able to go to hospital because there was no one to escort them or support them to go to hospital. One participant indicated that:

“I delayed to seek health care because I was alone with no one to help. When I was not sick I used to come alone”.

For others, it was their significant others who ensured that they went to hospital or provided them the resources to be able to go to hospital as indicated that:

“I was coughing, and they called my daughter and she came and said, take her to the hospital and I will come to pay the bill. So they took me to the clinic”.

Support from others was important in increasing adherence to treatment. One participant mentioned how she had a treatment supporter whose role it was to ensure that she was taking the medicine. The participant indicated that:

“I would take all the medications; even here the health workers insisted that we take the medications. There is no day I ever missed”.

Social support is found to be influencing health-seeking behaviour for TB. In a similar study, the family was perceived by participants to be influential in helping patients seek care, through economic support and in assisting to identify appropriate health facilities for medication and providing staff for adherence to medication (Ayisi et al 2011:515)

Social Stigma related to TB was highlighted as a factor related to health-seeking behaviour as this relates to the extreme disapproval of or discontent with a person who is suffering from pulmonary TB or its symptoms by members of the community. Stigma seemed to have played a role in influencing health-seeking behaviour of some participants in this study, as one participant mentioned that:

“When I was coughing and spitting, they were discriminating against me. The kids could not come to me, even my relatives. They wouldn’t allow me to touch food or anything. It made me feel bad, and I felt as good as dead. People feared me”.

Also by being stigmatised and avoided, the participants were unlikely to come into contact with others who would either help them to seek health care or advise them to do so. A participant said that:

“I took three years; no one would come to visit me, except my wife and kids. And when I began treatment and one person came to see me, he went and told the villagers that I have HIV and that I have been given HIV tabs (the big red medicines), so let me die, nobody will even bother going there (meaning coming to him)”.

Due to association of chronic or long standing and non resolving symptoms with HIV or the tendency for people to associate any long standing condition of unconfirmed cause with HIV, some participants reported having been discriminated against because people thought they had HIV, as indicated in the following statement:

“The cause of my delay to seek health care was stigma. My mother was helpless, my father had died and my brothers did not mind. They thought it was HIV and even my relatives. So they said, if she dies that is her problem since they said I had gone to look for HIV. So it’s my ex husband who took me to the hospital and they checked me and found that it was TB”.

Stigma is associated with concealment of symptoms, treatment default, and isolation from support networks, decreased self esteem, self-perception, and self-care

(Giorgianni 2004:17). Several studies have shown that TB is stigmatised; with most authors identifying the perceived contagiousness of TB as a leading cause of stigmatisation (Ayisi et al 2011:515; Buregyeya et al 2011:940; Courtwright & Turner 2010:36). Lack of knowledge regarding routes of TB transmission may also contribute to TB stigma. Even among people with relatively good knowledge of TB transmission and transmissibility, the perceived risk of transmission can lead to stigmatisation and isolation of individuals with TB. In areas of high HIV prevalence, where HIV and TB co-infection is common, the link between the two diseases has contributed to the stigmatisation of TB (Buregyeya et al 2011:939).

TB is perceived as a marker for HIV positivity; therefore, HIV-associated stigma is transferred to TB-infected individuals. Sometimes, TB stigma may occur because an affected individual's community believes he or she must have done something to deserve to be infected. This judgment may reflect the belief that TB is divine punishment for a moral or personal failing, which then licenses stigmatisation (Courtwright & Norris 2010:36)

4.5.3 Theme 3: Advice to others experiencing similar symptoms

This theme related to information that the participants indicated they would give others who have similar symptoms like they did during their illness. Some participants mentioned that they had sought health care after they had been advised. One participant indicated that:

"I came here at Nabiganda, they also gave me some treatment, but it did not help. Then someone advised me that I needed to be tested to find out the cause of the chest pain. So one day I was in the trading centre and a car with the person who gave me the advice was in that car. But the situation was bad, I had pain in the ribs, but I was not coughing. So I went to Iganga. The doctor tested me and told me I was suffering from TB".

4.5.3.1 Category 3.1: Seeking health care

Seeking health care included advice on when and where to seek health care, including the reasons to give others advice. The participants indicated that if they saw someone

with similar symptoms like they had, they would advise that person to seek treatment immediately without delay. One participant indicated that:

“I have to tell them to go immediately and be checked and not delay. For me the delay caused my condition to worsen. They used to think it was just fever and for a whole year I did not get proper treatment, and when I finally went to the hospital, the condition had worsened; and am happy they treated me”.

Regarding where they would advise a person with similar symptoms to seek care, the participants indicated that they would advise the person to seek treatment from the government hospital and not the clinic or traditional healers. This was based on the experiences the participants had in seeking care for their own symptoms, as one participant indicated that:

“I would advise him to go to hospital and get treated and not delay because his condition will worsen. I would advise him to go to the hospital to get tested, so that they can identify what he is suffering from and he begins treatment. His sickness could be similar to mine”.

However, one participant who was still on treatment was non committal, saying they could only make a determination after they are fully cured. The participant indicated that:

“I would tell them that is how I was, but I went to the hospital, but that is if I get cured. But even if I don't get cured, I would still tell them to go and try their luck in the hospital”.

One of the participants indeed mentioned that they had already advised one of their friends on proper health-seeking behaviour for TB. The participant said that:

“In fact there was someone with chest pain, I told him... my friend, even me I had chest pain, but to get proper treatment, I had to first be tested, because I just used to take medicines not suited for my condition. And when I gave him the advice, he went to Mbale, he was tested and they also found him to be suffering from TB. So he was started on tablets and he is still taking the tablets. He is also now much better than he was”.

Among the reasons provided by the participants for providing advice to others with similar symptoms to seek early treatment from the hospital was the confidence they had acquired in the ability of the hospital to treat TB, as one participant mentioned that:

“I would advise one with similar symptoms to go early to the hospital because of their state. They would need to be tested and if found to be suffering from TB like I was, they would then be cured. Because am sure me I will be cured”.

Another reason was consideration for others and not wishing them to go through the pain and agony that the participants had gone through in seeking proper health care for their TB. One participant indicated that:

“I would advise them so because of the pain I went through, and I don’t want anyone to suffer like I did. I would want the person to be alive and well”.

It was also indicated that advising others was related to being exemplary; in terms of the importance of seeking early health care from the health facility. A participant said that:

“I can be an example, people now see me that I have improved ever since I began taking proper treatment. And if they too get sick, they will come to the health centre because they have seen me get better”.

4.6 DISCUSSION OF THE FINDINGS

4.6.1 Theme 1: Nature of health-seeking behaviour

The findings indicate that the health-seeking behaviour of participants in this study was generally poor, characterised by *treatment shopping*, use of private providers with poor quality of service and delay in seeking proper treatment for TB from the government health facilities. However, once participants ended up in the government health facilities and their TB was correctly diagnosed and put on treatment, compliance to treatment was good despite the side effects and pill burden because of the perceived benefits of the treatment in resolving symptoms that patients had been having for a long time.

Early detection and treatment of TB is critical to controlling the disease (WHO 2003). However, similar to the findings in this study, a number of studies have consistently found delays by patients seeking treatment for TB (Steen & Mazonde 1998:629; Lawn, Afful & Acheampong 1998:636; Kiwuwa, Karamagi & Mayanja 2005:122).

Cough and fever (*olumbujju*) were common symptoms at the onset of the participants' illnesses. These symptoms alone did not always prompt the patients to seek medical treatment early. Symptoms in the early stages of TB are not very specific and may be attributed to self-limiting illnesses, such as viral infections such as Flu, and only when symptoms became worse or persist would the person consult a health service. Symptom misinterpretation has been associated with patient delay in other studies internationally, where they are attributed to external causes such as overwork or exposure to cold (Lambert & Van der Stuyft 2005:946). The delay in health-seeking behaviour is likely to have increased the risk of morbidity, mortality, and transmission of TB to contacts.

The participants were found to have engaged in *shopping* for TB treatment which involved movement of the patients from one health provider to another to search for a cure for their symptoms. This finding is collaborated by other studies which have documented similar behaviour by TB patients (Okeibunor et al 2007:98; Ayisi et al 2011:515). As part of their *treatment shopping* behaviour, most of the participants mentioned visiting several private providers including clinics and chemists before eventually seeking care from the public health care system. This could have contributed to the observed delay. Consulting private health care providers has been found to aggravate treatment delay in urban South African TB patients (Van Wyk et al 2011:1076).

Specifically, the poor quality of TB services in the private sector leads to delay in diagnosis and initiation of treatment for TB patients seeking care from the private sector. This poor quality of TB services in the private sector has been documented by Bell, Duncan and Saini (2011:1010) who in their study of knowledge, attitudes and practices of private sector providers of TB care in TB high burden countries found that all categories of TB care providers lacked comprehensive knowledge of national treatment guidelines. Procedures for referral, treatment monitoring, record keeping and case holding were not systematically implemented. However, it was also found that there was a high degree of willingness among private providers to collaborate with national TB programmes.

The finding that the participants visited the private sector to seek treatment for their TB symptoms has policy implications in the Ugandan context where the private sector plays a great role in service delivery but also has poor quality services (Konde-Lule et al 2010:29). There is need to strengthen the capacity of private providers to diagnose and properly treat TB patients or to be able to identify and refer potential TB patients appropriately.

4.6.2 Theme 2: Factors associated with the health-seeking behaviour

This study identified a number of health system factors, personal factors and social factors as having contributed to the participant's health-seeking behaviour for TB. Literature identified health system factors that lead to delayed initial contact of TB patients with health services; and missed opportunities for early diagnosis of TB patients during patients' initial contact with the health workers, leading to delayed diagnosis (Faussett et al 2002:798; Yimer, Bjune & Alene 2005:112; Harling, Ehrlich & Myer 2008:498). This is referred to as health system delay.

Data provided by the participants indicated that low suspicion of TB at health facilities caused further delay in obtaining correct treatment, once the participants decided to seek care at the health facility. None of the participants who visited a health facility mentioned having been diagnosed with TB the first time. This confirms findings from a previous study in Kenya that showed that health units failed to investigate chronic coughs in a certain proportion of TB suspects (Fox 1988:723). Another study also shows that most health facilities serving the urban and rural poor in the developing world are ill-equipped and their staff unqualified, hence the low suspicion for TB among patients who visited these facilities (Malmborg, Mann, Thomson & Squire 2006:754).

There are many consequences of missing the diagnosis of TB, and this raises several programme and policy issues. For the patient, misdiagnosis and faulty treatment leads to loss of scarce time and money in the search for treatment, and may increase the duration of illness and the possibility of death. For public health officials, misdiagnosis causes an underestimate in the rate of the incident of TB, and increases the duration of infectivity. Interventions that could improve the likelihood of TB diagnosis at health facilities may include implementation of standard screening procedures, additional

training of health care workers and education of patients so that they expect and request diagnostic testing for TB when appropriate.

Another health system factor in this study that contributed to poor health-seeking behaviour particularly non-compliance to treatment is unavailability of anti TB medicines in the health facilities. Other studies have also identified stock out of medicines as one of the factors contributing to treatment interruption and non adherence by TB patients (Buregyeya et al 2011:940; Ayisi et al 2011:515). This was particularly of concern in this study, where patients mentioned that they were willing to be compliant to treatment despite the long duration of treatment, because the treatment was providing them relief from their symptoms.

Some TB patients started with relatively non-specific symptoms, partially explaining the observed delay in seeking care or difficulties in obtaining appropriate treatment among the study participants visiting health facilities. However, the participants also held ideas about TB, most of which were inconsistent with the fact that bacteria cause TB. Some participants' explanations of the causes of TB in this study suggest the presence of misconceptions about the causes of TB. Some patients attributed their sickness to witchcraft whilst others attributed their sickness to hard physical work or exposure to cold. Similar findings have been reported in a previous study (Liefoghe et al 1997:815). As part of community health education and at the point of enrolment of clients into the TB treatment programme, there is a need for health education about the causes of TB as a way of addressing myths and misconceptions about the disease and to encourage proper health-seeking behaviour.

Some of the participants mentioned that suffering from TB had affected their relationships with friends and family leading to stigmatisation. The stigmatisation was mainly from non-family members although some participants also mentioned being stigmatised by family members. This finding is consistent with another study that has documented social stigma of TB to be more extra-familial than intra-familial (Ayisi et al 2011:515). This is important because social support provided by family often plays a pivotal role in promoting early TB diagnosis and adherence to treatment.

However, some of the participants in this study expressed how they were treated as though they had HIV related to their cough and loss of body weight. The association between HIV and TB could extend existing TB stigma, as observed elsewhere (Bond & Nyblade 2006:552; Godfrey-Faussett & Ayles 2003:70). This study also suggests that stigma related to HIV infection may hinder appropriate health-seeking behaviour for TB related symptoms. Stigma is linked to concealment of symptoms, treatment default, and isolation from support networks, decreased self esteem, self-perception, and self-care (Giorgianni 2004:17). Health education should therefore aim at reducing TB related stigma.

4.6.3 Theme 3: Advice to others experiencing similar symptoms

The participants mentioned that they could advise those with similar symptoms to seek early care from the government health centres. This indicates that through their experiences, the participants gained insight into the importance of early and proper health-seeking behaviour. Their insights could be used to help others to seek early and proper health care for pulmonary TB. By acting as “TB champions” these people who pulmonary TB had successfully treated would be used to share their experiences and to encourage proper health-seeking behaviour for pulmonary TB.

4.7 CONTEXTUALISATION OF THE RESEARCH FINDINGS WITHIN THE HEALTH BELIEF MODEL

The findings support various individual theories of health-seeking behaviour such as the health belief model. The health belief model considers beliefs about the impact of illness and its consequences, health motivation or readiness to be concerned about health matters, beliefs about consequences of health practices as being factors that influence health-seeking behaviour. Particularly, the health belief model identifies perceived susceptibility, and perceived severity to a disease; perceived benefits and barriers to seeking medical attention and cues to action as determinants of health-seeking behaviour (Sheeran & Abraham 1995).

In this study, a low sense of perceived severity of early TB symptoms might be interpreted from the statements as indicated in the themes. The low perception of the

severity of the disease influenced choice of provider; that is private clinic instead of the government health centre and how soon participants sought care from the health centre. The findings from the study also indicate various barriers that prevented participants from seeking early health care for their symptoms. The various barriers related to lack of knowledge of available services, perception of poor quality of available services, stigma, lack of social support and lack of transportation resources to enable proper health care seeking. The participants also indicated various cues to action that led them to seeking medical care. These included advice and support from peers and worsening of symptoms. The findings relate well with the health belief model as discussed in chapter two of this study.

4.8 CONCLUSION

In this chapter the major findings of the study were presented according to the themes which emerged during data analysis. The findings indicated that health-seeking behaviour for TB by the participants was generally poor. Factors associated with health-seeking behaviour included health system factors, individual factors and social factors. Based on their experiences participants noted that they would advise others with similar symptoms like they had to seek treatment early and from the government health facility. In the next chapter, conclusions and recommendations to this study are discussed.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter the conclusions and recommendations are presented based on the findings of this study. The purpose of the study was to identify the factors associated with health-seeking behaviour of diagnosed pulmonary TB patients in Butaleja district in Uganda, with an aim to develop recommendations to promote positive health-seeking behaviour. The study answered the following question: “What are the factors that influence your decision to seek health care when you are sick?”

5.2 RESEARCH METHOD AND DESIGN

A qualitative approach, with exploratory and descriptive design was used. Data was collected by means of in-depth individual unstructured interviews with seven participants at Nabiganda health centre. The unstructured interview format was followed and each interview lasted about 25 minutes. Probing questions were used to guide the dialogue. The same central question was used for all participants with additional probes depending on the individual participant’s responses to the initial question.

Permission was sought and received from the participants to audio record the conversations. The recordings were transcribed verbatim and the resulting texts were analysed. The computer analysis tool ATLAS/ti 7 was used to aid in the management and analysis of the textual data and to help with the storage and retrieval of information more quickly and accurately.

5.3 CONCLUSIONS

The study set out to establish the nature of the health-seeking behaviour of diagnosed pulmonary TB patients in Butaleja district and the factors associated with this health-seeking behaviour. Three main themes emerged from data and conclusions regarding the themes are discussed in the section that follows.

5.3.1 Nature of health-seeking behaviour

There were different pathways to final utilisation of the government health facilities for the diagnosis and management of the patient's pulmonary TB. Generally the TB patients visited the private health facilities as their first point of call before eventually visiting the government health facilities. For some patients, there was dual health care seeking from both the formal health system and the traditional healers. The patients reported a significant delay from onset of symptoms to final diagnosis. Treatments received in the private health clinics were symptomatic and not based on any diagnosis. In the government health facilities, attempts were made to diagnose patients through X-ray and sputum analysis before any treatment was provided.

The health-seeking behaviour of participants in the study can be said to have been generally poor, characterised by delay in seeking for proper treatment of TB from the government health facilities and use of private providers with poor quality of service. However, once they ended up in the government health facilities, their TB was correctly diagnosed and they were put on proper treatment. Compliance to treatment was good despite the side effects and pill burden. Compliance was related to the perceived benefits of the treatment in resolving symptoms that the patients experienced for a long time before being definitively diagnosed with pulmonary TB.

5.3.2 Factors associated with health-seeking behaviour

The study findings indicated a number of factors associated with the health-seeking behaviour of diagnosed with pulmonary TB which included health system factors, personal factors and social factors. With regard to health system factors, knowledge about available TB services and accessibility to these services by the patients

influenced health-seeking behaviour. Private clinics were more accessible to the patients and thus were used as the first point for health care seeking.

Perception about the quality of available services including the confidence of the patients in the health providers and availability of medicines also influenced health-seeking behaviour. Actual or perceived non-availability of TB medicines in the government health facility affected the decision of TB patients to seek health care from the government health facility, with participants favouring the private clinics. However, when participants eventually sought care from the government health facility, the effectiveness of the medicines received in alleviating symptoms increased confidence of the participants in the government health facilities.

There were a number of missed opportunities where patients with symptoms initially came into contact with health providers but were not thoroughly evaluated and screened for pulmonary TB. This contributed to the observed delayed diagnosis and initiation of proper treatment for some of the participants.

Personal factors including individual's knowledge about TB, lack of funds to enable proper health care seeking and the individual's health beliefs influenced health-seeking behaviour for the participants. Some participants lacked knowledge about TB and the need to test; and this coupled with the missed opportunities where health workers did not thoroughly evaluate and screen patients with symptoms at initial contact led to delayed diagnosis and initiation of treatment. Also, the participants cited lack of funds for transportation as a personal factor that inhibited their ability to seek care for their symptoms, either on their own initiative or when referred to other health facilities.

Individual beliefs about what had caused the illness, how it could be cured and who should be involved in the process affected choice of provider for health care seeking. Some participants thought that the symptoms they had were not to be treated in the hospital either because they thought they were being caused by witchcraft or the ancestors; or that they did not know what was causing the symptoms. Therefore they ended up seeking initial care from traditional healers; and only went to the formal health care system when the symptoms did not resolve. Those who went to the formal health care system sought initial health care from private clinics instead of government health

centre because they perceived their symptoms to be minor. The individual explanatory model for sickness indicates that whereas some societies see disease as a result of natural scientific phenomena and advocate medical treatments that combat microorganisms or use sophisticated technology to diagnose and treat disease, other societies believe that illness is the result of supernatural phenomena and promote prayer or other spiritual interventions that counter the presumed disfavour of powerful forces.

The social factors that were identified as having influenced the health-seeking behaviour of the participants in the study included social support and social stigma. Social support from others, both financial or just being there for the participants, influenced health-seeking behaviour for the participants. Some patients reported not being able to go to hospital because there was no one to escort them or support them to go to hospital whereas others indicated that they were able to seek health care either because a close relative escorted them there or provided them with funds to go and seek health care. Suggestions and encouragement from relatives, friends, peers and health care providers also influenced the health-seeking behaviour of some of the participants. The suggestions were based on the peers and friends' own experiences or knowledge and depending on how accurate the knowledge was, this would promote or hinder proper health-seeking behaviour.

Social stigma played a role in influencing health-seeking behaviour of some participants in the study. Some participants indicated that being stigmatised by their close friends or relatives because of the symptoms they had, made them feel worthless and reluctant to seek health care, as they feared the likelihood of being stigmatised by others whom they even did not know. Also by being stigmatised and avoided, participants were unlikely to come into contact with others who would either help them to seek health care or advise them to do so.

5.4 GENERAL CONCLUSIONS

The findings of this study based on the experiences of the seven participants interviewed lead to the conclusion that the health-seeking behaviour of the diagnosed pulmonary TB patients in Butaleja was poor due to a number of individual factors, social

factors and health system factors. The results indicated a need for a concerted multi-stakeholder effort to address the identified poor health-seeking behaviour. The district health administration needs to devise strategies to ensure that people with symptoms suggestive of pulmonary TB seeking early health care from the government health centre, are promptly diagnosed and started on treatment; and that they are compliant with their treatment. This will enable the district health administration to achieve its target for TB control and reduce the mortality and morbidity associated with pulmonary TB in the district of Butaleja.

5.5 RECOMMENDATIONS

Recommendations for this study have been categorised into those aimed at addressing health system factors, personal factors identified and those aimed at addressing the social issues. To improve health-seeking behaviour and strengthen TB control in Butaleja the study recommends that the Butaleja Health Administration considers the following as part of their TB control efforts:

5.5.1 Health system level interventions

The following interventions should be implemented to address the several health systems issues that this study has identified as contributing to poor health-seeking behaviour for pulmonary TB:

5.5.1.1 Update health workers' skills in TB diagnosis and management

Findings from this study indicate that despite coming into contact with health workers early in the disease process, a number of participants experienced delayed diagnosis of their TB. This can be attributed to lack of skills and knowledge among health workers to identify potential TB cases and have them investigated. Health workers in Butaleja district should therefore be provided with training in early detection, diagnosis and management of pulmonary TB. The training could be through workshops or on-job training using a mentoring approach by other experienced health workers

5.5.1.2 Provide information about health facilities in the district that offer TB services

The Butaleja district health administration should proactively provide information to the community about which health facilities in the district offer TB diagnosis and treatment services. This is important because a number of participants mentioned to be seeking TB treatment services from health facilities away from their community because they did not know that such services existed at the local health facility. This resulted into poor health-seeking behaviour due to lack of transport to access the far-away health facilities. The information could be provided using sign posts placed outside of the health facilities, fliers or through radio messages.

5.5.1.3 Ensure an un-interrupted supply of TB medicines

To ensure that TB patients do not miss their medicines and hence are compliant with their treatment, there is need for the district health administration to ensure an un-interrupted supply of TB medicines at the treatment centres. This will be achieved through ensuring that health facility managers accurately determine the needs based on their client load, place in their requisitions to the district store in a timely manner and that district distributes the medicines to the facility in a timely manner. Besides improving patient compliance with treatment, an un-interrupted supply of TB (and other) medicines will improve the confidence of clients in the government health services leading to improved health-seeking behaviour.

5.5.1.4 Strengthen the ability of private providers to identify and refer potential TB patients

Most of the participants in this study reported seeking treatment for their symptoms early in the disease process from private health providers, particularly in the clinics and chemists. However, the private health providers did not suspect that patients could have been suffering from TB and hence did not provide the appropriate care. There is therefore need for the Butaleja district health administration to train clinics and chemist owners in identifying pulmonary TB suspects and referring them to the health centres

for accurate diagnosis and proper treatment. This could be achieved through training workshops targeted at the private providers.

5.5.1.5 Establish partnerships between the government health facilities and the private sector for management of pulmonary Tuberculosis

Findings from the study indicated that many of the participants sought care from the private sector. However, few private health facilities offer TB treatment in Uganda since TB treatment is supposed to be a free service in the public sector health facilities. It is therefore important for the Butaleja health administration to establish partnerships with the private sector to ensure that potential TB patients attending health facilities are referred to the public sector facilities for appropriate medical care. This may entail design of referral forms that private providers may use to refer TB suspects in addition to empowering them to follow up referred patients to ensure that they seek proper diagnosis from government health facilities. Selected private sector facilities which meet certain certification criteria may also be accredited by the district health administration and provided with government support including free anti TB medicines to enable them to properly manage pulmonary TB patients who may still prefer seeking care in the private sector.

5.5.2 Community level interventions

5.5.2.1 Design and implement a comprehensive community based health education programme to improve community attitudes on pulmonary Tuberculosis

The participants felt stigmatised by their community and relatives due to their TB. Some participants mentioned that due to the stigma associated with TB and its link to HIV, their relatives did not support them in seeking appropriate medical attention for their TB. To ensure that community attitudes are supportive of proper health-seeking behaviour for pulmonary TB, health education should be started at family and community level to improve awareness about TB, the need to seek early and proper treatment and to address stigma towards TB patients. This can be achieved through various media including community drama, songs, posters, community gatherings and through radio

talk shows. The health education should be culturally sensitive and take into consideration the understanding of pulmonary TB health-seeking behaviour by the Nyole adults as revealed in this study. The Butaleja district health administration could partner with community based organisations in the design and implementation of the health education programmes.

5.5.2.2 Strengthen community based DOTS especially use of treatment supporters to improve treatment adherence

A key component of Uganda's Community based DOTS model for management of pulmonary TB is the use of community volunteers to supervise and support TB patients in taking their prescribed medicines. The CB-DOTS model shifts treatment from hospitals to ambulatory care with direct observation by volunteers selected by their communities and enhances the community's active role in DOTS and public health. The Butaleja district health administration should strengthen CB-DOTS in the district by working with communities to identify and train TB health volunteers. These volunteers could also act as community health educators on matters related to pulmonary TB, including referring TB suspects for proper evaluation by trained health workers.

5.5.3 Individual level Interventions

5.5.3.1 Improve individual knowledge about pulmonary Tuberculosis

The Butaleja district health administration should design and implement a comprehensive health education programme to improve individuals' knowledge about pulmonary TB. This is important because findings from this study indicated that some participants had little knowledge about the causes of TB; and the need to seek early medication attention when suffering from the symptoms suggestive of TB, such as prolonged coughs. The programme should focus on educating individuals about the causes of TB, its signs and symptoms and the need to seek early health care. The campaign should also focus on the fact that there are effective medicines against TB. The programme should also educate individuals on how to prevent pulmonary TB. The health education programme could include radio talk shows, printing of posters, health education talks in schools and at the health facility. Additionally, use could be made of

“TB champions”, who may be people who have had their pulmonary TB successfully treated to share their experience and to encourage proper health-seeking behaviour for pulmonary TB.

5.5.3.2 *Provide adequate counselling to individuals diagnosed with pulmonary Tuberculosis*

Whilst the participants were compliant to their prescribed TB treatment, medication was sometimes stopped due to side effects. An important intervention to ensure compliance with TB treatment is proper counseling for individuals diagnosed with pulmonary TB. This is important because of the long duration of TB treatment, the high pill burden and the toxic nature of TB medicines which can lead to severe side effects causing discontinuation of treatment. Also, the resolution of some symptoms like severe chest pain on commencement of treatment may lead to some patients discontinuing treatment. Health workers in Butaleja district should therefore provide adequate counseling to pulmonary TB patients on treatment to ensure compliance with treatment. This aspect of TB care should be emphasised during training of health workers and during technical supportive supervision by the district health administration to the TB treatment centers. Health workers should also be provided with counseling aides to help them in their work.

5.5.4 Recommendations for further research

Further research is needed to explore the community’s knowledge and attitudes towards TB, in line with the findings of low knowledge about TB and reported stigma towards TB patients in this study. Also, further research is needed to explore the knowledge of health workers (both in the public and private sector) regarding pulmonary TB.

5.6 CONTRIBUTIONS OF THE STUDY

The findings of this study may contribute towards TB control efforts in Uganda generally, and particularly in the rural district of Butaleja by providing a better understanding and appreciation of the factors associated with delayed TB diagnosis and

non-compliance with treatment in the district. Specifically, the findings of this study will be used to make recommendations to the District Health Administration in Butaleja and other entities involved in TB control in the district on how to improve health-seeking behaviour for pulmonary TB patients.

The results of the study will provide reliable data to help health care planners and providers in Butaleja district in designing congruent TB control programmes (including health education) that will lead to increased effectiveness of TB control efforts through early diagnosis and effective treatment through implementation of a CB-DOTS strategy that takes into consideration local factors.

5.7 LIMITATIONS OF THE STUDY

The study was conducted in one health care centre in Uganda and focused on the Banyole tribe residing in the Butaleja district only, thus limiting the generalisation of the findings to other tribes. The inability of the researcher to gain sufficient trust from the participants to enable them to fully share information about their health-seeking behaviour with the researcher might have been a limitation. Whilst some of the participants mentioned going to the traditional healers to seek health care, they were reluctant to divulge more information, perhaps due to fear of ostracisation. This limitation could have been addressed by interviewing some of the health workers who treat the TB patients and have some insight into this area.

5.8 CONCLUDING REMARKS

Data presented in this study provided sufficient information in relation to the research question and objectives. In view of the findings from this study, it is clear that the health-seeking behaviour of pulmonary TB patients that participated in this study was poor. There is therefore a need to improve health-seeking behaviour among TB patients. Implementation of the recommendations presented may assist in improving the health-seeking behaviour of pulmonary TB patients in Butaleja district thus contributing to effective TB control in the district.

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INTERNET SOURCE

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Annexure A

Approval from the University

Annexure B

Approval from the Uganda Council of Science and Technology

Annexure C

Letter seeking consent from the Butaleja District Health Office
and approval

Annexure D

Participant consent form

Annexure E
Interview schedule

ANNEXURE A: APPROVAL FROM THE UNIVERSITY



**UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE**

HS HDC/73/2012

Date of meeting: 30 July 2012 Student No: 3562-029-3
Project Title: Factors associated with health seeking behaviour of pulmonary tuberculosis patients in a specific district in Uganda.
Researcher: Mujasi Paschal Nicholas
Degree: Masters in Public Health (MPH) Code: MPHPR09
Supervisor: Dr MC Matlakala
Qualification: D Litt et Phil
Joint Supervisor: -

DECISION OF COMMITTEE

Approved

Conditionally Approved

**Prof D van der Wal
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE**

**Dr MM Moleki
ACTING ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

ANNEXURE B: APPROVAL FROM THE UGANDA COUNCIL OF SCIENCE AND TECHNOLOGY

From: Leah Nawegulo <lnawegulo@uncst.go.ug>
To: pmujasi@yahoo.co.uk
Cc: leahlabo@gmail.com, winnfry@gmail.com, jnabbuto@uncst.go.ug, jnabbuto@yahoo.co.uk
Sent: Friday, 17 August 2012, 7:26
Subject: Notice of UNCST approval, SS 2915

Dear Mr. Mujasi,

RE: FACTORS ASSOCIATED WITH HEALTH SEEKING BEHAVIOUR OF PULMONARY TUBERCULOSIS PATIENTS IN A SPECIFIC DISTRICT IN UGANDA (SS 2915)

This is to notify you that the Uganda National Council for Science and Technology (UNCST) approved the above protocol on **14 August 2012**.

The approval is subject to the following condition:

1. Payment of the research administration and clearance fee of 50 US Dollar.

Payment is made to Standard Chartered Bank Speke Road Branch; the account title is UNCST and the account number is 8705611811400. If however you wish to pay in Uganda shillings, the account number is 0105610632101. If you intend to wire the research fees, the swift code is SCBLUGKA. Note that bank charges will entirely be the researcher's responsibility.

2. Obtaining of clearance to the study districts from the Research Secretariat, Office of the President;

The process of obtaining clearance from the Research Secretariat, Office of the President is handled by UNCST on behalf of the researcher. Once approval has been secured, you will be notified.

Yours sincerely,

Leah Nawegulo

for: Executive Secretary

UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Hf of sbuf e! cz! DbnTdboof s! gspn! j out j h/ dpn

ANNEXURE C: LETTER SEEKING CONSENT FROM THE BUTALEJA DISTRICT HEALTH OFFICE AND APPROVAL

02 Jul 2012
P.O. BOX 1 BUTALEJA (U)
BUTALEJA DISTRICT LOCAL GOVT

MUJASI PASCHAL NICHOLAS
P.O. BOX 34539 KAMPALA
UGANDA
October 1, 2012

THE DISTRICT HEALTH OFFICER
BUTALEJA DISTRICT

Dear Sir/Madam

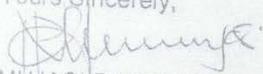
Re: Request for permission to conduct research at Nabiganda Health centre

I am a post graduate student registered for the Master of Public Health (MPH) programme at the University of South Africa. As part of my study, am required to conduct a research project.

The topic for my research project is: **"FACTORS ASSOCIATED WITH THE HEALTH SEEKING BEHAVIOUR OF PULMONARY TUBERCULOSIS PATIENTS IN A SPECIFIC DISTRICT IN UGANDA"**

The purpose of this letter is to request permission to be allowed to collect data in Butaleja district at Nabiganda Health centre; from Pulmonary TB patients that receive health care from the facility. After the study, findings will be shared with your office.

Attached/enclosed with kindly receive a copy of the research proposal and the ethical clearance certificate from the academic institution.

Yours Sincerely,

MUJASI PASCHAL NICHOLAS
Research Student

Please Mr. Mujasi Paschal, your request has been noted and permission granted.

02 Jul 2012
P.O. BOX 1 BUTALEJA (U)
BUTALEJA DISTRICT LOCAL GOVT

ANNEXURE D: PARTICIPANT CONSENT FORM

FACTORS ASSOCIATED WITH HEALTH-SEEKING BEHAVIOUR OF PULMONARY TUBERCULOSIS PATIENTS IN A SPECIFIC DISTRICT IN UGANDA

Consent form

Dear research participant

This is a request to you to participate in a research study entitled “**Factors associated with health-seeking behaviour of pulmonary Tuberculosis patients in a specific district in Uganda**” that is being conducted in Butaleja district.

The purpose of the study is to describe the health-seeking behaviours of Nyole adults diagnosed to be suffering from pulmonary TB and the cultural factors that influence this health-seeking behaviour.

Your participation in this research is voluntary, and you will not be penalised or lose benefits if you refuse to participate or decide to withdraw from the study after you have agreed to participate. Your participation will involve answering questions during an interview session. The interview will not be longer than is necessary. We do not anticipate significant risks involved in your participation.

A tape recorder will be used to tape the interview, but the tapes will be discarded at the end of the study. The information you provide will be kept confidential and you will not be identified as the person from whom the information was obtained. On request, a written summary of the research results will be availed to participants

Your participation is important because it will help the researcher to get the necessary information to achieve the study objectives. The information you provide will also be used by the researcher to make recommendations that can help improve health care services delivery in the District for pulmonary TB patients.

Should you have any questions regarding the study or your participation, please contact Mr Mujasi Paschal on telephone number 0752-339760.

Consent

The nature of the study “**Factors associated with health-seeking behaviour of pulmonary Tuberculosis patients Butaleja district in Uganda**” that is being conducted in Butaleja district including the above information, has been described to me orally.

I understand what my involvement in the study means and I voluntarily agree to participate.

Name of participant

Signature of participant

Date

Name of interviewer

Signature of interviewer

Date

Signature of witness.....

Date.....

ANNEXURE E: INTERVIEW SCHEDULE

FACTORS ASSOCIATED WITH HEALTH-SEEKING BEHAVIOUR OF PULMONARY TUBERCULOSIS PATIENTS IN BUTALEJA DISTRICT IN UGANDA

Interview Schedule:

Biographic data

How old are you?

What is your highest level of education?

Where do you live?

What do you do for a living?

Central Research Question

“What are the factors that influenced your decision to seek health care when you were sick?”

Probing questions:

1. How did the sickness start?
2. What did you think was causing the sickness?
3. What did you do/what type of help did you seek from the time the sickness started up to when you came to the health centre?
4. Why did you choose to seek the type of help you did when the sickness started?
5. What treatment/help were you given?
[Probe for any treatment received before attending the health centre and also when attending the health centre]
6. What challenges/problems did you have taking your treatment?
7. What advice would you give people who would have similar symptoms like the ones you had when your sickness started? Why?