DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR DISCLOSING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA

Submitted in accordance with the requirements

for the degree of

DOCTOR OF PHILOSOPHY IN PUBLIC HEALTH

in the subject

Health Studies

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: PROFESSOR DITABA DAVID MPHUTHI

CO-SUPERVISOR: DOCTOR. KHOLOFELO LORRAINE MATLHABA

May 2023

DECLARATION

Name: Ephrem Abathun Ayalew

Student number: 10342435

Degree: Doctor of philosophy in Public Health

I declare that this thesis, DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA, is my own work and that all sources that I have used have been duly indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.Furthermore, I declare that the thesis was submitted to Turnitin software for originality assessment and that it meets the acceptable requirements.

_________________ 01/05/2023

Ephrem Abthun Ayalew Date

ACKNOWLEDGMENTS

Praise be to Almighty Lord Jesus, for the grace, courage, health and hope.

I thank and appreciate my wife, Haimanot Altaseb, for her never-ending encouragement and support. I am grateful to my two children, Abigiya and Wengel for their patience.

I thank my supervisors, Professor Ditaba David Mphuthi and Dr. Kholofelo Lorraine Matlhaba, for their support and invaluable feedback at every step of my thesis.

I thank Dr. Barbro Norrström Mittag-Leffler and Dr. Eleanor Anderson Reid for their positive energy and inspiration. You encouraged me to continue working on this research project amid many difficulties.

I thank my parents, colleagues and friends for their moral support. I extend my sincere appreciation to all the research participants without whose input this study would not have been.

DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR DISCLOSING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA

Name of student: Ephrem Abathun Ayalew

Student number: 10342435

Degree: Doctor of philosophy in Public Health

Supervisor: Prof. Dittaba David Mphuthi

Co-supervisor: Dr. Kholofelo Lorraine Matlhaba

ABSTRACT

Background: Breaking bad news is a difficult task and on occasions, such news is withheld from the patient. This task of disclosing life-threatening illness and poor prognosis requires a full understanding and appreciation of contextual cultural issues. There is scarce evidence of the cultural preferences regarding disclosure of bad news when a patient is diagnosed with life threatening-illness in the Ethiopian context. This study aimed to explores the Ethiopian community cultural preferences on the disclosure of bad news when a family member is diagnosed with a life-threatening disease to develop guidelines for this eventuality.

Methods: A qualitative research approach and purposive sampling method were applied. In-depth interviews and observation were employed to collect data from fifty-one participants. In all, twenty-five in-depth interviews and twenty-six observations were undertaken. Field notes were taken during field observations. The study participants were patients, healthcare professionals and community members. Data was transcribed verbatim and analysed by using ATLAS.ti 22. The guideline developed was sent to nine experts and community members for their feedback on its applicability and cultural sensitivity.

Findings: Patients with life-threatening-illness disclosed that they prefer full but culturally sensitive medical information regarding their diagnosis of serious illness. Disclosure of poor prognosis should preferably be delivered to the patient family. The religious beliefs, values and rituals of Ethiopian culture are important during the disclosure of news on life-threatening. The respondents identified some advantages of breaking disclosing bad news. Participants submitted that such news should be incremental rather than stunning, amiable, roundabout, sensitive and sympathetic. A six-step, culturally adaptive guideline for breaking negative news was developed and validated.

Conclusion: Patients with life threatening-illness should be informed of their medical condition in the presence of family. Disclosure of bad news in such circumstances was perceived as helpful in curtailing expenses and meeting the patients' needs in palliative care. The patients submitted on their participation in decision on treatments. Cultural values, religious beliefs and preferred approaches should be considered carefully when conveying bad news. The availability of culturally adaptive guidelines could assist healthcare professionals to accommodate the patients' values, beliefs and preferences when disclosing bad news.

Keywords

Disclosing bad news; Ethiopia; guidelines; healthcare professionals; life-threatening illness; palliative care.

TABLE OF CONTENTS

LISF OF TABLES

FIGURES

ANNEXURES

ACCRONYMS AND ABBREVATIONS

019P19:	Observation 19 Participant 19
023P23:	Observation 23 Participant 23
024P24:	Observation 24 Participant 24
FN:	Field notes
I10P10PT:	Interview 10 Participant 10 Patient
I11P11HCPDR:	Interview 6 Participant 6 Healthcare Professional Doctor
I12P12HCPDR:	Interview 12 Participant 12 Healthcare Professional Doctor
I13P13HCPDR:	Interview 13 Participant 13 Healthcare Professional Doctor
I1P1PT:	Interview 1 Participant 1 Patient
I25P25HCPDR:	Interview 25 Participant 25 Healthcare Professional Doctor
I26P26HCPDR:	Interview 26 Participant 26 Healthcare Professional Doctor
I27P27HCPRN:	Interview 27 Participant 27 Healthcare Professional Registered Nurse
I28P28HCPRN:	Interview 28 Participant 28 Healthcare Professional Registered Nurse
I29P29HCPDR:	Interview 29 Participant 29 Healthcare Professional Doctor
I2P2PT:	Interview 2 Participant 2 Patient
I30P30HCPRN:	Interview 30 Participant 30 Healthcare Professional Registered Nurse
I31P31HCPRN:	Interview 31 Participant 31 Healthcare Professional Registered Nurse
I33P33PT:	Interview 33 Participant 33 Patient
I34P34PT:	Interview 34 Participant 34 Patient
I35P35FM:	Interview 36 Participant 36 Family Member
I37P37FM:	Interview 37 Participant 37 Family Member
I38P38FM:	Interview 38 Participant 38 Family Member

I3P3PT:	Interview 3 Participant 3 Patient
I4P4PT:	Interview 4 Participant 4 Patient
I5P5PT:	Interview 5 Participant 5 Patient
I6P6HCPRN:	Interview 6 Participant 6 Healthcare Professional Registered Nurse
I7P7COM:	Interview 7 Participant 7 Community Member
I8P8COM:	Interview 8 Participant 8 Community Member
I9P9HCPDR:	Interview 9 Participant 9 Healthcare Professional Doctor
IAPC:	International Association of Palliative Care
O14P14:	Observation 14 Participant 14
O16P16:	Observation 16 Participant 16
WHO:	World Health Organisation

CHAPTER ONE

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Healthcare professionals often have to deliver bad news to a patient or family regarding diagnosis and prognosis. The task of disclosure of bad news exerts extreme pressures on healthcare professionals, requiring expert and culturally sensitive communication skills to maintain hope and avoiding extreme emotional reactions while divulging such bad news (Sobczak, Pawłowski, Pietrzykowska & Spola, 2016:174). Furthermore, a lack of skill in this communicative act of delivering bad news has remained a significant impediment in the health profession (Banerjee, Mannaa, Coylea, Shena, Pehrsona, Zaidera, Hammondsa, Kruegera, Parkera & Bylunda, 2016:5).

How healthcare professionals communicate a diagnosis of life-threatening could cause psychological distress and anxiety to patients (Zwingmann, Baile, Schmier, Bernhard & Kelle, 2017:3170). While effective communication is a vital skill in delivering bad news, understanding the cultural context as well as patient autonomy are imperative constructs. In this regard, effective communication between healthcare professionals and patients assists patients in understanding their diagnosis and treatment plan (Custer, Rein, Nguyen, Wentworth & Dhamoon, 2019:3), while such lack of communicating bad news exerts a negative impact emotionally (Anderson, 2019:862).

Studies in non-African countries illustrate that a majority of patients prefer to be informed and have as much information at the earliest concerning their diagnosis, present health status and planned tratment (Aminiahidashti, Mousavi & Darzi, 2016:35; Syed & Karim 2016:269-270:49). However, in African countries, the next of kin have need to be informed as they are often the decision-makers when such a life-threatening illness is diagnosed (Ayers, Vydelingum & Arber, 2017:4).

In Ethiopia, healthcare professionals disclose bad news to the next of kin because the family's cultural power expects receiving and deciding on such serious information. As a result, information about diagnosis and prognosis is frequently withheld from the patient when a life-threatening illness is diagnosed in Ethiopia (Abebe and Abebe 2017:259; Ayers et al 2017:4). This practice violates the right of patients to exclusive information, and excludes patients from making decisions pertaining to treatment and planning regimes, undermining in the process patient-centred care. In essence, ther is a need for striking a balance with respect to patients' wishes and cultural contexts.

Patients' preferences for the revelation of bad news are inconsistent with how such news is divulged by healthcare professionals (Tang, Hong, Rau, Wang, Juang, Lai, Fujimori & Fang 2017:1001). It is therefore fundamental to develop a guideline supporting healthcare professionals in the diagnosis, prognosis and disclosure of life-threatening illnesses (Baig, Tanzil, Ali, Shaikh, Jamali & Khan, 2018:1338).

Present knowledge on the assessment of patient preferences when they are diagnosed with life-threatening illness in India shows that patients prefer to be informed in the presence of their next of kin (Rao, Sunil, Ekstrand, Heylen, Raju & Shet, 2016:1781). In Ethiopia, it is unclear what the patients' cultural preferences are relative to receiving bad news regarding their diagnosis and prognoses, or whether they prefer traditional communication modalities through their next of kin. It is the next of kin who ultimately decide either to tell the patient or conceal the truth (Ayers et al 2017:4). Some of the reasons submitted by next of kin for concealing the truth from patients include the fear that the patient could lose hope, causing distress and generating the perception that there is no relevance in living as the disease is seen as incurable (Abebe & Abebe 2017:259). This traditional approach, however, excludes patients from the decision-making process and choice of treatment options.

1.2 BACKGROUND TO THE RESEARCH PROBLEM

A patient may grant consent to their family or next of kin to make culturally appropriate medical decisions according to beliefs, and values that determine the choice of treatment in an African context (Brown, Goliath, Rooyen, Aldous & Marais, 2018:3). On the contrary, in other countries with more distinct patient autonomy, the patient is the principal decision maker as the primary recipient, with or without the presence of next of kin.

The patient has full rights to accessing information about diagnosis, status of disease and decision on the potential medical treatment. Patient autonomy refers to the right of patients to be informed about their medical condition and making their own medical treatment decisions. This also entails the right to be protected from unwanted treatment (Krause & Boldt 2018:67). However, an assortment of reasons such as cultural values, lack of guidelines, and lack of training could impede the breaking of such bad news (Gan, Zheng, Yu, Zhou, Miao & Lu, 2018:1460).

In the Ethiopian context, the next of kin often withhold the bad news from the patient to protect their loved ones from the news on terminal illnesses (Ayers et al., 2017:4). As a result of such cultural influences, the healthcare professionals might not disclose such bad news to the patient. Ignorance of a disease diagnosis and prognosis may affect a patient’s ability to make the right decision regarding treatment modalities. A decision without sufficient knowledge about the disease may lead the patient into a financial crisis because treatments for cancer are often expensive (Kasahun, Gebretekle, Gecho, Woldemariam & Fenta, 2020:7). A previously published needs assessment in Ethiopia confirms that none of the patients with life-threatening illnesses knew their diagnosis and many had sold major items such as farmland, livestock and gold to pay for treatments that were likely to be futile (Reid, Gudina, Ayers, Tigineh & Azmera, 2018:626). Communicating bad news helps patients to make informed therapeutic decisions.

Cross-cultural differences affect the preference to disclose bad news among communities (Kpanake, Igier & Sastre 2019:4; Kpanake, Sorumb & Mulletc, 2016:1314; Rajasooriyar, Kelly, Sivakumar, Navanesan, Nadarasa, Sriskandarajah & Sabesan, 2017:252). Furthermore, patients’ preferences for information and ways in which bad news communication could vary (Abebe & Abebe 2017:259; Zekri & Karim, 2016:270). Thus, a single technique or guidelines for disclosing bad news does not work for all communities across all countries, and a culturally sensitive guideline for the delivery of bad news needs to be developed (Baig et al., 2018:1338).

1.3 STATEMENT OF THE RESEARCH PROBLEM

Globally, breaking bad news to patients or next of kin is a common but challenging task for healthcare providers. It requires excellent clinical and communication skills to strike the delicate balance between realistic hope, individual preferences and cultural issues versus medical bioethics. However, it has been observed that most healthcare professionals lack these skills, and commonly convey bad news using approaches that fail to navigate the specific cultural and emotional ontological views and needs of Ethiopians.

The communication of bad news is taken seriously by family as they expect to be the first recipients of such news regarding the illness of a patient closely related to them. The patient's right to full information about diagnosis and medical status is disregarded as this generates distress and confusion, especially when the patient is not informed or involved in the decisions on treatment. Lack of transparency and poor communication of the negative prognosis affects the relationship between healthcare professionals and the patients. Nevertheless, present knowledge about patients’ preferences regarding how they would like to be informed and how much detail they want to know relating to their condition is poor in Ethiopia.

Moreover, healthcare professionals and next of kin project that patients are likely to be distressed and hopeless if informed about their terminal condition. One of the major challenges for healthcare professionals relates to awareness of patients' preferences relative to how and when to break bad news, how much information should be disclosed, and to whom the bad news should be delivered in the eventuality of serious medical diagnosis or prognosis. The knowledge gap whether the patient prefers the bad news to be delivered to the family or directly to them or in the communion of family drives this study.

There are guidelines for breaking bad news available in the literature that is produced in different countries to be utilized when bad news is conveyed.

Setting, perception, invitation, knowledge, and strategy and summary are the six steps recommended in the SPIKES protocol (Buckman 2005:139). The following six steps are advised by a different model: assessment, planning, preparation, disclosure, support, and conclusion (Abazari et al 2017:2). Seven steps were included in a protocol developed by Pereira et al (2017): presented seven steps: setting, assessment of the patient's knowledge, invitation, giving information, emotions, do not abandon the patient, and outlining a strategy (Pereira et al 2017:44). Sedhom & Bari (2016) proposed a four-step approach that includes setting diagnosis, conveying prognosis, having conversations about setting goals of care, and making decisions on treatments (Sedhom & Bari 2016:1). These guidelines relate to comparable approaches in some of their recommendations and steps while also advocating for different ways in some of their proposed steps.

Healthcare professionals use the available guidelines to deliver news on life-threatening illnesses which do not take into account the cultural beliefs of the people they treat. These guidelines on disclosing bad news do not consider specific cultural perspectives of communities such as Ethiopia. Currently, there are no guidelines assisting healthcare professionals on occasions when they have to disclose bad news in the Ethiopian context. Thus, culturally sensitive guidelines must be availed on protocols for breaking bad news based on the expressed preferences of patients and their families.

1.4 THEORETICAL FRAMEWORK

A qualitative approach is followed in this research, characterised by conducting the study in natural settings, immersion in the study world and interpreting the phenomenon from the perspectives of the study participants (Denzin & Lincoln 2018:43).

This study is grounded in the "Ubuntu" theory, striving to understand how people make sense of and perceive their world on issues in related to breaking news on terminal illnesses. In this pursuit, the study seeks to identify the meanings that participants ascribe to illness and communication protocols so as to establish themes (Merriam & Grenier 2019:5). These meanings are derived from the application of Ubuntu as an ontological orientation in the Ethiopian context. The ethos of interconnectedness lies at the core of Ubuntu.

Notwithstanding, it is difficult to give a single definition of Ubuntu as there re foundational essences in the collaborative and collective enactment of moral integrity (Mugumbate & Chereni, 2019:28). The moral quality embodied in Ubuntu is anchored in empathy, forgiveness and belief in a supreme being (Gade 2012:489). Ubuntu implies interdependence and the influence of others on one's identity. Ubuntu claims that “I am because you are and you are because I am” (Nare, 2016:57).

The Ubuntu ontological orientation is applied in this proposed study because the essence of Ubuntu overlaps with Ethiopian culture. The ethos of the collectivity of culture and humanness is shared across the two cultures. Any theory has its own limitation: Ubuntu has its limitation in those individual differences, rights, preferences could be not reflected in the orthodox view of collective culture. Berry et al., (2002:30) argue that the exact transmission of culture does not permit individual creativity and change within the framework of Ubuntu (Berry, Poortinga, Segall and Dasen 2002:30). In this study, Ubuntu ontology is interrogated relative to the specifics of the cultural beliefs of patients living with and diagnosed with life-threatening illnesses.

1.5 OPERATIONAL AND CONCEPTUAL DEFINITIONS

Patient refers to “a person who is receiving medical treatment” (Oxford Learner’s Dictionary, 2023). In this study patients refer to an individual diagnosed with life-threatening illness and receiving medical treatment or care.

Life-threatening illness refers to a serious illness that could result in death or have a serious effect on the life of the patient (Merriam-Webster 2021; Sloan, BrintzenhofeSzoc, Kichline, Baker, Pinzon, Tafe, Li, Cheng & Berger, 2017). In this study, life-threatening illness refers to a non-curable condition that has been declared causing death and need palliliative care.

Healthcare professionals are physicians who are qualified to practice as general practitioners, medical residents, and specialists. Furthermore, healthcare professionals refer to registered clinical nurses qualified to practice as a nurse and caring for patients diagnosed with life-threatening illness, and expected to break bad news while working in palliative care settings (WHO 2013). In this study healthcare professionals refer to individuals who are trained in their specialised fields.

Community members: community is defined as “all the people who live in a particular area, country” **(**Oxford Learner’s Dictionary, 2023**).** In this study, community member refers to individuals who know the cultural concepts related to delivery of bad news, individuals with or without family or next of kin diagnosed with life threatening illness in Ethiopia.

Disclosing bad news means conveying or communicating bad news to a patient or next of kin (Monden, Gentry & Cox, 2016:101). In this study, the concepts disclosing, delivering and breaking bad news are used interchangeable and refers to instances where healthcare professionals deliver unpleasant news about the diagnosis or poor prognosis related to life-threatening illness.

Palliative care is defined as care for patients diagnosed with life-threatening illness with the aim of comforting as well as relieving physical, psychosocial and spiritual suffering (WHO 2020). The WHO definition of palliative care is adopted in this study.

Guideline refer to a set of reules, instructions, and advice that can be used as a guide to do some activities (Oxford Learner’s Dictionary, 2023).

Cultural sensitivity: culture refers to a society's customs, beliefs, and values (Oxford Learner’s Dictionary, 2023). In this context, cultural sensitivity is defined as being conscious of cultural values, customary ways of doing things, beliefs, and preferences concerning the delivery of bad.

Bad news means “news of unpleasant, unfortunate or sad events” and a situation that is harmful and causes problems (Definition.net, 2023). In this study, bad news is defined as news of the diagnosis or poor prognosis of a life-threatening disease, and treatment failure related to a life-threatening condition.

The WHO Handbook for Guidelines: the guideline helped in providing direction, and was adapted to follow and consider issues when developing the guideline for delivering bad news.

1.6 LITERATURE REVIEW

To determine what is already known about the delivery of bad news, a literature review was performed using various databases. The following search terms - breaking bad news, cultural perspectives, preferences, guidelines and healthcare professionals - restricted to no more than five years old were used. The search was limited to published articles in English and peer reviewed articles were used.

Any bad news for the individual patient has multidimensional impacts. Bad news refers to adverse pronunciation that significantly modifies the future views of patients who have received information concerning their medical diagnosis or prognosis (SilveiraI, BotelhoII & Valadão 2017:325). Any news of a serious diagnosis and prognosis conveyed to a patient or next of kin is described as disclosure of bad news. The way bad news is conveyed could either adversely affect the patient or encourage the patient to make appropriate decisions (Sobczak, 2018:2399).

The community's preferences and wishes about breaking bad news differ across countries. A study in Sri Lanka established that most patients prefer getting informed of their medical condition (Rajasooriyar et al., 2017:252). Conversely, studies in Francophone countries in Africa established different perspectives of patients' preferences. Kpanake et al., (2016:1314) showed that the study participants preferred to conceal the truth from the patient and for it to be delivered to the next of kin. Another study by Kpanake et al., (2019:4) verified that participants from European (French) background preferred to receive the truth regardless of diagnosis and prognosis in accordance with their culture where western patient autonomy prioritised health care system and culture. Nevertheless, participants from Africa (Togo) preferred next of kin to be informed (Kpanake et al 2019:4; Kpanake et al., 2016:1314).

The effective communication of bad news cannot be achieved without understanding the cultural components and needs of patients. Healthcare professionals could meet patients' preferences and maintain good communication with them only by accommodating culturally sensitive communication approaches (Brown, Goliath, Rooyen, Aldous & Marais, 2018:4). Cultural values and beliefs determine the discourses used to convey bad news, the role of the family in decision-making and the concept of autonomy that must be considered while breaking bad news in a culturally sensitive protocol (Abazari, Taleghani, Hematti, Malekian, Mokarian, Mohammad, Hakimian & Ehsani, 2017:3; Aminiahidashti et al., 2016:35). Autonomy is a concept where self-determination is crucial and the patient is the principal recipient and decision-maker (Krause & Boldt, 2018:68), while a collective decision prevails over individual rights in non-Western cultures (Ayers et al., 2017:4; Brown et al., 2018:4). Literature from different countries shows that most people prefer getting informed of their medical conditions (Aminiahidashti et al., 2016:35; Fisseha, Mulugeta, Kassu, Geleta, & Desalegn, 2020:1021). Nevertheless, these results are derived from quantitative research where obtaining in-depth understanding of the cultural factors is significantly limited.

The way bad news are conveyed needs to be customised from the view of each community as people prefer diverse communication dynamics depending on patients' wishes, beliefs and values in different cultural context (Aminiahidashti et al., 2016:35). The existing guidelines for breaking news have limitations as they are not only developed for their respective cultures but based on theoretical articles. In contrast, a qualitative study demonstrated a culturally sensitive breaking bad news guideline based on empirical evidence on the preferences of people. The guidelines propose a different approach on how to break bad news to a patient and their family members (Abazari et al., 2017:2).

1.7 PURPOSE OF THE STUDY

The study aims to understand the Ethiopian community's cultural preferences for receiving bad news when the patient is diagnosed with life-threatening illness in palliative care. This understanding culminates in the development and validation of a culturally sensitive guidelines for breaking bad news to patients and next of kin in Ethiopia.

1.8 THE RESEARCH OBJECTIVES AND QUESTIONS

1.8.1 Research objectives

The objectives of this study are designed to:

- Identify and describe preferences of individuals such as patients diagnosed with a life-threatening illness, community members and healthcare professionals regarding breaking bad news in palliative care in phase one.
- Establish an in-depth assessment of cultural preferences and the need for information on breaking bad news when patients are diagnosed with life threatening illnesses in phase two.
- Develop and validate guidelines for breaking bad news in an Ethiopian culturally sensitive context in phase three and four.

1.8.2 Research questions

The following are research questions are operationalised in the study:

- What are the preferences of individuals regarding breaking bad news in palliative care when diagnosed with life-threatening illness?
- What are the needs on information related to breaking bad news when patients are diagnosed with life-threatening illness?
- How could guidelines be developed and validated for breaking bad news in culturally sensitive contexts in Ethiopia?

1.9 SIGNIFICANCE OF THE STUDY

Appropriate protocols for breaking bad news require understanding of the culture and context. The study describes the cultural preferences of patients and the community regarding breaking bad news. The findings of the research could be used for developing culturally sensitive guidelines. The guidelines promote culturally sensitive protocols in breaking bad news and fill the gap of culturally suitable guidelines currently available for the Ethiopian context (Fisseha, Mulugeta, Kassu, Geleta, & Desalegn, 2020:1022).

The task of breaking bad news requires skills that facilitate effective communication to mitigate patient’s autonomy or the right to know and make informed decisions. Effective communication of bad news essentially facilitates and helps healthcare professionals in how they convey bad news in a culturally appropriate way by ensuring the rights of patients to know about their conditions. Hence, the study is relevant in mitigating and clarifying ethically difficult situations when breaking bad news. The guidelines facilitate enhanced communication between healthcare professionals and patients with life-threatening illness so that they receive adequate information certainty truth about their condition.

Moreover, when patients are informed, they can make an informed choices on treatment, and minimize costs for futile treatment through cogent decisions.

Many people who require palliative care do not have access to it. The World Health Organization recommend palliative care be integrated into the primary health care. “Health equity is achieved when everyone can attain their full potential for health and well-being. Health and health equity are determined by the conditions in which people are born, grow, live, work, play and age” (World Health Organization 2023). Equity in public health can not be achieved without getting proper information on the disease condition. This study contribute to the public by advocating delivering serious medical news by using the developed guideline. Furthermore, the aviailability of the guideline encourages patients to seek palliative care service when they have appropriate information and are aware of their conditions. The study results also introduced a new knowledge on the cultural preferences when patietns are diagnosed with life-threatening illness which can be used as a soure of evidence in palliative care settings.

1.10 RESEARCH PARADIGM

A constructivist worldview informs this research. Paradigms are different in the way they interpret reality. The constructivist presumption of truth is underpinned by interaction within society (Green & Thorogood, 2018:42).

As a qualitative study, the assumption is reality is socially constructed by interaction between people, cultures and communities, with the sole aim directed at understanding how individuals view their world (Merriam & Grenier, 2019:3). In constructivism, truth is defined as subjectivity, the creation of multiple meanings is enacted through the interaction of individuals and the cultural beliefs that they hold. Based on this view of the world, the researcher strives to understand the viewpoints and experiences of the participants and to interpret these viewpoints so as to develop themes from the perspective of participants.

Constructivism allows an understanding of the research problems associated with breaking bad news from the diverse viewpoints of people. The constructivist world view allows an understanding of the participants' values, beliefs, expectations and perceptions about breaking bad news (Merriam & Grenier, 2019:4). The paradigm allows the researcher to obtain information and understand the reality from people's perspectives. This paradigm is preferred as knowledge and reality are equally produced through the interaction of the researcher and study participants.

Ontological assumption is concerned with understanding the world (Leavy 2017:12). The ontological assumption of this study underpins with the constructivism philosophical assumption where reality is multiple and socially constructed. The epistemological assumption refers to the nature of knowledge and ways of knowing (Leavy 2017:12) and in this research, the epistemic orientation develops from in-depth interviews consolidated by observation as data collection methods to explore the phenomenon. Methodological assumptions were made by applying a qualitative research approach allows to collect descriptive data, to explore people's perspectives and their experiences, and to collect data through interviews and observation (Patten & Newhart, 2017:22). Axiological assumptions were the researcher's self-awareness, background and experience allows for a deeper understanding of the phenomenon. Triangulation of data collections, reflexivity, and being self-aware were steps taken to minimize researcher bias.

Data was obtained through interviews and observation. Multiple views were obtaind from the study participants and the results were described.

Data analysis and interpretation were done from the participants' perspectives and themes were developed. Knowledge was constructed from the results and through interpretation and discussion of the results.

1.11 RESEARCH DESIGN AND METHODS

Methodological approaches to research rely on quantitative, qualitative or mixed-method paradigms. Methodology refers to the procedures followed to address the research inquiry (Taylor, Bogdan & DeVault, 2016:3).

Research approach is a roadmap to answer the research question, and it is the general plan of a research anchored on a research approach (Bairagi & Munot 2019:70). Research methods entail all the techniques and tools used to collect and analyse the research data and to report and answer the research questions (Bairagi & Munot, 2019:23).

In this study, a qualitative research approach is utilised, and data are generated through in-depth interviews and observations to understand people's perspectives, experiences, perceptions, and cultural issues regarding breaking bad news. This qualitative research seeks to generate descriptive data from people's own views, experiences and meanings (Green & Thorogood, 2018:9; Taylor et al., 2016:7). Furthermore, qualitative research allows inquiry into the personal experiences of people in their context, to describe and develop themes (Morse 2016:1).

1.12 STUDY SETTING, STUDY POPULATION, SAMPLING AND SAMPLE SIZE

1.12.1 Study setting

The study was carried out at selected hospitals and palliative care provider organisations in Addis Ababa, Ethiopia.

1.12.2 Study population

The research population are patients who have a life-threatening illness, healthcare professionals as well as community members.

1.12.3 Sampling

In this study, purposive sampling method was used to recruit study participants.

1.12.3.1 Sample size

The sample for this study was selected patients diagnosed with life-threatening illness and healthcare professionals as well as community members. The sample size for this study was determined by data saturation.

1.13 DATA COLLECTION METHODS AND PROCEDURE

1.13.1 Data collection methods

Data was generated by using interviews and observational methods in a selected hospital and palliative care organisation. Data was generated in phases. In phase one, data was collected through interviews with patients, healthcare professionals, and community members. In phase two, the researcher generated data through observations on breaking bad news conversations between healthcare professionals and patients and their families, and non-verbal cues in the study settings. Phase three and phase four entailed data triangulation and development of the guidelines respectively.

By using grand tour question, the researcher used one-by-one in-depth interviews followed by the semi-structured questions. A field notes recorded information obtained from the observation and non-verbal communications with the study participants. Interviews and the observation of conversations between healthcare professionals and patients were audio-recorded with full consent of the participants.

Inclusion criteria

Patients diagnosed with life-threatening illness who have full insight about their condition and prognosis were included.

Healthcare professionals, physicians, nurses, health officers involved in caring for people with life-threatening illness or in palliative care settings and have at least two years of experience in breaking bad news were included.

Literate and lay community members such with some knowledge about the cultural concepts, and who could articulate their perspective were included in this research. Furthermore, individuals with or without having family or next of kin diagnosed with life threatening-illness, individuals who knew the cultural concepts related to delivery of bad news were involved in the study.

Experts who were actively working in the palliative care works or care of patients with life-threatening illness were purposively selected for the study. Experts with knowledge and experience in palliative care, research and treating patients with life-threatening illness were included for validation of the guidelines.

All participants were older than 18 and cognitively competent, regardless of gender.

Exclusion criteria

Mentally incompetent patients with life-threatening illness and patients who were not informed of their diagnosis and or prognosis were excluded from this study. Moreover, patients who have psychological problems, emotionally affected due to their condition were equally excluded. Healthcare professionals not involved in breaking bad news, with less than two years of work experience and undergraduate medical students were not included.

Minors less than 18 years old and seriously ill patients were excluded from the study.

1.13.2 Data collection procedure

Data was collected by the researcher between December 2021 and July 2022. A private room was arranged in the study area. The study participants were selected through purposive sampling at a selected referral hospital and palliative care providing organisation in Addis Ababa, Ethiopia.

The researcher introduced himself and provided information about the purpose of the study, and the study procedure. The study participant got adequate time to ask any question, clarification and the researcher amplified relevant details. A written consent will be taken prior to taking part in the study. Research assistant for the transcription of collected data was recruited. Moreover, a research assistant was recruited to help selecting prospective study participants in one of the study areas.

COVID-19 prevention guidelines

The data collection procedure was adaptive to the national COVID-19 restrictions to avoid the risk of infection both for research participants and the researcher. The researcher followed the national COVID-19 prevention policy as detailed in Chapter 3.

1.14 DATA ANALYSIS METHOD

Thematic analysis approach was used in this study. The data analysis phases included (1) data preparation and organisation, (2) initial immersion, (3) coding, (4) categorising and theming, and (5) interpretation of the findings (Leavy, 2017:150). The interviews were carried out in Amharic and the collected data was transcribed verbatim into English. Computer assisted data analysis using ATLAS.ti 22 software and manual data analysis approach was carried out. The data review, analysis and writing up process were conducted when the data was being collected.

1.15 DEVELOPMENT OF GUIDELINES FOR BREAKING BAD NEWS

Phase four presents the development of the guidelines on breaking bad news followed the adapted WHO guidelines (WHO 2014) and validation.

The four-step process informed the development of breaking bad news guidelines and validation (The process of guideline development, and the developed guidelines are presented in Chapter 5 in detail):

Step one: The collected data was analysed to develop themes and sub-themes.

Step two: The components and steps of breaking bad news guidelines were developed based on the research findings, literature review and existing guidelines. The draft guidelines were sent to the academic supervisors, experts as well as community members for validation and feedback.

Step three: The guideline was tested by healthcare professionals at the study area. Then, feedback was collated and incorporated.

Step four: The final guidelines were developed after incorporating feedback from experts and community members.

1.16 ENSURING RIGOUR

Rigour ensures the integrity of the research process and the systematic method through which it is carried out. Different strategies were used to establish rigour of the findings in this study as described below:

Credibility

Tracy (2013:235) states that there are various strategies that a researcher could use to ensure credibility of a study, such as triangulation, thick description and member checking. A researcher needs to spend time in the field to obtain explicit information and the best experience about the phenomenon (Tracy 2013:236).

In this study, the researcher spent a long time with the study participants to learn in detail, observe and provide thick description and to enhance credibility of the study. Member checking strategy was used to enhance validity of this research. Some of the study participants were asked to provide feedback on the data collected and interpreted to confirm whether the findings of the study are representative of their narratives. Moreover, peer review by the researcher's colleagues who are familiar with the topic, experts in the field, by the supervisor and the researcher were carried out.

Triangulation of data collection, the credibility of this proposed research were ensured by collecting data through a combination of observations and interviews.

Dependability

The study procedure was explained in detail to the participants. The study design and how it was carried out, details of how data were collected and the project effectiveness were discussed to ensure dependability of this proposed research (Nowell, Norris, White and Moules, 2017:2).

Transferability

The transferability of this study was enhanced by providing thick description and by using purposive sampling method (Merriam & Grenier 2019:26-28). Detailed description about the study settings, participants, findings and the research methods followed in the study, the time taken to gather data in the field, and the researcher roles were presented.

Conformability

Reflexivity techniques enhanced authenticity and prevented researcher bias in this study (Merriam & Grenier 2019:31). The researcher self-awareness, background and experience facilitated deeper understanding of the phenomenon (Ciesielska & Jemielniak 2018:157). Thus, the researcher was aware of values connected to this issueField notes were taken, and the researcher annotated the experience and background.

Authenticity

The internal audit considered all responses from the participants and by debriefing the participants. The participants were informed of the intention of the study prior to start and during the research. The guidelines were validated by some of the study participants, in tandem with expert input.

1.17 ETHICAL CONSIDERATIONS

Permission to conduct the study

A research ethics approval certificate from the University of South Africa research ethics review committee, letter of permission from the selected study areas were all requested prior to the initiation of the research. Ethical certificate from the University of South Africa facilitated access to the study areas and institutions and a written permission letter was obtained from selected study areas prior to beginning research. Documents such as informed consent, information sheet and request to participate in the study were translated into the local language (Amharic) for full appreciation of the scope and purpose.

Informed consent

The study participants of were informed and provided with adequate information on the purpose of the study, the right to withdraw from the study and written consent prior to data collection (Ciesielska & Jemielniak 2018:198).

The researcher gave adequate information about the topic, the purpose, benefits, and any potential risk prior to interviewing the research participants. Participants were informed that their participation was voluntary and that they had the right to answer some part of the question and refuse some other part or withdraw from the research at any time even if they had consented.

The right to refuse or withdraw

The participation in the research was entirely on the free will of invited participants, and without coercion.

Risk and benefits

Risk: this research did not have potential physical, political, or social risk. The research, however, may entailed anticipated potential mild emotional or psychological discomfort as the questions probed to explore reception and reactions to sad news. This potential risk was mitigated by reassurance, giving space to breathe out. Benefits: its potential benefits contributed to the overall improvement in cultural sensitivity in breaking bad news. The findings will be used to develop culturally breaking bad news guideline. This promoted better communication between healthcare professionals and patients, to patients with life threatening illness.

Confidentiality

Confidentiality was maintained by using the collected information for the research purposes only. The principal researcher and the supervisors have access to the information and this was secured against unauthorised access. To ensure privacy, interviews were conducted in a private place preferred by participants.

Anonymity

Prior to taking part in the study, study participants were provided with information about the research purpose, and their participation was entirely voluntary. Personal information and identification of participants was kept confidential by assigning codes to the data. No real names were used in any documents traceable to the participants.

1.18 STRUCTURE OF THE THESIS

This thesis is arranged into six chapters as outlined below:

Chapter one: Orientation to the study

Chapter two: Literature review

Chapter three: Methodology and the research design

Chapter four: Data analysis and presentation of the results

Chapter five: Development of culturally sensitive guidelines for breaking bad news

Chapter six: Conclusion, recommendation, and limitations of the study

1.19 SUMMARY

Chapter one provided an overview of the study and background to the study problem. It also outlined the purpose of the study, significance and defined key concepts and terms. It etched the theoretical background and brief literature review. The research design, data collection methods, data analysis plan have been briefly described, and the thesis structure is presented. The following chapter reviews literature regarding breaking bad news in palliative care in detail.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION TO THE LITERATURE REVIEW

To determine what is already known about the delivery of bad news and cultural competency, a literature review was performed through Google Scholar, Science Direct and PubMed databases, and following search terms: breaking bad news, cultural perspectives, preferences, guidelines, healthcare professionals and physicians. The UNISA library was also used to search for relevant. Papers were restricted to no more than five years old and was limited to published articles in English and grey literature.

A literature review was done because it serves as evidence for the research problem, as well as an examination and identification of existing information and its shortcomings related to the study area. The scientific literature is also researched in order to get a thorough understanding of what is already known about the study topic in the current body of knowledge. It also aids the researcher in remaining updated on the research topic, and establishing the proper research design and methods. Thus, the purpose of this literature review was to examine and analyse the existing knowledge, describe trends, outline the current literature and identify gaps about breaking bad news in palliative care setting. Emperical and scholarly literatre were used, and narrative type of literature review was applied before data collection whereby the literature review appear in sections.

2.2 DEFINITION OF PALLIATIVE CARE AND ASSOCIATED CONCEPTS

Palliative care aims to improve the quality of life of patients with life-threatening illnesses and by preventing and alleviating suffering, not only physical pain but psychological, social and spiritual problems. Furthermore, palliative care helps patients to live as actively as possible and accept death as a normal process (World Health Organisation 2020). Similarly, Palliative Care Australia and European Association for Palliative Care define the procedure as a holistic; physical, psychosocial and spiritual care which aims to preserve the quality of life of patients with incurable illness, their family and community.

In addition, “palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death” (European Association for Palliative Care 2021; Palliative Care Australia 2021).

The National Health Service of the United Kingdom, Ministry of Health New Zealand and Canadian Hospice Palliative Care Association concur that palliative care is holistic care for individuals with life-threatening or incurable illness. Palliative care helps the patient to live as actively as possible, aims to comfort and improve quality of life through management of pain and other distressing symptoms, as well as supporting the family. It can also be given at all stages of the disease trajectory (Canadian Hospice Palliative Care Association 2021; Ministry of Health New Zealand 2016; National Health Service United Kingdom 2018). Improving quality of life is the main goal in the definitions of palliative care. According to the World Health Organisation (WHO) definition, quality of life is “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO 2021).

The WHO and other definitions about palliative care as described above are broad, and contain common elements; however, they restrict the care to life-threatening illness or incurable illness. The definition of the International Association of Palliative Care (IAHPC) covers many of the domains and concepts of the WHO definition, but equally critiques the restricted definition based on illness prognosis rather than the needs of patient. Hence, palliative care is defined by the IAHPC as active holistic care offered to patients with serious health-related suffering due to severe disease that impairs patients' quality of life, produces unpleasant symptoms, affects daily functions and risk of death, and end of life care (Radbruch, Lima, Knaul, Wenk, et al., 2020:760-61). Suffering is defined as health related when it is associated with illness or injury of any kind” (Radbruch et al 2020:756). Furthermore, palliative care is given throughout the course of the disease in conjunction with disease-modifying treatments when necessary, according to the patient's needs, the cultural values and beliefs of the patient, family and caregivers. Palliative care may positively influence the course of illness and intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process (Radbruch et al 2020:761).

Similarly, the United States National Institute on Aging define palliative care as specialised medical care for people living with a serious illness and focuses on providing relief from suffering. It aims to enhance the quality of life for the patient and family caregivers based on the needs of the patient rather than prognosis (Centre to Advance Palliative Care; National Institute on Aging 2021). Moreover, palliative care can be provided with curative therapy in the early stages of disease and distressing symptoms can be treated alongside treatment aimed at curing their serious condition (National Institute on Aging 2021; NHS 2018).

Symptoms are burdensome for patients since they influence the patient’s daily activities and comfort. Management of pain and other distressing symptoms promote the patients to live as actively as possible, maintain social activities and daily functions (Buss, Rock & McCarthy, 2017:281). A study in Italy and Belgium found that early and systematic integration of palliative care with cancer therapy rather than providing it when needed improves quality of life of patients with advanced cancer (Maltoni, Scarpi, Dall’Agata et al., 2016:65; Vanbutsele, Pardon, Belle et al., 2018:6-7). In the same way, the American Society of Clinical Oncology recommends that patients with advanced cancer should get palliative care early in their diagnosis and in conjunction with active cancer treatment (Ferrell, Temel, Temin, et al., 2017:99-104). Early provision of palliative care offers the advantage of lowering unnecessary hospital admissions and healthcare service use (WHO 2020). A qualitative study has documented that patients with life-limiting illness lead their life as active life even when they are terminally ill in a palliative care setting (Kastbom, Milberg & Karlsson, 2017:934). Thus, palliative care must be continuous care that provides relief, and follow an interdisciplinary team approach to address the holistic needs of patients (Buss, Rock & McCarthy, 2017:283).

The African Palliative Care Association (APCA) defines palliative care as holistic care for people with life-threatening illness, their family, and carers, providing pain relief and psychosocial, spiritual and emotional care to maintain and improve a patient's quality of life. Moreover, it helps the patient to “live full and rich lives for far longer than they otherwise would” and the care starts from the time of diagnosis of disease up to the end of life (African Palliative Care Association 2021).

The Ethiopian national palliative care guideline and training manual have adopted the WHO definition of palliative care (Ministry of Health-Ethiopia: Palliative care service participant manual 2021:8; Ministry of Health Ethiopia: National palliative care guideline 2016:1).

Hospice care, like palliative care, is for people with incurable illness and the goal is to relieve suffering and improve the quality of life of patients (NHS 2018; National Institute on Aging 2021). Hospice is a component of palliative care and for critically ill patients and usually provided in one's home (Buss, Rock & McCarthy 2017:283). Both terms, hospice and palliative care, are used synonymously and have no difference in their approaches to care in Canada (Canadian Hospice Palliative Care Association). However, in the United States hospice care differs from palliative whereby the person referred for hospice care has to discontinue curative treatment and has a predicted life expectancy of six months or less (National Institute on Aging, 2021). In the United Kingdom, patients are deemed to be approaching the end of life when they are likely to die within the next 12 months (NHS 2018). A study in China showed the median time from palliative care referral to death was four months (Cheng, Fung & Wong, 2018:849). Another study in Australia established that the average duration of stay for patients admitted to the oncology unit for end-of-life care was eleven days (Batten, Nguyen, Burke, Harryanto, Mitchell & Davis, 2018:2). However, Lim (2016:456) argues that if end-of-life care is seen in terms of survival or illness prognosis, patients who may benefit from it would be disregarded, and the holistic needs of people at the end of their lives would not be addressed. Thus, end of life care should be based on the patient's needs for care rather than disease prognosis (Lim 2016:456).

Palliative care includes building rapport with patient and family, "exploration of understanding and education about illness and prognosis; clarification of treatment goals; assessment and support of coping needs (e.g., provision of dignity therapy); assistance with medical decision making; coordination with other care providers" (Ferrell et al 2017:104). In the same vein, the elements of end-of-life care include making decisions on do not resuscitate, conversations about death and dying, place of death, choices of care, discussions concerning diagnosis, prognosis and disease trajectory and advance care plan (Fan & Hsieh, 2020:4-5). Healthcare professionals ought to initiate end- of- life conversations with their patients, family and discuss care issues. A qualitative study in the United States found that decision making, treatment planning, culturally sensitive care, ethical issues and educating families are aspects of end-of-life care. Furthermore, communication between healthcare professionals and patient or/ and /family, as well as among health professionals dealing with end-of-life care, disclosure of prognosis and withdrawal of curative treatment, remain challenging tasks in palliative care (Price, Strodtman, Montagnini, Smith & Ghosh, 2019:3).

End- of- life care conversations involve disclosure of dying, setting of death, goals of care and advance care planning. Symptom management is essential to enhance the quality of life and dying with dignity. However, there may be uncertainties about some aspects of treatment in a palliative care setting and ethical dilemmas may result in uncertainty (Be´Langer, Rodri´guez, Groleau, Gare´, Macdonald & Marchand, 2016:5; Lim, 2016:457). Ethical dilemmas commonly occur in end-of-life care and healthcare workers need to be familiar with them so that they can make better decisions (Chessa & Moreno, 2019:389). End-of-life care issues that may put healthcare professionals in a dilemma include:

(1) “Withholding and withdrawing life-sustaining treatment, such as cardiopulmonary resuscitation, ventilator support, artificial hydration and nutrition;

(2) Sedative medications used at the end of life;

(3) Confusion in terminology with euthanasia” (Lim, 2016:463).

The causes of suffering at end-of-life care are multidimensional, including distressing physical, social, spiritual symptoms, setting of death and functional status (Dalal & Bruera, 2017:2). A study in Australia confirmed that patients diagnosed with incurable illness were admitted to hospital to get relief from symptoms and disease complications (Batten, Nguyen, Burke, Harryanto, Mitchell & Davis, 2018:2). Family members have reported that the place of death, discussions about palliative care and do-not-resuscitate orders are related to the quality of life of patient at the end of life (Waterman, Pilver, Smith, Ersek, Lipsitz & Keating, 2016:6).

Family caregivers play a significant role during end-of-life discussions as they are the proxy caregivers, decision makers and recipients of the ultimate bad news. Moreover, failure of family caregivers to accept the death of a patient may cause them to ask for inappropriate life-prolonging treatments for dying patients (Fan & Hsieh, 2020:4). Hence, healthcare professionals seek to alleviate the suffering of patients at the end of life through effective communication, understanding of the patient's and family's needs, management of pain and symptoms, and psychosocial support (Zadeh, Eshelman, Setla & Sadatsafavi, 2018:5-6).

Patients approaching the end of their lives may experience anxiety related to the fear of becoming a burden, the impact of their death on loved ones, and the fear of suffering (Byrne & Morgan, 2020:379). A study in Scotland showed that patients with terminal illnesses experienced end-of-life symptoms such as a sense of impending death and uncertainty. Moreover, they reported having a bad experience of physical deterioration which influenced their future view of social life due to a diagnosis of serious illness and poor prognosis of their illness (Carduff, Kendall & Murray, 2018:3-5). A qualitative study in Sweden showed that the patients' view of life changed over the time of having a lifethreatening illness and they turned to focus on relationships with their loved ones and "living for the moment and an increased sense of liberation from fears" and more attention was placed on living a meaningful life (Kastbom, Milberg & Karlsson, 2017:934). As a result, patients may seek palliative care when their disease become worse (MacArtney, Broom, Kirby, Good & Wootton, 2017:627).

A study in Uganda verified that preferences of patients, caregivers, and healthcare professionals in the aspects of end-of-life care such as medical condition information, funeral preparation, and death conversations about dying were different. Moreover, the choices in pain relief between patients and caregivers and healthcare professionals were also different, and pain relief was sought as important only among 52.2% of patients (Campbell et al., 2018:4).

Social support, friends' support, prayer, spiritual care from clergy are aspects of end- of life care that patients, caregivers and healthcare professionals saw as important

(Campbell et al., 2018:4). Some patients accept their death and are curious to know what there is after death (Kastbom, Milberg & Karlsson, 2017:937). Spiritual beliefs, convictions around death, views on life after death, death and dying all effect palliative care services and communication. Accordning to a study in Tanzania, it was suggested that spiritual fathers be involved in conveying bad news to patient or their next of kin (Lewis, Oates, Rogathi, Dunmaijer, Shayo, Meguro, Bakari, Dewhurst, Walker, Dewhurst & Urasa 2018:573). For some people, religion and spiritual care are central in end of life (Balboni & Balboni, 2018:817; Ferrell, Chung, Koczywas, Borneman, Irish, Ruel, Azad, Cooper & Smith, 2020:1079). In contrast, a study in New Zealand showed that most of the study participants were not religious, but hopeful and had a low degree of distress at the end of their life (Byrne & Morgan, 2020:379). Furthermore, participants obtained hope apart from religion and “the most important determinants for the whole sample population were being able to recall joyful memories and to give and receive love from family and friends” and a sense of meaning in life (Byrne & Morgan, 2020:380).

End- of -life care domains preferred by patients at the end of their life include resuscitation plan, comfort and palliative care (Batten, Nguyen, Burke, Harryanto, Mitchell & Davis, 2018:3). Individuals may prefer avoiding resuscitation whereby physicians record the wish of the patient and would therefore not perform invasive intervention at the end of life (MedlinePlus 2020). Evidence shows that most patients have received active but not invasive treatments at the end of their life (Batten et al 2018:2-3). Furthermore, studies from various countries verify that people have different preferences for end-of-life care; some people prioritise enhanced quality of life, while others prefer life prolonging treatments. (Higginson, Daveson, et al., 2016:7-8). Another study also showed that some patients chose advanced life support when dying, while the others do not want such aid when dying (Chen, Flaherty, Guo, Zhou, Zhang & Hu, 2017:1392).

Patients’ satisfaction with care and respecting their right could be interfered by poor patient-centred approaches. Patients reported that healthcare professionals may not involve them in treatment decisions, accept their opinion and may not meet their preference when providing treatments (Berhane & Enquselassie, 2016:50).

Participating in making decisions on one's own life or health care choice, and maintenance of autonomy are vital attributes for a good death (Kastbom, Milberg & Karlsson, 2017:936; Rainsford, Phillips, Glasgow, MacLeod & Wiles, 2018:1579). Moreover, comfort, presence of family, relief from suffering and preferred place of death are fundamental elements of good death for those patients approaching death (Kastbom et al., 2017:936937; Rainsford et al., 2018:1578). In the same way, healthcare professionals viewed the elements of good death as having adequate symptom control, respect of the patient's will regarding treatments and own death, no over treatment, presence of loved ones, good communication and a space for sharing emotion. For some patients, nonetheless, acceptance of death, and patient's awareness of the upcoming death are less important elements of good death (Bovero, Gottardo, Botto, Tosi, Selvatico & Torta, 2019:4).

In spite of the fact that preparing for death is not culturally acceptable and causes discomfort for some, many patients expressed the benefits of preparing for death such as arrangements of funerals and leaving a will (Kastbom et al., 2017:936). Death may not freely be spoken and discussed in palliative care communication; as a result, the term palliative care is used as a euphemism for death. Generally, people may be afraid of death at the end of their life (Chen et al, 2017:1392). Palliative care is also associated with dying sentences among patients experiencing life-limiting illness (MacArtney et al 2017:628). Thus, this can hinder conversations to receive palliative care (Collins, McLachlan & Philip, 2017:138). End of life discussions establish relationships between health care providers and family, discussing wishes and preferences, and providing comfort (Saini, Sampson, Davis, Kupeli, Harrington, Leavey, Nazareth, Jones & Moore, 2016:11-12). Furthermore, evidence confirms that patients want to be involved in end of life discussions, in spite of the family having a different preference (Woldemariam, Andersson, Munthe, Linderholm & Lindstrom, 2021:1345).

A study in Mongolia showed that healthcare workers have inadequate knowledge yet a positive attitude toward the end-of-life care (Kim, Kim & Gelegjamts, 2020:5). Furthermore, a growing number of quantitative studies in Ethiopia demonstrate that end of life care is poorly understood by healthcare professionals (Abate, Amdie, Bayu, Gebeyehu & G/Mariam, 2019:3; Etafa, Wakuma, Fetensa, Tsegaye, Abdisa, Oluma, Tolossa, Mulisa & Takele, 2020:5; Tesfaye, Anbessie & Gizaw, 2018:2).

Other studies, in contrast, have shown that healthcare workers have good knowledge and favourable attitudes toward end-of-life care, but the practice remains poor in Ethiopia (Anteneh, Kassa, Demeke & Guadu, 2016:115; Zeru, Berihu, Gerensea, Teklay, Teklu, Gebrehiwot & Wubayu, 2020:3-4). Training in end-of-life care, work experience in caring for chronically ill patients and palliative care and level of education are associated factors for better knowledge and favourable attitudes toward end-of-life care (Abate et al., 2019:3; Anteneh et al., 2016:120; Etafa et al., 2020:5-7; Zeru et al., 2020:3-4). Having inadequate knowledge about who needs palliative care, when palliative care should be started, fear of prescribing strong opioids and limited resources such as “inadequate space, access to essential medicines, specialist PC team” are significant barriers for end-of-life care (Lewis et al., 2018:504).

Patients with incurable illness strive to live as actively as possible and perform their daily functions while receiving palliative treatment (Carduff, Kendall & Murray 2018:3). Patients, caregivers and healthcare professionals have shown less interest about the prognosis of the illness (Campbell et al., 2018:4). Prognostication may be useful for preparing patients and family for death, transferring patients to hospice care or end of life care, promoting conversations on death and dying and decision making (Lee, Suh, LeBlanc, Himchack, Lee, Kim & Ahn, 2019:502). Nevertheless, being accurate remains a difficult task for healthcare professionals, and estimating prognosis is challenging even in developed countries (Buss et al., 2017:282; Lee et al 2019:4; NHS UK, 2021). And, it might not be culturally acceptable for other community.

Patient preferences cannot be maintained without open discussion on the medical and patient’s condition. Communication or breaking bad news benefit the patient to choose place of end-of-life care and death. End of life care involves maintaining the patient’s wish on the place of death and various factors may be associated with this preference (Higginson et al., 2017:7). Oftentimes, patients prefer to die in their home surrounded by loved family.

Home is the most preferred setting to die while hospital was the least choice at the end of life (Higginson et al., 2017:7). “Home became a more meaningful place, where family, friends and memories were kept alive. Several participants spoke of dying at home in a familiar and secure place” (Carduff, Kendall & Murray, 2018:5).

A study in Germany showed that palliative care patients are more likely to die at home than at the hospital (Engeser, Leutgeb, Glassman, Szecseniy & Laux, 2020:3). However, there are times when hospital and other institutional care are chosen for medical needs or to reduce the family burden (Kastbom, Milberg & Karlsson, 2017:936). A quantitative study conducted in Uganda confirmed a small percentage of patients (25%) and caregivers (11.7%) preferred that the patient die at home, while most healthcare professionals (72%) deferred in this preference (Campbell et al:4). Home based hospice care is preferred by family due to the benefits of being cared for in the patient’s own homeand in a familiar environment (Ko & Fuentes, 2020:333). A study in Tanzania also verified that people may prefer to be cared for in hospital at the end of their life due to lack of home based palliative or hospice care (Lewis et al., 2018:508). Despite the fact that home is the preferred place of death, there are times patients’ care needs cannot be met in home (Rainsford et al, 2018:1579). Furthermore, patients may get worried about being a burden for the family (Carduff, Kendall & Murray, 2018:5). A study in Australia showed that moving patients to hospital from home does not influence the quality of life of patients and “the preferred place of death was the ‘safe place’, regardless of its physical location” (Rainsford et al2018:1579). Thus, the choice of place setting of death may depend on the patient’s choice and accessibility of care services that the patient could need (Kastbom, Milberg & Karlsson, 2017:936).

2.3 PATIENT AUTONOMY AND ADVANCE CARE PLANNING

Autonomy is a concept in which self-determination is crucial where the patient is the principal recipient and decision maker in some culture. Collective decision-making (prevailing over individual rights when making serious decisions) is predominantly found in non-Western cultures (Ayers et al 2017:4; Brown et al 2018:4; Krause & Boldt 2018: 67-68).

In medical practice, the patient's right to know about their illness and to determine their own destiny is referred to as 'patient autonomy' and represents an important principle in the delivery of modern medicine (Krause & Boldt 2018: 67-68). This principle is violated when a diagnosis is not conveyed to a patient or conveyed to the next of kin without the consent of the patient (Tiruneh & Ayele, 2018:9-11).

According to a quantitative study done in China, around 70% of patients with life-threatening illnesses preferred to be informed of their diagnosis (Jie, Feng, Qiu & Zhang 2019:1476). However, another study reported that healthcare professionals withhold bad news from the patient at the family's request, and "physicians believed that they should prioritise "protective care" over the right to know" (Gan et al 2018:1460). A study in Canada found that the person's rights of deciding based on their view, values and beliefs are promoted and the patient is the only person who makes decisions on end-of-life issues and treatment (Be´Langer, Rodri´guez, Groleau, Gare´, Macdonald & Marchand 2016:8). In contrast, a qualitative study in Portugal reached the conclusion that disease prognosis is withheld from patients admitted to palliative care, yet their family caregivers are told (Hilário 2019:2-3).

When caring for a sick person, the role of family is significant in African culture and family members are expected of giving home nursing care for patients at the end of life (Lewis et al 201:508; Ntizimira, Ngizwenayo, Krakauer, Dunne & Esmaili 2016:277). A study in Tanzania found that healthcare professionals are persuaded in the conviction prognosis or diagnosis of serious illness should be told to next of kin to avoid psychological harm (Lewis et al 2018:509). Patients want to be involved in the decision process and prefer knowing the details of their medical conditions (Berhane & Enquselassie, 2016:50-51). Next of kin, nonetheless, may prevent healthcare workers from telling bad news to patient and would prefer to conceal the truth to maintain hope, due to fear that the disease could get worse (Hilário, 2019:4). Even though patients are not overtly told about their poor prognosis, they learn from their physical progress that their health condition is getting worse (Hilário, 2019:5). Some patients' experience has shown that healthcare providers involved them in conversations about their medical progress or treatments and made decisions based on this mutual understanding.

However, some other experiences show they were not involved in their care, resulting in poor healthcare providers-patient communication (Berhane & Enquselassie, 2016:51). Withholding bad news about diagnosis or prognosis may hamper conversations about advance care planning. Advance care planning involves appointing decision makers at the end of life and facilitating discussions between healthcare professionals and patient and family about their wishes and preferences (Buss et al., 2017:282). Proactive planning of care promotes patient autonomy to align with the needs of patients and family based on their values and beliefs (Chessa & Moreno, 2019:394). Helping the patient in making medical decisions, disclosure of prognosis, advance care planning, eliciting values and goals is one of the key palliative care domains (Buss, Rock & McCarthy, 2017:281). Advance care planning facilitates discussions on who is likely to become the proxy decision maker, plan preferred care and align with the needs of patients in the end of life (Buss et al 2017:282). "Ethically, the role of a surrogate decision maker is to promote patient autonomy by identifying what the patient would want were the patient able to speak. Communication with surrogates should reinforce the role of "being the patient's voice," in contrast to the surrogate choosing based on their own values or hope" (Chessa & Moreno, 2019:395).

The collective culture where people take a communal responsibility especially when a person is seriously ill receives emphasis in Ethiopia. It is similar in Rwanda, where family led decision-making is common when a serious medical diagnosis is identified, or patient is terminally ill. The family takes over the authority to decide for the patient regardless of the level of cognitive capacity or competence to decide. Meetings take place with several members of next of kin who physically surround the patient (Ntizimira, Ngizwenayo et al., 2016:277). The *'Merdo'* method is a widely used traditional way of conveying bad news in Ethiopia in which elders deliver the serious news (Abathun, Mamo & Reid, 2020:378). Nevertheless, advance care planning is an unusual practice in the Ethiopian healthcare system, and the concept of patient autonomy is only partly respected as the collective culture dominates over individual rights. Hence, the family may take the patient's place and make the decision on the end-of-life care (Abathun et al 2020:377-378).

Although communal culture prevails over that of individual rights and autonomous decisions, evidence shows that patients may want their rights on medical information to be kept confidential. Patients understand their rights, in terms of “respecting their autonomous capability” and they want to be given due respect and treated as a ‘person.’ “Patients want to be seen as the person that they were, having the capacity to work and being healthy” (Berhane & Enquselassie, 2016:51-52).

However, the choices of the patient around who should be involved when communicating bad news and, in the decisionmaking, may be influenced by varied factors. Thus, because culture influences ethics, it may be difficult to universally apply the entire bioethics to other cultures (Miljeteig, Defaye, Desalegn & Danis, 2019:7).

According to Ethiopian policy, patients have the right to be informed about their medical condition prior to receiving medical treatment. Furthermore, informed consent should be obtained from the patient, a designated person, and the patient's family members before medical treatments are administered. It also states that healthcare professionals must keep patients' information private. The policy also highlights information obtained from patients can be released and published for research purposes with informed consent and the individual's anonymity (Federal Negarit Gazette, 2014). The policy acknowledges the right of patients to be informed of their medical prognosis. Furthermore, a bad prognosis of a serious or terminal illness should be communicated to the patient's family if healthcare providers consider that telling the patient will cause serious emotional distress, leading the patient to hurt himself/herself (Federal Negarit Gazette, 2014).

2.4 NEED FOR PALLIATIVE CARE

Globally, about 35.5 million people who died in 2015 experienced serious health-related suffering as a result of life-threatening and life-limiting illness (Knaul, Bhadelia, Rodriguez, Arreola-Ornelas & Zimmermann, 2018:5). Non-communicable diseases are the leading cause of death in the world, and account for 41 million deaths every year (Bigna & Noubiap, 2019:1295). In the same vein, non-communicable diseases such as cancer, cardiovascular and diabetes are the leading causes, which account for 39% of all deaths in Ethiopia in 2016 (Shiferaw, Letebo, Misganaw, Feleke, Gelibo, Getachew, Defar, Abebayehu, Abebe, Amenu, Teklie, Tadele, Taye, Getnet, Gonfa, Bekele, Kebede, Yadeta, GebreMichael, Challa, Girma, Mudie, Guta & Tadesse, 2018:3; World Health Organisation 2018:87). In Ethiopia, the number of new cancer cases were 77,352 and the total cancer cases were 130,858, and the number of deaths due to cancer were reported to be 51, 865 in 2020 (WHO 2021). Furthermore, the number of deaths due to HIV/AIDS in 2020 were 12,685 (Federal HIV/AIDS Prevention Control Office 2021). Palliative care is needed for patients with various types of life-threatening and chronic illnesses.

This includes cardiovascular diseases, cancer, organ failure, HIV/AIDS and others (WHO 2020). It is predicted that 16.3 million individuals face health-related suffering as a result of cancer; 80% of them living in low and middle-income countries (Sleeman, Gomes, Brito, Shamieh & Harding 2021:232). According to the Globocan estimation, there are 77,352 new cancer cases every year in Ethiopia (International Agency for Research on Cancer 2021). However, pain is poorly managed and access to palliative care is limited in Ethiopia (Belay 2021).

According to the World Health Organisation, the number of people in need of palliative care each year is estimated to be 40 million, with 78 percent living in low- and middleincome countries. Nevertheless, only a small percentage (14%) of those in need of the service receives it globally (WHO 2020). Delays in diagnosis due to lack of screening programmes and late-stage presentations are not unusual in Ethiopia. Patients with cancer, for example, present with advanced stages of their illness (Abebe & Abebe 2017:257-258). As a result, these call attention to the needs for palliative care and endof-life care, as well as the breaking of bad news from which patients would benefit.

2.5 BREAKING BAD NEWS IN PALLIATIVE CARE

2.5.1 Definitions of bad news and breaking bad news

Any bad news is, indeed, serious for the individual since it affects all aspects of the patient. Any unpleasant situation is termed bad news (Definitions.net). Bad news refers to adverse news that significantly affects the future views of patients concerning their serious medical diagnosis or prognosis (SilveiraI, BotelhoII & Valadão 2017:325). In addition, bad news is described by healthcare professionals as a diagnosis of serious illness such as cancer, HIV/AIDS, failure of treatment and significant losses (Muneer, Elhassan, Osman, Abdalla, Abdelrahim, Ali & Abdalrahman, 2018:3; Nasrabadi, Joolaee, Navab, Esmaeili & Shali, 2020:3). Conveying bad news as well as conversations concerning poor prognosis or cessation of disease modifying treatment to patients or family members is described as breaking bad news (Messerotti, Banchelli, Ferrari, Barbieri, Bettelli, Bandieri, Giusti, Catellani, Borelli, Colaci, Pioli, Morselli, Forghieri, Galeazzi, Marasca, Bigi, D'Amico, Martin, Efficace, Luppi & Potenza, 2020:4).

2.5.2 Culturally adaptive bad news communication in palliative care

Effective communication of bad news cannot be achieved without understanding the cultural components and values of patients. The way bad news is conveyed could either adversely impact psychologically or benefit patients to continue with treatment (Sobczak et al 2018:2399-2400). Healthcare professionals could meet patients' preferences and maintain good communication with their patients by accommodating culturally sensitive communication approaches (Brown, Goliath, Rooyen, Aldous & Marais, 2018:4). A patient-centred care can be achieved when their preference and involvement in treatment are maintained (Berhane & Enquselassie, 2016:50). Hence, cultural values, beliefs, discourses used to convey bad news, the role of the family in decision making, and patient's right should be considered while breaking bad news in a culturally sensitive way (Abazari, Taleghani, Hematti, Malekian, Mokarian, Mohammad, Hakimian & Ehsani, 2017 et al 3-4; Aminiahidashti et al 2016:35).

Good communication skill is important to deal with a complex conversation and facilitate medical decisions in end of life care. Providing appropriate and clear information in a simple way promotes the capacity to address patients' needs (Ibañez-Masero, CarmonaRega, Ruiz-Fernández, Ortiz-Amo, Cabrera-Troya & Ortega-Galán, 2019:5). Patientcantred communication helps patients to ask, participate in their health-related decisions, get proper information about their illness/treatment, get emotional support, understand their diseases condition, express their stress, uncertainties or thoughts, and meet their needs at the end of life. Moreover, it has an impact on patients' understanding of their illness and conversations in the end of life (Epstein, Duberstein, Fenton et al., 2017:96). Good communication skill is central for conveying bad news. A good relationship, identifying the patient's priority, conversations about the patient's worries or uncertainties and eliciting patient's perspectives are suggested components of "patient-centred medical interviewing" (Hashim 2017:30). In addition, the relationship between patient and healthcare worker is central to holistic care and trust (Thomas, Best & Mitchell, 2020:139140). Drawing out of the patients' perceptions on their illness, about their state of health, feelings, expectations and understanding the impact of the illness are central in patient centred and culturally appropriate care (Hashim, 2017:31).

Patients may prefer a meaningful relationship and shared responsibilities when communicating with healthcare professionals (Sobczak et al., 2016:175). A study in China found that perceived emotional support from healthcare professionals, disclosure of family-supported medical condition, and discussion of treatment plans are related to trust in healthcare professionals and maintain patient's hope (Cao, Qi, Yao, Han & Feng, 2017:644-645). Individuals may prefer a paternalistic approach in a difficult situation to make informed medical decisions (Kassirera, Levineb & Gaertig, 2020:11370). A study in Italy has shown that family caregivers and healthcare workers may disclose full information to protect patient from harm and maintain hope (Ibañez-Masero, CarmonaRega, Ruiz-Fernández, Ortiz-Amo, Cabrera-Troya & Ortega-Galán, 2019:5-6). A quantitative study in Poland reported that family hinder conversations between health professional andpatient (Dzierżanowski & Kozlowski 2022:1510). Healthcare professionals are guided by a paternalistic approach in Ethiopian medical culture (Biyazin, Yetwale & Fenta, 2020:5). A quantitative study in Ethiopia verified that the majority of patients make their own decisions, yet shared decisions and paternalism approaches are also used to make treatment decisions (Biyazin, Yetwale & Fenta, 2020:5). Informed consent helps the patient to make the right decision based on own preferences. Nevertheless, it is clear that patients are not well informed of the risk/benefit, treatment options, and the type of procedure performed on them (Chane, Birhanu & Suga, 2020:29). Collective decision prevailing over the individual decision is remarkably ubiquitous in Ethiopian culture where oftentimes individuals make joint decisions with their family or close friend or by another person (Alemayehu & Meskele, 2017:216-217).

It is also clear that patients would like to make decisions on their treatment choice with attending physician, or some (17.8%) patients may prefer their physicians to make treatment decision for them by considering their opinion (Berhane, 2016:62).

2.5.3 Benefits of breaking bad news in palliative care setting

Palliative care helps not only to improve the quality of life but also to reduce and prevent costs on futile treatments. Evidence confirms that the oncology patients did not know their bad prognosis and many had sold major items to pay for treatments that were likely futile (Reid et al2018:627). Disclosure of bad news promotes informed decisions by the patient. The diagnosis of a life-threatening or terminal disease or prognosis is invariably a shocking time for the patient and family, affecting their view on the future or tomorrow. Despite the fact that it is a painful truth, it should be communicated to the patient or/and family. Healthcare providers have reported that bad news conversation is required to communicate treatment failure, diagnosis, disease recurrence and preparing patients for death (Zielińska, Jarosz, Kwiecińska & Bętkowska-Korpała, 2017:104). Conveying bad news in palliative care may help patients to get appropriate care, treatments, and accept the unpleasant news related to health status. This may result in improved quality of life and peaceful death (Lewiset al 2018:503). In contrast, withholding bad news may affect open communication between patient-family. This could also complicate grief among family and exclude patient in decision making, while open communication helps to meet the patient's needs (Ibañez-Masero et al 2019:6-7). Patients at the end of their life, however, may be reluctant to take pain relief medications/treatments, and may unrealistically seek for futile treatment leading to poor quality of life. Healthcare professionals unveiled that if bad news is not appropriately conveyed, patients may spend money on futile treatments (Lewiset al 2018:507).

The utmost benefits of palliative care may be obtained for both patients and the healthcare system if patients are informed of their medical conditions and the transition to palliative care is maintained. Evidence from research shows that patients who receive palliative care/end of life care have lower utilisation rate of intensive care unit, emergency unit, aggressive treatments, and have lower in-hospital death (Palma, Fortuna, Hegarty, Louis, Melotti & Moro, 2018:1347).

Moreover, receiving palliative care is associated with reduction of emergency care admission and aggressive treatments at the end of life (Ziegler, Craigs, West, Carder, Hurlow, Millares-Martin, Hall & Bennett, 2018:5). Access to end of life care promotes better care as well. A study in the UK showed that patients' who received palliative care are more likely to prefer dying in hospice/home than those who did not. And patients who received palliative care in hospice or home live longer than those cared for in hospital (Ziegler et al 2018:3).

Anxiety was higher among patients who are not informed of their bad news than informed; breaking bad news reduces anxiety. It is also observed that patients who are uncertain about their disease situation are worried or distressed and this lessens their quality of life (Gramling, Stanek, Han, Duberstein, Quill, Temel, Alexander, Anderson, Ladwig & Norton, 2018:317). Patients need to be fully informed and participate in making decisions and treatment choices (Sobczak et al 2016:175), because such knowledge enables patients to make the right medical decisions (Rao, Sunil, Ekstrand, Heylen, Raju & Shet, 2016:1781). They also reported that knowing the truth helps them to cope with their difficult situations (Bongelli, Bertolazzi, Piccioni & Burro, 2021:4). Discussions on medical conditions in palliative care reduce the effect of uncertainties on quality of life of the patients (Gramling et al 2018:318).

2.6. CULTURAL PERSPECTIVES ON BREAKING BAD NEWS

2.6.1 Patients' preferences and perspectives on breaking bad news

The choices of people about how to be told of bad news vary from one community to another. Thus, the way bad news is conveyed needs to be customised from the view of each community as the dynamics of patients' preferences, beliefs and values vary in different cultural contexts (Aminiahidashti et al 2016:35). Preferences about bad news disclosure may entail whether the patient wishes to know or not, how much they would want to know, the time and place of disclosure. A study conducted in Saudi Arabia found that patients want to know their condition before initiating treatment as they want to organize the remainder of their lives and complete the unfinished business (Alzahrani, Alqahtani, Alhazmi, Gaafar, Bajabir, Alharbi, Alharbi, Kheshaifaty & Alzahrani, 2018:1661-

1663). According to research conducted in China, patients want direct communication on their medical ‘terminal illness’ yet family wish to withhold such knowledge (Liu, Yang, Huo, Fan & Gao, 2018:2176). Moreover, a study in Sri Lanka showed that the majority of study participants from community and patients prefer to be informed of their medical condition (Rajasooriyar et al 2017:252). Conversely, a study in a francophone country in Africa generated different perspectives of patients’ preferences with some concealing the truth from the patient and others opting for disclosure to the next of kin (Kpanake et al 2016:1314). In the same vein, another study by Kpanake et al (2019:4-5) found that participants from a French background preferred receiving the truth regardless of diagnosis and prognosis.

Nevertheless, participants from Togo) preferred next of kin to be informed (Kpanake et al 2019:4-5; Kpanake et al 2016:1314). A study in Ethiopia established that patients want their family to accompany with them when they receive bad news (Fisseha et al 2020:1021).

To satisfy the patients’ and family needs, disclosure of bad news must conform to their preferences. Nonetheless, family and patient may have different choices (Alzahrani et al 2018:1661). Family may also have the power over the patient and decide whether to tell the patient or not (Hahned, Lianga, Khoshnoodd, Wangb & Li, 2020:289). On one hand, studies found that patients wish to know about their medical situation (Liu, Yang, Huo, Fan & Gao, 2018:2177; Rao et al 2016:1781), but on the other hand there are studies that verified the position that family want to withhold the bad news from the patient (Abebe & Abebe 2017:258; Sarwar, Rehman, Fatima, Suhail & Naqi, 2019:697). A quantitative study in Saudi Arabia compared the differences between patient and family preferences on cancer diagnosis disclosure and telling details of the illness. It established that the majority of patients’ preferred to be personally told of their medical condition compared to the family group (Alzahrani et al 2018:1661). In the same vein, a quantitative study in Ethiopia showed that majority (97.2%) of patients prefer disclosure of the consequence and prognosis of their illness in clear words (Fisseha et al 2020:1021). Contrary to this result, another research in Ethiopia found that patients wanted their family to be informed of the poor prognosis (Woldemariam, Andersson, Munthe, Linderholm & Lindstrom, 2021:1344). In addition, the truth about the diagnosis is concealed from the patient, while the family is told (Kebede, Abraha, Andersson, Munthe, Linderholm, Linderholm & Lindstro¨m 2020:8).

Preparation of patient, cultural preference and delivery of bad news build higher level of trust in healthcare professionals (Cao et al 2017:644-645). Patients wish to have advance notice with some amount of information than direct telling, preferring progressive disclosure in small-sized bits at a time (Fisseha et al 2020:1021). Furthermore, patients want to be informed of their medical diagnosis soon after the diagnosis while family prefer be told gradually (Liu, Yang, Huo, Fan & Gao 2018: 2177). On the other hand, patients may desire to know the details of their medical conditions (Zielińska, Jarosz, Kwiecińska & Bętkowska-Korpała 2017:106). Failure to ask patients how much they want to know about their condition could adversely affect their satisfaction with care (Fisseha et al 2020:1021). In addition, divulging all information and sudden communication disregarding patient preferences could affect comprehension and satisfaction with care at the end of life (Ibañez-Masero, Carmona-Rega, Ruiz-Fernández, Ortiz-Amo, Cabrera-Troya & Ortega-Galán, 2019:5). Thus, tailoring communication style with patients and healthcare professionals' preferences increases patient satisfaction. Patient-centred care regards the involvement of patients posititvely. A study confirmed that providing warning when breaking bad news is not associated with reduction of anxiety (Porensky & Carpenter, 2016:71).

Research in Iran has shown patients believed that the patient should be told the medical conditions, prognosis and life expectancy (Aminiahidashti, Mousavi & Darzi, 2016:35). A study in Italy has shown that patients were accompanied by someone when bad news is communicated (Bongelli, Bertolazzi, Piccioni & Burro 2021:4). In addition, research conducted in India verified that patients would prefer family to be involved in some capacity (Rao et al 2016:1781). Nevertheless, some patients may prefer to receive bad news in the absence of their family or friends (Ozyemisci-Taskiran, Coskun, Budakoglu & Demirsoy, 2018:350). Patients' preference on when to receive bad news may vary; some want to know soon after the diagnosis while others want to know later, and patients wish physicians to use the word ‘growth’ or illness rather than cancer (Rao et al 2016:1781). Patients have reported that knowledge on their medical condition, end of life care and available treatment options informs how they make serious decisions (Rao et al 2016:1781). A quantitative study conducted in Ethiopia has revealed that patients, family, and community members had the same preference on disclosure of poor prognosis that should be told for family caregivers only. Nonetheless, there was preference mismatch between the community, and the patient and family on communication of life expectancy; the community wanted that life expectancy be communicated to family caregivers only, while patients and family preferred that patient be informed (Woldemariam, Andersson, Munthe, Linderholm & Lindstrom 2021:1344). Moreover, the patients’ preference about disclosure of bad news vary from the family members.

The majority (55%) of patients want to be informed of their diagnosis with the presence of their family, while the majority (57%) of family caregivers wanted only family to be told (Woldemariam et al 2021:1345).

Family caregivers may be traditionally delegated to make decision as they are responsible for nursing care (Kebede et al 2020:8). Nonetheless, some patients may choose to keep the bad news confidential, even from family members due to fear of stigma, and the incorrect perception that their disease is a punishment from God (Kebede et al 2020:11).

Patient’s preferences of care, amount of information, treatment choice and decisions and way of communication are mediated by the cultural beliefs and perception towards health. In Ethiopia, patients believe that their illness is a punishment from God or a curse (Mesafint, Berhane & Desalegn 2018:113). A study in Australia verified that patients and caregivers avoid conversations about a life-threatening illness, death and dying as culturally inappropriate. They would rather want to focus on spiritual rituals and this helped to cope with their problems (Kirby, Lwin, Kenny, Broom, Birman & Good 2018:6). Hence, such cultural beliefs shape patients perceptions of suffering, care and decision making. Evidence shows that patients’ are not satisfied with the information provided and their emotional issues are not addressed (Ozyemisci-Taskiran, Coskun, Budakoglu & Demirsoy 2018:349).

Physicians indicated that cultural conversations about death being taboo and having no religious belief make death overwhelming for patients, expenses, and a lack of training are impending factors for the delivery of bad news (Gan et al 2018:1460).

2.6.2 Healthcare professionals' perceptions and practices in breaking bad news

Healthcare professionals believe patients should be told the bad news regardless of the different wish family may have. However, they tell the detail when patient asks for it. Some healthcare workers prefer to tell the bad news to patient first and then tell the family gradually (Alshammary, Hamdan, Tamani, Alshuhil, Ratnapalan & Alharbi, 2017:69). Studies from Poland and Saudi Arabia show that healthcare professionals believe that patients should be informed first of the serious medical condition. However, conversations about death and dying are difficult tasks for physicians, and their own fear of death is associated with it (Alshammary et al 2017:69; Dzierżanowski & Kozlowski 2022:1509). Moreover, breaking bad news is stressful for healthcare workers partly due to fear of diminishing a patient's hope (Sobczak et al 2016:174-175; Zielińska, Jarosz, Kwiecińska & Bętkowska-Korpała, 2017:104).

The way bad news is conveyed could increase patient satisfaction (Trant, Szekely, Mougalian et al., 2019:352) or lessen the patient's hope, if negatively framed (Porensky & Carpenter, 2016:71). The task of conveying bad news may affect both patients and healthcare professionals. Receiving bad news could cause emotional distresses to patients and family (Alzahrani et al 2018:1661). In the same way, physicians reported that fear is a common emotional reaction among patients (Messerotti et al 2020:7). It is evident that bad news has psychological and emotional consequences to healthcare professionals (Fisseha et al 2020:1022). Using a guideline when breaking bad news reduces negative impacts on patient, family and healthcare professionals. Moreover, it enhances the healthcare professionals' confidence and communication skills while reducing the emotional burden associated with bad news disclosure.

Research shows that breaking bad news is a common, but tough task for healthcare professionals (Dafallah et al 2020:762; Sarwar et al 2019:697; Gonc¸alves, Almeida, Amorim, Baltasar, Batista, Borrero, Fallé, Faria, Henriques, Maia, Fernandes, Moreira,

Moreira, Neves, Ribeiro, Santos, Silva, Soares, Sousa, Vicente & Xavier 2017:280). Maintaining hope when disclosing a serious medical news is a challenging part and discussing prognosis and transition to palliative take the lead (Messerotti et al 2020:4). Research conducted in Poland disclosed that patients are not satisfied with how healthcare professionals identify their needs, prepare and invite them to know about their illness (Marschollek, Bąkowska, Bąkowski, Marschollek & Tarkowski, 2018:376-377). A study in Portugal disclosed a difference in disclosure of diagnosis versus prognosis; most (69%) physicians disclose diagnosis while only 30% often disclose disease prognosis to patients (Gonc¸alves et al 2017:279). In contrast, a study in Sudan has shown majority (70.4%) of healthcare professionals give disease prognosis to next of kin than patients (Muneer et al 2018:3).

Healthcare professionals may prefer to break bad news to family or to the patient in the presence of family. A study in Italy showed that majority of healthcare workers (74%) do not ask patients how much detail they want to hear before delivering bad news and 62% would prefer to give the information for the patient and family (Messerotti et al 2020:4).

According to quantitative research conducted in Pakistan, only 34.3% of physicians' usually convey bad news to next of kin and 28.4% mostly break the bad news to patients in the presence of their next of kin (Sarwar et al 2019:698). The patient should be given an opportunity to choose as privacy can be deprived if family is present at disclosure (Kebede et al 2020:9). Evidence has shown that bad news disclosure and end of life care decisions are ethical dilemmas that healthcare professionals frequently encounter (Miljeteig, Defaye, Desalegn & Danis, 2019:6-8).

Being unable to address patients' concerns could affect patient-healthcare workers communication. An effective modality of bad new presentation can build trust between patient and healthcare workers (Zwingmann et al 2017:3172). However, healthcare professionals are incompetent to identify the patients' concerns, and have insufficient communication skills (Bain, Lian & Thon, 2020:118). Evidence demonstrates that there is insufficient training and skills of healthcare professionals on breaking bad news (Bain, Lian & Thon 2020:118; Biazar, Delpasand, Farzi, Sedighinejad, Mirmansouri &

Atrkarroushan, 2019:199). Healthcare workers oftentimes learn how to deliver bad news through intuition, observing seniors, reading book/articles, and may not be aware of a specific breaking bad news approach (Zielińska, Jarosz, Kwiecińska & BętkowskaKorpała 2017:105). Hence, training could help healthcare professionals develop improved skills on bad news disclosure. Organised workshops on a specific breaking bad news guidelines called SPIKES has shown improved bad news disclosure abilities and confidence amongst health care professionals (Westmoreland, Banda, Steenhoff, Lowenthal, Isaksson & Fassl, 2019, 63-64).

The manner in which bad news is communicated can affect how patients cope with their illness (Bongelli, Bertolazzi, Piccioni & Burro, 2021:4). Culturally appropriate discourse is required to provide empathetic and emotional support after bad news is presented to the patient. However, it is difficult for healthcare workers to find the right words to express sympathy, partly due to lack of skills (Banerjeea, Mannaa, Coylea, Shena, Pehrsona, Zaidera, Hammondsa, Kruegera, Parkera & Bylunda, 2016:5-6).

It remains a difficult responsibility for healthcare workers not only how to deliver, but also to whom the bad news should be relayed. On one hand, competing family to withhold bad news and the right of patients to be informed of their medical conditions lead healthcare professionals into an ethical dilemma (Hahne, Liang, Khoshnood, Wang & Li, 2020:289). A study in China confirmed that majority of physicians tell the bad news to the family members first and to the decision to inform the patients is informed by the family preferences (Hahned, Lianga, Khoshnoodd, Wangb & Li, 2020:288). Similarly, a study in Brazil has shown physicians tell bad news to the family (SilveiraI, BotelhoII & Valadão 2017:325). The reasons provided by physicians for such practice are that physicians believed that patients cannot cope with the bad news and “fear of conflict with family” (Hahned, Lianga, Khoshnoodd, Wangb & Li, 2020:288). Fear of getting blamed by family members for the patients’ emotional reaction against disclosure of bad news is also another hindering factor to abide by the wishes of the family. Physicians believed that they need to develop their skill on bad news disclosure (Hahned et al 2020:289). Family and community may chose healthcare workers withhold the bad news yet patients do not subscribe to this stance (Woldemariam, Andersson, Munthe, Linderholm & Lindstrom, 2021:1345). Hence the mismatch between patient and family preferences can result in a challenge for healthcare workers in breaking bad news.

2.6.3 Family preferences/perspectives on breaking bad news

Family members are involved in making decisions on end of life care and they share the healthcare costs of the patient (Mesafint et al 2018:114). They may also be the primary patient attendant (Abebe & Abebe, 2017:258). Hence, family may have needs of end of life care information, including the goals of treatment, symptoms at the end of life, benefits of hospice care, life-prolonging treatment options and its benefits and risk in order to make medical decisions (Ko & Fuentes 2020:332). Consequently, healthcare workers need to give sufficient time when transiting the patient to hospice care. This would address uncertainties, answer caregivers' questions and make sure that they understood the situation (Ko & Fuentes 2020:332).

Decision making can be deferred to family on behalf of the patient who are responsible for the provision of end of life care. However, family caregivers may not get adequate opportunity to discuss with healthcare providers about end of life care, and may have insufficient information on hospice care. This may hamper maintaining patients' choices and needs at the end of life (Ko & Fuentes 2020:331). In contrast, evidence documented suggests that healthcare workers fulfilled information needs of family caregivers (IbañezMasero, Carmona-Rega, Ruiz-Fernández, Ortiz-Amo, Cabrera-Troya & Ortega-Galán, 2019:5). Communication skill is required to elicit patient's preferences, convey bad news, respond to emotional reaction and provide patient-centred care. A qualitative study in the United States reported that to establish good communication with healthcare workers, family members valued health professionals' humility for patients, good health professionals-family relationships, respect, good care, and concern for them. This also can help to reduce negative feelings and create a sense of security (Jóhannesdóttir & Hjörleifsdóttir, 2018:485-486).

It is imperative to provide accurate information, ensure information flow, and maintain privacy in order to foster good communication between family and healthcare professionals. Accepting the situation also assists the family in coping, staying with the patient until the end, and establishing good communication with healthcare workers (Jóhannesdóttir & Hjörleifsdóttir, 2018:489). The costs for treatments my interfere with the family decisions; healthcare professionals voiced that family request them to hide the bad news and give untruth information to the patient (Gan et al 2018:1460). Nevertheless, healthcare workers giving false hope may cause worry to the healthcare workers (Alshammary et al., 2017:69).

2.6.4 Factors contributing for preferences of care and making decisions in bad news disclosure

Fear of violence and maintaining the patient-healthcare professional relationship are reported reasons leading healthcare professionals to avoid telling the truth about the patient (Gan et al 2018:1460). A strong anticipation of total cure, followed by fear of being unable to answer to patient's questions and fear of own death were confirmed as barriers for breaking bad news (Muneer et al 2018:3). Moreover, the protective attitude of the next of kin is another barrier that exerts an impact on the process of breaking bad news. Among the reasons for not telling is that next of kin believe that telling poor prognosis would not have a benefit to the patient and it would rather create dissatisfaction (Kebede et al 2020:8). The next of kin perceived fear of loss of hope and negative psychological impact associated with bad news disclosure are shared fear by physicians (Gonc¸alves et al 2017:279).

Socio-demographic factors are also associated with bad news disclosure. Those who are younger and have higher education had higher preference for disclosure of bad news to the patients. Moreover, having a sense of personal control and the coping mechanisms are related with a greater desire to be informed about the diagnosis (Rao et al 2016:1780). Income and higher education have been verified as associated factors that increase the likelihood of receiving medical diagnosis (Liu, Yang, Huo, Fan & Gao 2018:2177).

There are various factors that could influence individuals' choices of care. Lack of understanding about palliative care can hinder patients from seeking palliative care. A qualitative study in Australia proved that patients and family caregivers did not have adequate understanding on palliative care and the implication of transition to palliative care (Kirby, Lwin, Kenny, Broom, Birman & Good, 2018:4). Furthermore, some patients did not have interest for discussions on end of life, and disease prognosis. As a result, patients and caregivers hide reporting pain and navigating pain relief as they believed that patient should tolerate and endure physical pain (Kirby et al 2018:5-6).

2.6.5 Cultural perspectives in palliative care

Cultural values and beliefs inform how people see illness, and respond to it (Getachew et al 2020:4; Mesafint et al 2018:114). History, values and beliefs towards life, social structures construct a community's world view and influence how one appreciates the world. Cultural attributes for understanding or viewing the meaning of life, sufferings, and the way we live also influence one's preferences on how bad news should be conveyed, including making decisions on palliative care. Cultural perceptions about terminal illness and breaking bad news could influence the protocols (Nasrabadi et al 2020:3-4). Some cultural values appear to facilitate effective bad news communication. A study in Saudi Arabia disclosed that "religion, relationship between doctor and patient, and support from family and friends" are factors that allow patients and family members to cope with disclosure of cancer diagnosis (Alzahrani et al 2018:1661).

Life-threatening illness affects not only the body but also other aspects of the person. It affects patients psychologically and causes distress (Kim, Kim, Song, Kim, Kang, Noh, Chung, Kim & Rha, 2017:4). Psychological support has been linked with enhanced quality of life (Vanbutsele, Pardon, Belle, Surmont, Laat, Colman, Eecloo, Cocquyt, Geboes & Deliens, 2018:6-7). A quantitative study in Switzerland verified that "spiritual well-being and meaning life" are important factors in protecting palliative care patients from psychological distress. Moreover, depression and spiritual well-being influence the quality of life of patients with life-threatening illness in palliative care (Bernard, Strasser, Gamondi, Braunschweig, Forster, Kaspers-Elekes, Veri, Borasio, & the SMILE Consortium, 2017: 516-517). Evidence has documented religion and spirituality as imperative for patients experiencing life-threatening illness (Balboni & Balboni 2018:817). Religion, religious rituals, and belief in God offer a purpose for life (Chiatti, 2019:344).

Furthermore, spirituality is an important aspect of patient's quality of life, and spiritual support play important role in palliative care (Ferrell, et al:2020:1079). This support is given according to the patient’s belief, culture and values as the view of spirituality and religion is influenced by culture. Religious rituals or spiritualty help people with lifethreatening illness cope with their serious health problems and pursue to live as actively as possible (Arrey, Bilsen, Lacor & Deschepper, 2016:10). The experience of healthcare workers and patients confirms that spiritual care is organised around comprehensive care. Assessment of the spiritual needs of patients is paramount in palliative care and communicating bad news (Moosavia, Rohanib, Borhanic & Akbari, 2021:5).

Death and dying are not openly discussed in the medical culture in Ethiopia. Conversations about death and dying are difficult tasks even for healthcare professionals (Dzierżanowski & Kozlowski, 2022:1509). The family may be notified that all the possibilities of fixing the problem have been exhausted. In such circumstances, they have to take the patient to home when death is imminent. This could construed as meaning that illness is far advanced and there is no chance of cure (Belay 2021). This decision to take the patient home in Ethiopian medical culture could be equivalent to transitioning to palliative care in other countries (Messerotti et al 2020:4; Kirby et al 2018:4). Family may be the immediate reposite to take care dying or seriously ill patient. Furthermore, friends, neighbour or next of kin visit the patient and take the responsibility of informing the impending death (Belay 2021).

A qualitative study in Belgium among Sub Saharan Africans established that people with life-threatening illness have strong faith in God and spirituality/religion has a significant place for perceived quality of life (Arrey, Bilsen, Lacor & Deschepper, 2016:9). Spirituality helps patients to maintain strength, hope and give meaning to life (Balboni & Balboni, 2018:817-818).

Cultural beliefs shape patients perception of suffering, preferences of care and decision making, and needs for ultimate care. Good healthcare professionals-patient relationships, giving due time, respecting and maintain cultural preferences are deemed to be elements of a good care (Chiatti 2019:345). People view the causes of ill health or illness from ae religious or spiritual perspective in Ethiopia. Thus, prayers, using holy water and healing are the first remedies patients seek in Ethiopia (Mesafint et al 2018:114; Workneh, Emirie, Kaba, Mekonnen & Kloos, 2018:4). Patient’s preferences of care, their treatment choice, preference of the type and amount of information and decisions are mediated by the cultural beliefs and values. Often patients with life-threatening illness may seek treatment from traditional or religious places (Getachew, Tesfaw, Kaba, Wienke, Taylor, Kantelhardt & Addissie, 2020:4). The discourse around disclosure is always embedded in the wish wish for health ‘*tena yistelegn’* which means ‘may you have health’ or asking how your health in Ethiopian culture is (Workneh et al 2018:3). Withholding bad news is considered as care for the patient in Ethiopia (Chiatti 2019:345). How patients’ perceive health may inform how bad news ought to be disclosed. This may contribute to negative perceptions on bad news and predicting how disclosure should be culturally customised.

Parents raise children through religious, spiritual and cultural principles (Chiatti 2019:344). In general, religion and spirituality serve as the foundation for Ethiopian culture, and health, sickness are all understood from this ontological orientation (Chiatti 2019:344; Getachew, Tesfaw, Kaba, Wienke, Taylor, Kantelhardt & Addissie, 2020:4; Workneh, Emirie, Kaba, Mekonnen & Kloos, 2018:4; 952). Health is perceived not only as the absence of disease, but as “proper eating, drinking, and social interaction and performing local ceremonies as part of the community” perspectives (Workneh et al 2018:3). Some of the cultural perceptions and views on health and illness have a negative effect on the health practices or conventional health seeking behaviours in Ethiopia (Workneh et al 2018:3).

Serious health news may impact multidimensional aspects of the person’s life. Support from family, friends, professionals and religious fathers are central. Social and religious support have a high value in Ethiopia where social bonding is a premium. Spiritual care service is determined according to the needs and cultures of the patient, and prayer and other spiritual support may be beneficial. Patients want healthcare workers to consider these religious beliefs when breaking bad news (Aminiahidashti, Mousavi & Darzi, 2016:35). The existing guideline/protocols for conveying bad news does not entail those values. Cultural values and beliefs influence care preferences, communication patterns or discourse, end of life care plans/ advance care planning, decision making processes and perceptions. A qualitative study in Ethiopia involved participants from diverse religious group and established that participants perceive health as a provision from God (Kahissay, Fenta & Boon, 2020:951). “Irreverence to God or Allah is believed across religions and belief systems to cause illnesses, absence of peace and lack of food” (Kahissay et al 2020:952). Amulets, using holy water are used therefore to protect individuals from ill health (Kahissay et al 2020:953).

2.7 GUIDELINES FOR BREAKING BAD NEWS

2.7.1 Available guidelines, and related gaps

Healthcare professionals need to have a culturally adaptive guideline for breaking bad news (Borjalilu, Karbakhsh, Hosseini, Sadighi, Kavian 2018:18). Guidelines for breaking bad news benefit healthcare professionals (Messerotti et al 2020:7). However, there appear to be low awareness and lack of training in the breaking of bad news guideline currently available to healthcare professionals (Fisseha et al 2020:1022). Research done in Canada found that patients are content with the components of breaking bad news guideline known as SPIKES (Mirza et al 2019:4). Nonetheless, the study also added that qualitative findings have shown certain patients’ preferences that are unmet by the prescribed protocol (Mirza et al 2019:5). Existing studies employ a quantitative research approach to examine preferences of patients, family members and healthcare professionals for conveying bad news (Alzahrani et al 2018:1663; Fisseha et al 2020:2022; Messerotti et al 2020:4; Rajasooriyar et al 2017:252). Literature from different countries shows that most people would prefer to be informed of their medical conditions (Aminiahidashti et al 2016:35; Fisseha et al 2020:1021). Nevertheless, these results are from quantitative research where obtaining in-depth understanding of the cultural factors are limited.

The existing guidelines for breaking bad news have limitations as they are not developed for diverse cultures and they derive their recommendations from published articles. SPIKES is the common protocol used for breaking bad news. A study in Sudan showed that only one-quarter of the respondents followed a standardised protocol for breaking bad news, of whom 55.6% followed the SPIKES protocol, while 52.5% used their idiosyncratic approach (Muneer et al 2018:2). SPIKES is a common guideline which is taught in medical schools in Canada (Mirza, Ren, Agarwal & Guyatt, 2019:2). Furthermore, it is the common protocol used in the literature on breaking bad news (Mirza et al 2019:4; Sarwar et al 2019:697). However, a qualitative study in Iran demonstrated a culturally sensitive guideline developed from empirical evidence on the preferences of people. These guidelines propose a different approach.

According to Sedhom and Bari (2016:1), four stages of bad news communication approach may help healthcare professionals in this undertaking. The stages encompass setting diagnosis, conveying prognosis, conversations about setting goals of care and making decisions on treatments (Sedhom & Bari 2016:1). The available guidelines for breaking bad news have shared: they inform healthcare providers to make an assessment of how much the patients already knows and how much they are prepared to know. Moreover, the guidelines advice on the importance of preparation, selecting appropriate place and communication skills that the healthcare providers need to help with emotional reactions after conveying the bad news (Anuk and Bahadar, 2020:117-118). Application of breaking bad news guidelines helps to avoid substantial psychological distress (Zheng, Lei & Liu, 2019:5-6). Breaking bad news guidelines support both healthcare professionals in assessing the patient’s perceptions and needs, building trust and conveying the truth (Abazari et al 2017:2-4; Pereira, CalôNego, LemonicaDe & Barros, 2017:44).

Nevertheless, healthcare professionals’ knowledge and skills about the bad news delivery approaches are limited (Zielińska et al 2017:104). Evidence points to a growing trend in developing culturally adaptive approaches for breaking bad news for the patient (Abazari et al 2017:2-4; Baig et al 2018:1338; Pereira et al 2017:45-56). This pattern has also been documented in Africa (Brown et al 2017:6). In addition, a family communication approach has been designed as a mnemonic ‘ARCHES' based on reviewed literature to help healthcare providers. Using such a strategy is beneficial to communicate with the patient's relatives, who request the bad news be kept hidden from the patient (Holmes & Illing, 2021:130). Present qualitative studies on understanding the phenomenon in-detail are limited in Ethiopia (Kebede et al 2020:8-9). Furthermore, a study in Ethiopia shows that the way bad news is disclosed by healthcare professionals does not meet the patients' needs (Fisseha, Mulugeta, Kassu, Geleta, & Desalegn 2020:1021). Therefore, further research and in-depth understanding of the cultural preferences about breaking bad news are needed. Moreover, a culturally adaptive guidelines based on empirical evidence needs to be available.

Patients' understanding about their disease and keeping privacy affect the level of patient satisfaction when bad news is disclosed (Marschollek et al 2018:376). Research in Ethiopia confirmed that settings, lack of privacy to talk about serious and sensitive issues, language barriers and lack of time are among challenges that affect relaying bad news to patients (Kebede et al 2020:6). As a result, patients are not presented with sufficient details about their health, and this in turn has an effect on the personal support of doctors (Kebede et al 2020:7).

Incompetent bad news communication skills and lack of knowledge about the available guidelines can impede healthcare professionals from conveying bad news. Research verifies that skills training in breaking bad news guidelines for healthcare professionals is a mandatory practice for the medical professions (Gorniewicza, Floyda, Krishnanb, Bishopa, Tudivera & Lang, 2017:662). Furthermore, training fosters good communication skills in breaking bad news (Corey & Gwyn 2016:493). However, healthcare professionals disclose bad news without adequate training and most of them learn about the disclosure through observation when others do it (Sarwar et al 2019:697). Similarly, a study done in Italy verified that 76% of physicians learned how to break bad news by observing their seniors, mentors and through experience (Messerotti et al 2020:7).

Evidence-based learning and preparing prior to breaking bad news are associated with low level of burnout among healthcare professionals (Messerotti et al 2020:10). Nonetheless, research from Africa, Europe, and Asia disclosed that healthcare professionals do not have adequate courses in breaking bad news (Borjalilu et al 2018:17-18; Gonc¸alves et al 2017:279; Muneer et al 2018:2). A large survey done in 40 countries shown that only 33.4% of the study subjects (nurses, physicians, medical students and allied professionals) have attended formal training in breaking bad news and those who had the training are more likely to break bad news in sensitive ways as opposed to those who did not have formal training (Alshami, Douedi, Avila-Ariyoshi, Alazzawi, Patel, Einav, Surani & Varon 2020:5-6). Lack of knowledge and skill on how to convey bad news may lead to false reporting on the truth of patients' medical condition (Nasrabadi et al 2020:3).

2.8. SUMMARY

Recent literature published in journals was assessed and analysed with a focus on cultural preferences in breaking bad news, palliative care, and the conveyance of bad news. The factors and benefits of breaking bad news were thoroughly discussed. The existing guidelines for breaking bad news were reviewed and elaborated. In sequence, the research methodology and designs are discussed in detail in the following chapter.

CHAPTER THREE

METHODOLOGY AND RESEARCH DESIGN

3.1 INTRODUCTION

This chapter systematically describes the research methodology. The qualitative research approach provides a sound foundation for the study. The chapter covers the study design, research inquiry approach, sampling procedure, criteria for selecting participants, sample size, data collection and analysis process.

This research strove to understand the cultural preferences on breaking bad news in palliative care settings. It also describes how the research question was answered by applying the selected research design and approaches.

3.2 THEORETICAL FRAMEWORK

An inductive approach observes the phenomenon and develops descriptive data (Court 2018:25). Qualitative research follows inductive and exploratory approaches to inquiry (Patten & Newhart 2017:22). Qualitative study is value-laden as it is influenced by the researcher's beliefs and values (Bhattacharya, 2017:36). The researcher is aware that his religious beliefs, cultural values, awareness of patient’s rights, educational background, training and experience in palliative care all might potentially influenced his understanding and interpretation of the data. Nevertheless, the interpretation of the findings grounded in the data and the participants’ point of view. Qualitative research acknowledges that participants’ subjective viewpoints or perspectives (Court, 2018:4).

Qualitative research inquiry is characterised mainly by the study being carried out in natural settings; the researcher is involved and immersed in the study world and interprets the phenomenon from the participants’ perspective. Moreover, it uses interviews and observations to unpack this reality (Denzin & Lincoln, 2018:43). Qualitative research uses an inductive method and collects data to describe and develop themes (Merriam & Grenier 2019:6). Furthermore, a researcher uses inductive reasoning and creates ideas, observations and understandings rather than testing hypotheses and theories as the quantitative approach does (Taylor et al 2016:8).

This research seeks to understand how people ascribe meanings to a phenomenon, perceive their world about issues related to breaking bad news to convey meanings and establish themes. Therefore, the researcher used a qualitative approach to learn from the experiences and perspectives of people with life-threatening illnesses, community members, and healthcare professionals on the occasion of breaking bad news.

The researcher acknowledges the study phenomenon can be influenced by the participants and the researcher’s beliefs, values and experiences. Both the researcher's (etic) and research participants' (emic) perspectives were explored to describe the research phenomenon (Madden 2017:20).

The Ubuntu theory was used for this study. The ethos of being collaborative, collective and interconnected are the concepts undergirding the essence of Ubuntu. Ubuntu has its foundational essence in the human being moral (Mugumbate & Chereni, 2019:28). Similarly, Ubuntu is viewed as the essence that people are interconnected and that each individual is a product of others who collectively learn and make meaning (Oviawe 2016:3). Ubuntu implies interdependency and the influence of others on one's identity. Ubuntu proclaims that “I am because you are and you are because I am” (Nare, 2016:57).

Ubuntu theory was chosen for this study because it resonates and overlaps with the Ethiopian culture. The ethos of a collective culture and humanness are shared across cultures. Nevertheless, as any theory, Ubuntu has a limitation. Individual differences, rights, and preferences are not privileged in the orthodox view of collective culture. In this study, Ubuntu was considered in discussing cultural beliefs related to breaking bad news.

3.3 RESEARCH PARADIGM

The constructivist worldview informs this research. As a qualitative study, constructivism (Court 2018:6). interprets reality differently from positivism which assumes that there is a steady universal reality, independent of human perception and ready to be discovered (Green & Thorogood 2018:41). The constructivist presumption of truth is determined by interaction within society, acknowledging that people construct their knowledge out of their life experiences, culture and interactions with their community (Court, 2018:4).

Based on this worldview, the researcher seeks to understand the viewpoints and experiences of the study participants and describe them to develop themes from the participants' perspectives in this study.

A constructivist worldview allows understanding of the research problems associated with breaking bad news from the participants' perspective and diverse viewpoints of people. Furthermore, this study engages with culture and people's preferences that are subjectively experienced. Constructivism paradigm ontologically assumes that reality is constructed by societies and multiple realities emerge as a result of people's own values, beliefs and perceptions. In this study, multiple results are presented, analysed and discussed based on the participants' own values, beliefs, experiences and perceptions about the delivery of bad news.

3.3.1 Ontological assumption

Ontology refers to the "researcher's sense of what is "there" in the world we investigate" (Taylor et al., 2016:17). Ontology is concerned with the features of reality (Leavy 2017:12). The ontological assumption of this research underpins the constructivist philosophical assumption where reality is multiple and socially constructed through daily interactions with others (Denzin & Lincoln, 2018:57). It is assumed that people construct their reality and meanings based on their experiences, values, belief and interactions (Bhattacharya 2017:11).

Meanings do not exist objectively, rather they are linked to the context and socially constructed. Hence, knowledge, meanings, or reality are culturally mediated. There is not one reality; meaning reality is constructed and developed through daily interactions with others (Denzin & Lincoln 2018:57). Therefore, the researcher sought to explore these realities from the individuals' point of view and descriptive data were produced by the participants and researcher in this study.

3.3.2 Epistemological assumption

Epistemology refers to ways of knowing the study phenomenon (Bhattacharya 2017:2). It is a branch of philosophy that helps to understand how the research is carried out to generate knowledge (Leavy, 2017:12). The epistemological assumptions of this research are underpinned by qualitative research approach, and in-depth interviews, and observations as data collection methods to explore the phenomenon. Furthermore, knowledge was constructed within the study context by the participants and researcher (Denzin & Lincoln 2018:57). Moreover, it assumed that people assign meanings to their activities or events based on their experience, and the subjectivity and individual's perspective are acknowledged (Leavy, 2017:13). Thus, this study employed qualitative and ethnographic approaches to understand cultural preferences about breaking bad news.

3.3.3 Methodological assumptions

Methodological assumptions were made as follows: Applying a qualitative research approach allows to collect descriptive data, to explore people's perspectives, their experiences, perceptions, and cultural issues about the research phenomenon. It also collects data through interviews and observation (Patten & Newhart, 2017:22). Qualitative research is characterized by an inductive process, performing the study in natural settings, and attempting to understand and interpret the phenomenon from the perspective of the study participants (Denzin & Lincoln 2018:43; Patten & Newhart 2017:22). Furthermore, the qualitative research approach is attributed to using the researcher as data collection instrument and understanding of individuals' beliefs (Brink, Van der Walt & Van Rensburg, 2018:104). This study applied qualitative approach and in-depth interviews and observation data collection methods to obtain empirical data.

3.3.4 Axiological assumptions

Axiology refers to the role of the researcher's values and beliefs on the research procedure, knowledge production, and actions taken by the researcher (Julia, Renée & Jill 2014:83). In qualitative research, subjectivity cannot be avoided but systematical approached can be followed to enhance trustworthiness of the research. Thus, the researcher's experience, values and beliefs influence in constructing the knowledge in this study. The researcher's self-awareness, background and experience allows for a deeper understanding of the phenomenon.

To reduce researcher bias, the following techniques were used: different data collection approaches were used to gather information on the same phenomenon, reflexivity, and being self-aware. Moreover, the participants' perspectives were interpreted and described from their emic views.

3.4 RESEARCH QUESTIONS

The following are the research questions addressed in this study:

- What are the preferences of individuals regarding breaking bad news when diagnosed with life-threatening illness in palliative care?
- What are the needs of information on breaking bad news when patients are diagnosed with life-threatening illness?
- How could guidelines be developed and validated for breaking bad news in culturally sensitive contexts in Ethiopia?

3.5 THE RESEARCH DESIGN AND METHODS

This section describes the research approach, population, sampling and data collection methods used. The steps taken in data analysis and guidelines development are described as well as how the chosen design and methods were implemented.

3.5.1 Qualitative research approach

Research approaches are derived from quantitative, qualitative or mixed-method paradigms. According to Leavy (2017:9), there are five types of approaches that include qualitative, quantitative, mixed methods, arts-based methods and community based participatory research (Leavy 2017:9). Research design is a roadmap to answer the research question (Bairagi & Munot 2019:70).

Methodology refers to the procedure followed to address the research inquiry or to seek answers (Taylor, Bogdan & DeVault, 2016:3). Methodology encompasses research methods and focuses on the activities involved in conducting research. Furthermore, research methods entail all the techniques, approaches and tools used to collect and analyse and report the research data that responds to the research questions (Bairagi & Munot, 2019:23).

Qualitative research is defined as an “interpretative approach to data collection and analysis that is concerned with the meanings people attach to their experiances of the social world and how people make sense of the world” (Pope & Mays 2020:2). Qualitative research aims to collect data about the social world and analyse descriptive data. The choice of qualitative research is informed by its suitability to answer the questions and the purpose of the study. Qualitative approach is used to query and describe the personal experiances and behaviours from the individual’s perspective and develop theme. Qualitative approach is also chosen to answer what and how research query (Pope & Mays 2020:2). Qualitative approach is mainly characterized by descriptive data which presents findings in words and its methods of data collection such as interviews and observations (Green & Thorogood 2018:7). This approach has assisted to answer the research questions and meet the set objectives through its data collection methods which helped to obtain information on the study phenomenon in detail. Gathering data through interviews helped to answer the “what and how” research questions as well as to describe the preferences, values, beliefs and experiances of the study participants in this research. It also assisted to obtain detail information about the particiapnts behaviour, challenges and study setting through observational data colletion method. By using purposive sampling method, it favoured to involve key informats who have the experience in receiving and knowledge related to breaking bad news.

Based on the ontological and epistemological assumptions of the study, the perception, preferences, experience, values and beliefs of the study participants regarding breaking bad news were known through interviews and observations and. By applying qualitative approach, it was possible to obtain detailed descriptive data which was constructed within the study context and used to develop a guideline.

In this research, the qualitative research approach was used to explore the views of people, their experiences, preferences, perceptions, and cultural issues about breaking bad news.

Qualitative research seeks to answer inquiries about behaviour, culture, perceptions and experiences. It also collects data through interviews, observation or reviewing field notes (Patten & Newhart, 2017:22).

Qualitative research is characterised by an inductive process, performing the study in natural settings, and attempting to understand and interpret the phenomenon from the perspective of the study participants (Denzin & Lincoln 2018:43; Patten & Newhart 2017:22). Qualitative approach obtains descriptive data through semi-structured one-on-one interview and observation, and the findings are presented in the form of words. It also involves a purposive sampling method to explore the phenomenon in detail. The study participants are chosen by the researcher to represent those in the study and explore their experience, knowledge, and shared culture of breaking bad news (Patten & Newhart, 2017:23). Furthermore, the qualitative research approach is attributed to using the researcher as data collection instrument and understanding of individuals' beliefs (Brink, Van der Walt & Van Rensburg, 2018:104).

The purpose of this research is to understand the Ethiopian community's cultural preferences for receiving bad news when the patient is diagnosed with life-threatening illness in palliative care settings in detail and develop a guideline. As a result, a qualitative research approach was used to answer the research questions in this study. This research approach was also applied to explore the phenomenon in-depth and to explore experiences, preferences, cultural beliefs and understanding of breaking bad news in the palliative care context from the patients, healthcare professionals, and community members' points of view. This study was carried out in the natural settings at the selected study areas for the best understanding of the participants' perspectives regarding breaking bad news. The researcher has collected data through a combination of observation by going to the study area during routine working days, and in-depth interview. Semi-structured questions were used during interviews. Smaller sample were collected by using a purposive sampling method and detailed descriptive findings were produced.

3.5.1.1 Strength of qualitative research approach

Qualitative research enables to explore and describe the phenomenon in its context in depth. Qualitative study may not aim to generalize the findings to the target population but rather to understand the phenomenon in more nuanced perspectives (Bhattacharya 2017:19). The approach is good for a research topic on which little is known (Patten & Newhart 2017:22). Qualitative research data collation methods help select key informants who have the knowledge about the study topic and can give detailed information by using purposive sampling technique. Therefore, this study used a qualitative approach to collect detailed and descriptive data. Data was gathered through in-depth interviews and observations. Purposive sampling method was used to choose participants for the study.

3.5.1.2 Qualitative data collection and sampling methods

Qualitative research uses open-ended questions, yielding words that can express complex conversations. The questions can also be modified during interview. It uses a smaller purposive sampling method to select the research participants.

Qualitative researcher chooses key informants and study participants who may represent those under study and uses verbatim statements and quotations in the data analysis (Patten & Newhart 2017:23). Interview, focus group discussion and observation are data collection methods used in qualitative research for exploring individuals' perspectives and understanding the study phenomenon in-detail (Bairagi & Munot 2019:35; Court 2018:38). These sources of data are used in order to understand a phenomena related to beliefs, experience, preferences and cultural context in qualitative research (Court, 2018:4).

3.5.2 Interviews

There are three types of interviews: structured, unstructured and semi-structured. Structured data collection does not allow to probe a follow up question, thus in-depth data cannot be obtained (Bairagi & Munot, 2019:36). Structured interview uses closed ended questions and the researcher is "restricted to the questions." This method has a limitation for flexibility and restricts participants from expressing their perspectives freely (Brink et al 2018:143). Structured interview is where the researcher makes limited interactions with participants, uses structured questionnaire and controls the external environment to yield generalisability (Court, 2018:49). Unstructured interviews can be used in qualitative study to learn from participant’s life stories and the researcher seek to elicit themes by asking leading questions (Court, 2018:49).

Semi-structured interviews exhibit the advantages of unstructured and structured methods. The researcher can ask a follow-up question to obtain in-depth data (Bairagi & Munot 2019:37) using open-ended interview guide. In-depth interviews were done by applying semi-structured questions in this study.

3.5.3 Observations

A scientific observation has to be carried out in defined circumstances, methodical and objective ways. Observational data collection is used in qualitative health research to obtain data on behaviour, events or situations. It has the singular advantage of observing human behaviour as it occurs (Brink et al 2018:136). Structured observations in qualitative research describes the behaviour or event observed and allows such to be documented ahead of time (Brink et al 2018:136). In qualitative research, unstructured observation is used to observe behaviour or events as they happen and collect descriptive information without any presumptions of what to observe (Brink et al 2018:136). According to Brink et al (2018:137) there are two approaches to decide on when and how to conduct observations. The first one is time sampling, in which the researcher observes occurrences during a certain period, watching events for 15 minutes at a time across an eight-hour shift. The period can be randomly chosen or prearranged to the daily routine. The second method is event sampling, which entails observing an entire event. The researcher observes the whole process and series of the phenomenon (Brink et al 2018:137). This study followed the second method where the researcher observed the whole process of breaking bad news.

3.5.4 Sampling methods in qualitative research

Sampling approaches in research are categorised broadly as probability and nonprobability. Types of non-probability sampling method entails quota, convenience and snowball (Bairagi & Munot 2019:97). Non-probability sampling method applies nonrandom sample selection and the researcher selects participants who have deep knowledge on the phenomenon (Bairagi & Munot 2019:96).

Purposive sampling approach is commonly used in qualitative research, and the researcher makes the decision on selecting participants and key informants. The number of study participants depend on data saturation which occurs when there is no new information obtained during the data collection process (Brink et al 2018:126). Purposive sampling uses smaller sample size as larger sample size can increase the complexity of data analysis. According to Brink et al (2018:120) the trends in qualitative research show that 20-30 participants suffice for such a technique (Brink et al., 2018:120).

The disadvantages of purposive sampling entail bias, lack of representativeness of the population and generalisability (Brink et al 2018:126). Nevertheless, qualitative research focuses on understanding the phenomenon in detail from the participants' perspective instead of generalisation of the findings (Bairagi & Munot, 2019:8).

3.5.4.1 Rationale for choosing qualitative research approach

According to Pope and Mays (2020:2), qualitative approach is an interpretive strategy which is "concerned with the meanings people attach to their experiences of the social world and how people make sense of that world" (Pope & Mays 2020:2).

A qualitative approach allows for in-depth understanding and description of the experience of breaking bad news from the participants' experience and perspective, and developing a theme in this study (Patten & Newhart, 2017:22). A qualitative research approach is chosen because the study seeks to generate descriptive data from people with their own views, and meanings that they connect things in their lives about breaking bad news (Green & Thorogood, 2018:9). It also helps to explore the study phenomenon from the people's perspective, experience, and produces "*richly descriptive*" findings (Merriam & Grenier, 2019:6). Moreover, qualitative research helps to explore the views of the study participants, to answer the research questions as well as to describe the study phenomenon explicitly in this research. To this end, the individuals' preferences, needs, and cultural issues about disclosure of bad news are explored and described by employing qualitative study approach (Brink et al 2018:104).

Data was collected through multiple methods (Pope & Mays 2020:3) and from diverse sources. Therefore, data was collected via a combinations of interview, observation and field notes for this research.

3.5.5 Ethnography research approach

The study employed ethnography approach to examine human culture, including its values, customs, and beliefs (Bhattacharya 2017:25). The term ethnography refers to writing about people's culture (Court 2018:17). In addition, Brink et al (2018:106) state that ethnography is a qualitative approach used to describe cultural areas and the social world (Brink et al 2018:106).

Ethnography inquiry in this study sought to explore the values, beliefs, experiences and norms among healthcare workers, patients and community members to understand their cultural preferences about breaking bad news.

Ethnography is a pragmatic science that systematically studies and writes about people's culture, sociality, and behaviour and conveys the findings through writing in qualitative social research. Furthermore, ethnographic researchers observe and follow a direct and face-to-face approach in which ethnographers "do as others do, live with others, eat, work and experience the same daily patterns as others" (Madden, 2017:16). Ethnography design is employed to study a community who have common characteristics, and in the research, it helps to understand the cultural context of a specific phenomenon among people working in hospitals or live in the community (Brink et al 2018:106). Furthermore, participant observation is a cardinal feature of ethnography where the researcher collects the data face-to-face in the situ (Madden 2017:16). Ethnographic approach uses a direct fieldwork and face-to-face, and uses a participant observation, and interviews as a data collection tools (Madden, 2017:28).

Ethnography inquiry is chosen because this study aims to explore and describe the cultural perspectives of people about breaking bad news in palliative care setting. Culture refers to "the beliefs, values and attitudes that shape the behaviour of a particular group of people" (Merriam & Grenier 2019:80). The term 'culture' broadly means an entire ethnic group, or in a narrower sense, where it is limited to a subunit of a single institution, such as the hospital operating room, the classroom, the doctor's waiting room or a sports team" (Brink et al 2018:106). Thus, this research employed an ethnographic approach to describe people's perceptions, values, beliefs and attitudes, which they have built about their world in relation to the needs of information, and preferred ways of breaking bad news (Madden, 2017:16). In addition, the approach helped the researcher to understand the study phenomenon, how people attach meaning to their perspective and their worldview.

3.5.6 Research population

Research population refers to all people who have a common distinguishing future and with whom the research is conducted (Burke & Soffa, 2018:115).

The research population is a specific group of people that are the focus of a study; the target population is the total group of individuals who meet the sampling criteria, and the accessible population is "the portion of the target population to which researchers have reasonable access" (Gray, Grove & Sutherland, 2017:516).

The general population-The Ethiopian community/patients who receive bad news of life-threatening illness conditions. /All Ethiopian patients diagnosed with life-threatening illness

The target population- Patients diagnosed with life-threatening illness who have insight of their condition, healthcare professionals caring for patients with life-threatening illness as well as the Ethiopian community members who are familiar with the culture in regard to delivery of bad news.

Accessible population: Cancer patients with or without HIV/AIDS, healthcare professionals involved in delivering bad news in cancer hospital and palliative care provider organization, and individuals in Addis Ababa were accessible population in this study. The sample was obtained from theses population by using purposive sampling method.

The research population in this study were patients with life-threatening illness, healthcare professionals and community members. Thus, a sample was taken from the three populations: patients with life-threatening illness, healthcare professionals who have experience in breaking bad news to patients and community members through in depth interview and observations. There was a consideration to incorporate heterogeneous participants in this study. This was accomplished by choosing participants from various diversities such as all gender (male and female), different religious background, educational background (literate / illiterate), different tribes, and age (greater than 18-year-old), to enhance diverse viewpoints and the transferability of the findings (Merriam & Grenier 2019:26-28).

3.5.7 Sampling

The process of choosing research participants from a population in order to gather information about a phenomena is known as sampling (Brink et al 2018:115). Qualitative study uses non-probability purposive sampling method as it seeks to understand a phenomenon in detail (Schreier 2018:88). Purposive sampling technique was used as this works well for a study focused on understanding the phenomenon in detail than generalisation (Brink et al 2018:124).

Participants were chosen purposefully to obtain rigorous knowledge based on the inclusion criteria (Merriam & Grenier 2019:13). The researcher selected the study participants who have the experience on receiving bad news as well as those who have knowledge on breaking bad news (Bairagi & Munot 2019:96).

Data was collected from patients with life-threatening illness, healthcare workers and community members. These participants were selected and invited to take part in the study by the researcher as per the set selection criteria. Those who agreed were contacted by the researcher and interviewed at the patients' convenient time and place.

The purposive sampling method has advantages to deliberately select key informants who have the knowledge and experience in breaking bad news and gather rich data about the cultural preferences in bad news disclosure (Brink et al 2018:124). In addition, purposive sampling method helped to obtain heterogeneous sample such as study participants from different socio-demographic backgrounds.

3.5.8 Sample size

The sample for this study was taken from patients with life-threatening illness, healthcare professionals as well as community members.

The sample size for this study was fifty-one and was determined by data saturation. When the same information was revealed during interviews and observations, the researcher stopped recruiting participants and conducting the observation. Theoretical saturation refers to the collection of data until the data reaches a level where no additional new information is generated (Green & Thorogood 2018:78). The number of study participants is determined by data saturation in which the researcher stopped collecting data when there was no new information obtained (Brink et al 2018:126).

A total of twenty-five interviews and twenty-six observations of conversations between healthcare professionals and patients when conveying bad news were done. Data from conversations were described with quotes. Some of the verbatim statements were eliminated during analysis to avoid repetition of information and conversations on diverse topics other than the study's main focus

3.5.9 Study setting

This study was carried out in non-governmental organisation providing palliative care and a public hospital in Addis Ababa, Ethiopia (Figure 1 shows a map of Addis Ababa and Ethiopia.). These study settings were selected purposefully because they have palliative care expertise in the study topic, experienced participants and they are accessible.

The selected hospital is a college with a capacity of 700 hospital beds in Addis Ababa, Ethiopia. On average, the hospital sees 1 200 patients per day through its out-patient and emergency departments. It is one of the largest referral hospitals staffed by 2 800 medical and non-medical personnel.

The second study area was a non-governmental organisation working in the area of comprehensive palliative care for people with life-threatening illness in Addis Ababa. The organisation provides its services as home-based and out-patient care settings with two nurses and one clinical/health officer trained in palliative care and 9 administrative staff. The principal researcher works at this organisation, thus in order to minimize researcher bias, a research assistant was recruited to assist data collection. The assistant was provided with adequate information and training for two weeks about the purpose of the study, and the procedure used in the study. She assisted the principal researcher by connecting prospective study participants. Moreover, the researcher used bracketing to mitigate the potential bias from his own personal perspective and ensure meanings emerged from the participant’s viewpoint when analysis and interpretation is performed (Holloway & Galvin, 2017:24).

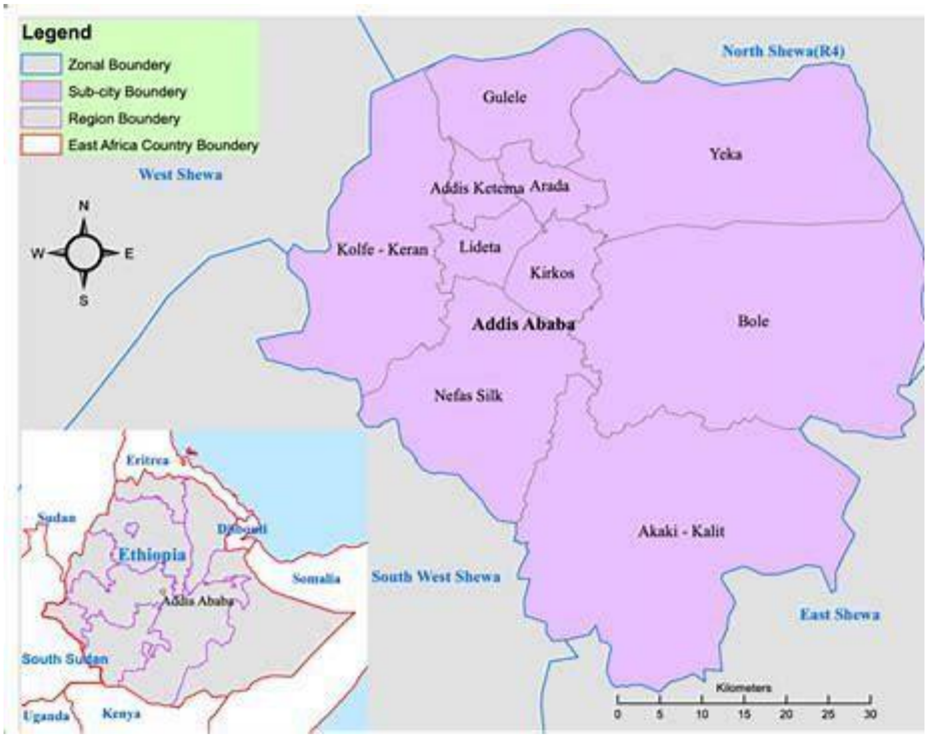


Figure 3.1: Map of Ethiopia and Addis Ababa

3.5.10 Data collection methods and procedures

In this research, the data were collected through one-on-one face-to-face in-depth interview and participant observation methods. Field notes were also taken during observation.

In phase one, data were collected through in-depth interviews. In phase two, the researcher collected data through observations on breaking bad news conversations between healthcare professionals and patients. Phases three and four presented the data triangulation and the development of guidelines, respectively.

3.5.10.1 In-depth interview

Merriam and Grenier (2019:14) state that interview is one of the major methods of data in qualitative research (Merriam & Grenier 2019:14). In-depth interview was applied with patients, healthcare professionals, and community members. The researcher introduced himself to participants and informed participants of the purpose of the research. The researcher used interview guide questions to explore the participants' perspectives about breaking bad news (Court 2018:30). Using the grand tour question, the researcher conducted the face-to-face in-depth interviews following the semi-structured questions. The grand tour or semi-structured questions were used for all participants (See annexture seven).

The follow-up questions were dependent on the participants' responses and the objectives of the study (Denzin and Lincoln 2018:1002). The researcher did face-to-face in-depth interviews with healthcare professionals, patients and community members to explore their perspectives about the preferences and information needs regarding breaking bad news (Taylor et al 2016:102).

A face-to-face interview generates detailed information about perspectives and experiences (Bairagi & Munot 2019:36). Interviews with the participants were done at the residence, study settings and a recreation area, based on the choice of the participants (Liamputtong 2020:117).

All interviews were recorded by using audio recorder following written consent. This helped the researcher listen attentively to the participants and interview in the study. The confidentiality and anonymity of the participants' responses was maintained by assigning a code number to their answers rather than mentioning their name.

During interview semi-structured questions were used in this research. This approach was amicable for this study because it has the merit of flexibility and offers freedom for the researcher to focus on the research topic and ask a follow up questions (Denzin & Lincoln 2018:1002). Interview guide was prepared by the researcher to explore the needs and preferences regarding breaking bad news (Liamputtong 2020:17).

3.5.10.2 Observation

The direct observations was the second method of data collection. Systematic observation of an event and an individual's conduct is a scientific method of data collection used to answer research enquiriesin qualitative study. The observational data-gathering approach allows the researcher to observe the study setting, activities, and participant behaviours related to the study topic in order to comprehend the situation in its natural setting, and triangulate the results with in-depth interviews (Merriam and Tisdell 2016:139). In qualitative research, one of the observational data collection approaches is event sampling, which involves observing an entire event. The researcher observes the whole process and series of the phenomenon (Brink et al 2018:137). This study followed this method where the researcher observed the whole process of breaking bad news. Fieldwork was carried out to collect data through observations of conversations between patients and healthcare professionals while conveying bad news. Observational data collection has the advantage of observing the study participants' behaviour as it occurs (Brink et al 2018:136). The researcher conducted the direct participant observation of all the events when healthcare professionals carry out conveying the bad news and patients receiving such in the selected study area. The researcher presented to the oncology department of the chosen hospital and observed the communication process between patients and healthcare professionals while breaking bad news (Merriam & Grenier 2019:5)**.** Hence, the researcher watched the language used to communicate bad news, the non-verbal language, how healthcare professionals and patients discussed bad news, how patients felt about the disclosure of bad news, what they liked or disliked about bad news disclosure, the communication process, how healthcare professionals reflect themselves and observe the culture during disclosure of bad news. Moreover, some of the conversations between patients and healthcare workers while breaking bad news were audio recorded and the data was transcribed for analysis. Field notes were taken after watching the process of talks between the patients and healthcare workers and soon after observations made. Field notes are detailed notes taken during observation to document events and behaviors (Bhattacharya 2017:140).

The ethnographic researcher body is involved in data collection through the sense organs. The researcher undertook fieldwork study while participating in taking the field notes (Madden 2017:19). “Touch, smell, taste, sound and sight come together to form the framework for memories, jottings and consolidated memos that form the evidentiary basis of ethnographic writing” (Madden 2017:19).

The field notes included details such as the date, location, and scope, reason for the observation, participants' descriptions, study area, and actions taken by the participants. The researcher carefully observed how healthcare professionals convey serious medical diagnosis, prognosis, discuss treatment failure, words used, values, non-verbal communications, and patients and physicians’ reactions. Further, the physical setting of the study area was carefully observed to explore how it is convenient for breaking bad news. Moreover, the researcher reflected his observations and interpretations about the activities, participants and setting in brackets and in italic (Merriam & Tisdel, 2016:151).

Observational data collection method helped to obtain detailed information (Brink et al 2018:137) related to population behaviour obtained in situ. Employing observational data collection method assisted in obtaining different perspectives first hand (Bairagi & Munot 2019:133). Furthermore, this method was used to check and triangulate the findings of this study from interviews. Observing the phenomenon offered a chance to learn about the cultural rituals, norms, values, and behaviour of the study participants as well as the healthcare workers in natural settings.

Phase three outlined the findings from interviews and observations in the results section of this thesis.

3.5.10.3 Data collection procedure

Data was collected by the principal researcher between December 2021 and July 2022 at the selected study areas. The researcher spent some time at the selected hospital to become familiar with the area, meet potential participants, and conduct informal interviews to identify suitable informants who could contribute germane information effectively to the study (Merriam & Tisdel 2016:127). The study participants were purposively sampled.

The researcher's own personal contact was used as entry point to find initial informants when recruiting participants for the interviews (Merriam & Tisdel, 2016:127). The researcher used the contact in the healthcare service to connect with prospective healthcare professionals for their participation in the study. The researcher had discussed with the palliative care unit head on the purpose of the research and participants. The unit head is a healthcare professional trained in palliative care. She linked the researcher with the oncology unit head who further helped the researcher by introducing his colleagues; healthcare professionals working in the oncology and surgical units at the selected hospital. The researcher involved those interested participants as per the set criteria and their free will. The researcher reached out to other healthcare professionals working in the second study area, experts and participants from community members.

Key informants of healthcare professionals were used for cropped into the study to connect with potential patients and family participants for in-depth interviews (Merriam & Tisdel 2016:127). In-depth interviews with patients were done at the patient's home or the study settings depending on the choice of the participant (Liamputtong, 2020:117) and the interviews took a total of 208 hours with an average of 45 minutes per session. The interview time was arranged based on the participants' convenient time as well. A private room was arranged in the study area for in-depth face-to-face interview when the area is chosen by the participants. The participants were welcomed and invited to sit down, get relaxed. When possible, the researcher offered a bottle of water for participants prior to the interviews to build a good rapport with the participants. The researcher introduced himself, and talked about general matters to ease the communication and build a good relationship prior to the research interview. The study participants were provided with adequate time to ask for clarification written consent to participate in the research and to be audio recorded was confirmed. Before asking the research questions, the study participants were asked to introduce themselves (Liamputtong 2020:114). Consequently, the conversations between healthcare professionals and patient were audio recorded with full consensus of the participants.

Observation of the conversations between patients and healthcare professionals on bad news were done at the selected hospital. Healthcare professionals were approached to elicit understandings of the ways in which they convey bad news. The prospective patient participants were invited to the research and their permission was requested before observation. Field notes were also taken to record the observed events and behaviours (Brink et al 2018:137). After every field observation, the researcher took time to take notes and transcribe the audio-recorded conversations with patients and physicians].

3.5.10.4 Inclusion criteria

Patients diagnosed with life-threatening illness who have full insight into their condition were included. Healthcare professionals, physicians and nurses involved in caring for people with life-threatening illness or in palliative care setting and who have experience in breaking bad news were involved.

Community members who may or may not be literate but have knowledge about the cultural concepts, and who could articulate their perspectives were included in this research. Furthermore, individuals with or without having next of kin diagnosed with life threatening-illness but substantively knew the cultural concepts related to delivery of bad news were involved.

Experts working in the palliative care works or care of patients with life-threatening illness, and experts with higher knowledge and experience in palliative care, research or treating patients with life-threatening illness were included for validation of the guidelines. Individuals from the community were also involved to validate the guidelines subsequently developed in this study. All participants were greater than 18-year-old, and cognitively competent for making interview regardless of gender or other background.

3.5.10.5 Exclusion criteria

Mentally incompetent individuals with life-threatening illness and individuals who have not been informed of their medical conditions were excluded in this study. Healthcare professionals not involved in breaking bad news, with less than two years of work experience and undergraduate medical students were not included. Minors who are less than 18 years old and people seriously ill were not involved in the study.

3.5.10.6 The COVID-19 prevention guidelines

The data collection was adaptive to the national COVID-19 restrictions to avoid the risk of infection both for research participants and the researcher. There was a plan for serious precautions declared by the Ethiopian government such as lock down and strict restrictions to social interactions.

The researcher provided hand sanitizer and face mask to study participants during faceto-face interview. A physical distance (2 meters) was strictly maintained. A room with adequate ventilation was used. Data from experts for validation was collected virtually.

Before and after sharing any objects such as pen or paper, hand sanitizer was used and cleaned. Furthermore, hard copies such as information leaflet, consent form were kept in envelope and adequate infection precautions such as hand wash and using sanitizer were followed. The researcher or the study participants did not show any of COVID-19 symptoms during the data collection period. The researcher had made sure whether the symptoms present prior to data collection.

3.5.11 Data management

Descriptive data was collected by applying purposive sampling method. During data collection, patient participants were selected by physicians and nurses who were informed of the study purpose and selection criteria by the investigator. Then, before taking part in the study, they were recruited to participate in the study and informed of the research purpose. Participants from the community and healthcare professionals were selected and recruited by the researcher. The researcher made a call and arranged for in-depth interviews. Data were collected at the participants' convenient date, time and place. Patients were interviewed in hospital, their home and one of them was interviewed in an open space in a park as he chose to have the interview in this space. Healthcare professionals and community members were also interviewed in their workplace.

The interviews were done in the local language, Amharic, and audio recorded. The audio recorded data were transcribed verbatim and translated into English. The first five transcripts were done by the researcher while the remaining data were transcribed by an Ethiopian research assistant who works in the community, and speaks both Amharic and English. The researcher discussed the purpose of the research with the research assistant in detail and a confidentiality form was signed. The researcher checked each transcribed data by comparing the transcribed datait with the Amharic audio record. Moreover, the transcribed data were checked for any errors during transcription and translation.

Thematic analysis was applied for identifying themes and sub-themes for data gathered through interviews. The analysis process included listening the audio record, rereading the transcribed English version and the field notes for ultimate familiarisation with the data and establishing patterns. The data was coded by using ATLAS.ti 22 computer software and manually. While coding, the data was examined for similar ideas that were then grouped and categorised. Sentences were assigned for coding the data based on the study purpose and 65 codes emerged. Similar ideas were identified and regrouped and categorised. The categorised and coded data was reread and reworked repeatedly to produce meaningful andcoherent interpretation. When the data are organised and grouped notes were amplified. To this end, themes and sub-themes emerged from patients, community members and healthcare professionals.

The observational data was analysed by the researcher. Some of the conversations between patients and their families were audio-recorded. These data were transcribed into English. Detailed field notes were taken during and after field work. When analysis was done, similar ideas were identified, organised, and the results are discussed using quotes and vignettes based on both the transcribed and field notes data.

3.5.12 Data analysis

Leavy (2017:150) mentions that the phases of analysis and interpretation of qualitative data include “(1) data preparation and organisation, (2) initial immersion, (3) coding, (4) categorising and theming, and (5) interpretation”.

According to Brink et al (2018:180), the first step in qualitative data analysis is managing and organising data. The data collected in different forms such as interviews and observation should be transcribed. At this stage the researcher becomes better familiarised with the data. The second step was ‘coding’. Similar ideas or information that occurred repeatedly were identified and categorised. At this step, the collected data was ‘chunked’ into phrases. The reliability of coding was checked by another person for consensus. Data categorisation and coding can be done by using computer program such as ATLAS.ti. The researcher continually contrasted the data gathered from the study populations and observations in the development of a final theme and subtheme (Brink et al 2018:181).

According to Court (2018:63), the thematic qualitative data analysis entails: analytic summary: reading and re-reading the collected and transcribed data to find “similarities, differences, patterns and questions”; categorise the data: group the data into their similar ideas. The idea that is assigned to each category can be sentence, word, story or phrase. Assign names to the categories; coding: The data was based on their categories. Naming or abbreviation by using initials or colour code was used to mark to identify each portion of the categorised data; Reading the categories: The researcher read the categorised data repeatedly. “Rework the categories, adding or moving material, collapsing categories or creating new ones, and renaming categories as new insights arise. Recode, reread, and adjust the categories again”. As a result, meaningful categories were produced and this subject of the categories is named as theme (Court 2018:63); Theme development: “Write about each theme, its content and characteristics. Examine the relationship between the themes”; Development of new idea: “In the end, you should have not merely a set of themes, but a system of themes, an analytic model that explains the data and answers your research questions”; and explaining findings. The ultimate study utilised previously published literature to explain the findings that were generated (Court 2018:64).

In this research, thematic data analysis approach was used to describe the results (Brink et al 2018:165). Both manual and computer assisted data analysis was approaches were carried out and hence the ATLAS.ti 22 data analysis software system. This computer program assisted to sort out, code and categorise the data (Court 2018:67). For this research, the data analysis included the following steps:

Preparation and organisation of data: the data collected through interviews and observations were transcribed, grouped, and assigned to a category. During preparing and organising the researcher was better familiarized with the data and immersed in the data by reading and re-reading the transcribed data to find similarities and differences. Data collection and analysis processes were done concurrently (Brink et al 2018:180; Court 2018:61), offering opportunities to adjust the way the next interviews were performed (Merriam & Grenier 2019:15).

Coding: the data was coded based on categories. This was done as soon as data collection and analysis began. The reliability of coding was checked by the research assistants. Moreover, the findings were validated by some of the participants. Data categorisation and coding was done by using ATLAS.ti 22 and manually.

C*ategorisingand developing themes*: many categories were developed at this step. The researcher was immersed with the data, reread and recoded to reach meaningful themes and sub-themes for the ultimate descriptive results (Brink et al 2018:180; Court 2018:63; Leavy 2017:150).

3.5.12 Development of guidelines for breaking bad news

The fourth phase of this thesis focused on the development of guidelines. Development of guidelines for the disclosure of bad news guidelines and validation was done following the adapted WHO Handbook for Guidelines (WHO 2014). The four-step process were followed for the development of breaking bad news guidelines in this study:

Step one: The collected data was analysed; cultural preferences were explored, themes and sub-themes developed, findings described and discussed. The WHO Handbook for Guidelines was reviewed to follow the development process.

Step two: The components and steps of guidelines for breaking bad news were developed on the basis of the research findings, literature review and existing guidelines.

The draft guideline was disseminated to the academic supervisors, experts as well as community members to validate and feedback was incorporated.

Step three: The guidelines was tested on a group of healthcare professionals at Hospice Ethiopia. The participants were purposively sampled and orientation was given on the draft guidelines on how to use them in their clinical practice to deliver bad news. Furthermore, the guideline was shared with experts, and community members and feedback was collated by the researcher.

Step four: The final guidelines was developed after incorporating all essential feedback from the test, experts and community members.

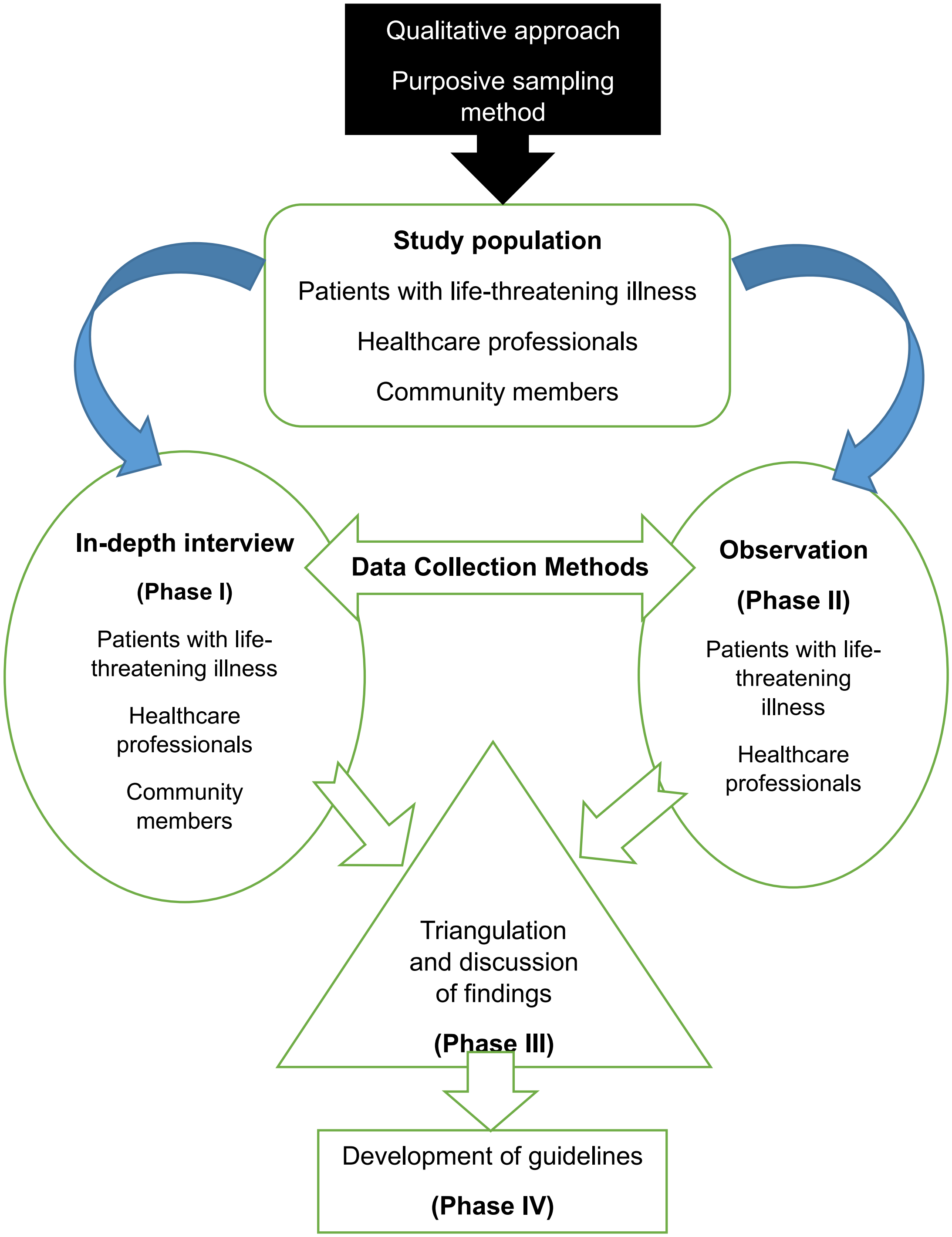


Figure 3.2: Summary of the study approach, population, data collection methods and findings

3.6 ENSURING RIGOUR

"Trustworthiness is a concept often used in qualitative research to evaluate the worth of a qualitative research presentation, based on the judgments of its readers and its suitability to be presented to them in a convincing manner" (Rizo & Levitt, 2021:662). According to Court (2018:29), trustworthiness is maintained to keep the quality of the research and its results by internal and external validity and reliability (Court 2018:29).

The rigour of this research was maintained by member checks, peer debriefing, triangulation in data collection, prolonged stay in the study area, reflexivity and methodological alignment of the research (Bhattacharya, 2017:23).

3.6.1 Credibility

According to Merriam & Grenier (2019:26), there are various strategies that a researcher could use to ensure credibility of a study, such as peer review, triangulation and member checking (Merriam & Grenier 2019:26). Furthermore, reflexivity and spending long period of time in the field ensure credibility (Merriam & Grenier 2019:27).

Spending prolonged time: in this proposed study, the researcher spent considerable time with the study participants to learn in detail, observe and provide thick descriptions and to enhance credibility of the study. To ensure detailed answers, a good relationship was built with the study participants by spending time with them. The researcher was engaged for four hours on average every day in the oncology and surgical units of the selected hospital. The researcher spent ten days, on various days, in the out-patient and in-patient sections of the study area. The participants were given due time to learn more about the purpose of the study and familiarise with the researcher. Therefore, the researcher reached data saturation in exploring the phenomenon in detail (Court 2018:31).

Member checks: Member checking assesses by seeking verification of accuracy of the results (Bhattacharya 2017:23). This method was used to enhance the credibility of the research findings by asking some of the participants whether their reality or views are fully represented by the researcher's interpretive modalities (Holloway & Galvin 2017:312).

The findings were shared with healthcare professionals and community participants to verify transcription, translation from Amharic to English by the researcher who also interpreted whether the findings of the study are representative of their narratives and consistent with their views. Moreover, peer review by the researcher’s colleagues who are familiar with the topic, experts in the field and with academic supervisors supported the authenticity of the results.

Debriefing: debriefing entails sharing the study results with colleagues. It involves reassurance about the confidentiality, allowing participants to ask any question about the study (Patten & Newhart 2017:36). The researcher shared the results of the study with colleagues who have the knowledge of the study phenomenon. There was a virtual call to discuss the findings while analysing the findings. The researcher shared the findings with supervisors for checking and received feedback (Court 2018:31). In addition, peer debriefing was used with the academic supervisors to check methodological rigour as well. The final draft of the guidelines was disseminated to experts and community members for validation. The research assistant was involved in checking for consistency with coding, themes and sub-themes while making analysis to maintain the research reliability.

Triangulation of data collection: Obtaining data from different sources helps to obtain overarching information and understand the phenomenon in detail and from different points of view (Court 2018:31). Data was collected through in-depth interviews, observation from patients, healthcare professionals and community members. The findings from these sources were triangulated and discussed in Chapter Four.

3.6.2 Dependability

The dependability of the findings of this research was ensured by reflecting how the study was carried out. Moreover, field notes were taken during observation (Merriam & Grenier 2019:28). Describing the study design and reporting how the research was carried out, including details of how data was collected in the study context all helped in ensuring the dependability of this research (Court 2018:33). Hence, this research was done at institutions where patients with life-threatening illness are treated and provided with care.

The selected hospital is one of the largest public referral hospitals that serves patients from all parts of the country. The other study area is also a non-governmental organisation serving patients with life-threatening illness in the community. Data from these settings was collected systematically. Descriptive data was collected through interview and observation. Field work was performed between December 2021 and July 2022 and field notes were taken. All interviews were done in the local language, Amharic. The audio recorded data were transcribed verbatim into English. The transcription was sent for some of participants for checking whether the transcription and English translation is consistent with their views.

3.6.3 Transferability

The transferability of the research was enhanced through purposive selection of the participants who have knowledge and experience on breaking bad news. In addition, the transferability of this study was enhanced by providing thick descriptions (Merriam & Grenier 2019:29). The guidelines that were ultimately developed guidelines was shared with experts and community members for evaluation and feedback.

3.6.4 Conformability

Reflexivity ensured the conformability of the study (Merriam & Grenier 2019:31). Data was triangulated through interview and observation. Subjectivity cannot be avoided in qualitative research and the researcher's own perspective; experience and values impact the research. The researcher's self-awareness, background and experience allows for a deeper understanding of the phenomenon (Bhattacharya 2017:35).

Reflexivity: the researcher described his background, values, beliefs and positions and how theses advise the study (Bhattacharya 2017:35). The researcher's positioality include being an Ethiopian citizen, married and with two children, one who is 39 years old, born and raised outside of Addis Ababa, and living in Addis Ababa since 2002. Furthermore, the researcher has 16 years of work experience as a nurse, clinical officer and executive director. He has been involved in research in palliative care, training healthcare professionals in palliative care, preparing manuals such as the Ethiopian National Palliative Care Training Manual, the Ethiopian Pain Management Manual and the National Strategic Plan for Palliative Care. These positions helped the researcher to explore and understand the study phenomenon better. His contacts also helped in recruiting participants with the sufficient and credible knowledge of the study phenomenon.

The researcher is an indigenous insider of the study population which offers an advantage in understanding the cultural rituals, values, beliefs and the practice. Moreover, he has the experience of working in palliative care charged with the ultimate responsibility of breaking bad news to patients and family members. Nevertheless, being an indigenous insider may influence the researcher by covering some important but familiar issues (Court 2018:36).

Self-reflectivity- the researcher carefully saw how his experience influenced what he observed, how he understands the participants' point of view and the participants' experiences (Court 2018:31). Being aware of this helped to keep to the participants' perspectives. The participants' perspectives were interpreted and described from their emic views.

3.6.5 Authenticity

The internal audit can be improved by taking into account all responses from the participants and by debriefing the participants. The participants were informed of the intention of the study prior to start and during the process of the research. The findings were validated by some participants.

3.7 ETHICAL CONSIDERATIONS

3.7.1 Introduction to ethics in research

Scientific research must ensure that the study is conducted in an ethical manner, morally acceptable, preventing violation of human rights and causing no harm with regard to the research method. The history of research with humans has shown that participants of clinical experiments were unethically treated and abused. Participants have not been regarded as an individuals; their right to agree or disagree to participate in the research was violated, and participants have been influenced by the study process and never been informed about the outcomes of many-a-study. Furthermore, the history of Tuskegee Syphilis study has shown that stereotyping about people and the perception of researchers towards the research participants exerts an impact on the research (Leavy 2017:26). The process of selecting prospective participants in the research, how the researcher communicates and interacts with the participants are serious ethical issues in research world (Leavy, 2017:24).

Research ethics involves beneficence, protecting study participants from physical and psychological harms. Any potential risks must be minimized by anticipating and planning to minimize their harm and maximize benefits. The second research ethics principle is justice, which states that the research burden and rewards should be distributed fairly. It is especially important that vulnerable or conveniently accessible subjects are not exploited based on these characteristics. Autonomy refers to participation in research on a voluntary basis, and the right to be informed of the benefits and risks of the study and consent to participate. It also entails that the study participant has the right to refuse any question or withdraw from the research at any time (Patten & Newhart, 2017:35). The principle of autonomy also involves the right to freedom from influence. The participant’s privacy should be maintained during interview; the collected information should be kept confidential and protected against unauthorised persons and anonymised in publications to avoid identifying the participants (Patten & Newhart, 2017:36).

Informed consent should include providing information to prospective participants about the purpose of the study, the procedures, potential benefits and risks of participating in the study, the right to refuse or withdraw. Moreover, informed consent needs to be taken with the the knowledge of the aim of the study and consent of participants in a written form (Patten & Newhart, 2017:35). In summary, the fundamental concepts of research ethics rely on informed consent, privacy and confidentiality, benefits and potential harm, honesty, and the right to refuse or withdraw (Court, 2018:82).

3.7.2 Permission to conduct the study

A research ethics approval was obtained from the University of South Africa. Ethical clearance from the University of South Africa was requested to conduct the study.

Additional letter of support from the University of South Africa (UNISA) was requested by one of the study areas, and this was obtained from UNISA, Addis Ababa region. To this end, a written permission to conduct the research was obtained prior to beginning the research.

3.7.3 Informed consent

Ethical issues in qualitative research arise with regard to the level of transparency of the researcher regarding the purpose of the study, the protection of the participants from harm and the consent (Merriam & Grenier, 2019:30). The participants were requested to participate in the study and their consent was on the basis of informed decisions about the purpose, procedures, benefits and any potential risk of the research (Court 2018:82). In this research, the participants knew that their participation was entirely voluntary; they had the right to refuse or withdraw from the study, and their ultimate decision did not affect the care they were receiving.

3.7.4 Information leaflet

The researcher provided adequate information about the topic, the purpose, benefits and any potential risk to the prospective participants prior to take part in the research. Participants were informed verbally and provided a hard copy of information leaflet. If participants could not read, the researcher or family members assisted. Participants were informed that their participation was voluntary and that they had the right to answer some part of the question and refuse or withdraw from the research at any time. Documents such as informed consent, information sheet and request to participate in the study were translated into the local language, Amharic for this research by the researcher.

3.7.5 The right to refuse or withdraw

The participation in the research was on the free will and voluntary basis, and without coercion. The right to accept or refuse to participate in the research was informed and their decision respected. Moreover, the participants' right to withdraw from the study at any time was respected (Court 2018:82).

3.7.6 Beneficence and risk

Any research should be for the benefit of individuals or a community, and it should not cause harm. Any potential harm should be anticipated and minimized (Court 2018:82). The risks and benefits of participating in this study were clearly described for the study participants prior to taking part.

Benefits: This study contributes to new knowledge on community preferences and cultural values and beliefs regarding breaking bad news and how individuals prefer such news to be conveyed when life-threatening illness is diagnosed. The findings were used to develop a culturally sensitive guidelines for breaking bad news to ensure patients know about their diagnosis and prognosis through effective culturally sensitive communication. Thus, this study benefits people diagnosed with life threatening illness by promoting acceptable communication of such bad news. Furthermore, it contributes to the care of patients with life-threatening illness by introducing new scientific knowledge through a culturally sensitive communication guidelines for breaking bad news in Ethiopia. This should facilitate better communication between healthcare professionals and patients so that patients get better information, receive the truth and can make informed choice of treatment. Moreover, the research helps individuals by minimizing needless costs for futile treatment by allowing them to make informed decisions.

Risk of harm: The human participants took part in the study through in-depth interview and observation. Patients diagnosed with life-threatening illness and next of kin whose family member is known to have life-threatening illness might have emotional and or psychological discomfort related to the personal and sad nature of the information shared by participants. Any of the healthcare professionals might have history of loss of family member or any other sad experience related to bad news communication and sharing their experience might provoke negative feelings, experiences and may cause emotional harm.

These mild risks were mitigated by informing participants on the study purpose, the study questions and by providing the information sheet prior to interview. The researcher stopped asking any more questions, giving space for participant to breath out, providing tissue paper and supportive care when any of anticipated emotional discomfort occurred. Emotional support through reassurance, encouragement, active listening and giving due time for the participant to reflect their emotion was supported throughout the study. During this study, there was no substantial harm that occurred to the study participants.

3.7.7 Confidentiality

Any personal identification about the participants was protected when processing the data, and in the reporting of the findings (Court 2018:82). The information collected for this research project is kept confidential and secured against unauthorised access. Only the researcher and academic supervisors have access to the information which is strictly secured against access to unauthorised person. Identification of the study participants was kept confidential by assigning codes, and all the data were saved on a coded file name. Interviews were conducted in a private place preferred by the participants. The information collected from the participants has been used for the research purposes only. Furthermore, the audio recording file and soft copy of the transcription are on a password-protected computer and shall be kept for a period of five years.

3.7.8 Ethical review

A research ethics approval certificate from the University of South Africa research ethics review committee, and letter of permission from the study areas were obtained prior to the initiation of the research (Flick 2018:237). An official letter of permission was obtained from the University of South Africa and given to the study areas. Ethical clearance was obtained from the Institutional Review Board (IRB) of the selected study areas. A written permission letter was obtained from selected study areas prior to beginning of the research.

3.7.9 Anonymity

The researcher ensured anonymity not only by encoding names, but also by omitting some information that might identify those participants during the reporting and publication process (Patten & Newhart 2017:36). The face-to-face interviews, observations during patient and physician’s conversation were audio recorded and transcribed for data analysis. The anonymity of the transcribed data was ensured by coding the data instead of naming during reporting or publication. This was clearly described for the study participants as well.

Thus, information about the study participants was kept anonymised by assigning codes to the data to maintain unidentified. No real names were used in any documents which can be traceable to the participants.

The participants' direct identifiers such as name were removed and indirect identifiers such as age, sex, occupation and religion are aggregated so that their personal information could not be identified.

3.7.10 Justice

A fair sample of study participants should be chosen to share the risks and benefits of the research. The study participants were chosen based on a set of criteria in order to equally distribute the study's risks and benefits, and they were not included due to a specific desire to benefit them or a personal relationship with the researcher. The research participants also were included from different demographic background (Gray et al 2017:289).

3.8 SUMMARY

The qualitative research approach was chosen for this study, and this choice has been justified. Healthcare professionals, patients with life-threatening illness and community members were data sources. In-depth interview and observation were used to collect data by applying purposive sampling method. The methods used to enhance data quality and research trustworthiness were elaborated. Furthermore, the data analysis and guidelines development processes, as well as the research's ethical considerations, were explained. The next chapter deals with data presentation and analysis.

CHAPTER FOUR

DATA PRESENTATION AND ANALYSIS OF RESULTS

4.1 INTRODUCTION

The previous chapter focused on the methodology and strategy components of the thesis. This chapter presents the data and subsequently discusses the way the data was analysed. Both manual and computer software were used to analyse the data outlined in this chapter. Descriptive data was produced and themes and sub-themes were developed. The study participants' views are reported by quoting under each theme and under discussion for observational data. Cultural values and beliefs, preferences about breaking bad news, the needs of information and preferred ways of telling bad news are reported and discussed.

4.2 DEMOGRAPHIC CHARACTERISTICS OF THE STUDY PARTICIPANTS

The participants in this study were diversified and included patients with life-threatening illnesses: cancer and HIV/AIDS. There were also healthcare professionals and community members (details of the demographic background is presented under Table 2,3 and 4). A total of fifty-one participants were involved, made up of twenty-five one-onone in-depth interviews and twenty-six observational data from conversations between patients and healthcare professionals. Hence, the one-on-one in-depth interviews were done with eight patients, twelve healthcare professionals, and five community members. Observations were made when bad news was delivered to twenty-six patients and families. Field notes were taken during and after observations. The patients' diagnosis included cancer of the breast, colon, oesophagus, prostate, cervix, liver, and HIV/AIDS. Their religious background was Orthodox Christian, Evangelical Christian (Protestant) and Muslim. The study participants' residency comprises both rural country and urban areas. The patient participants' educational levels ranged from illiterate to completed high school, elementary school, and college diploma, and their ages ranged from 25 to 70 years old. The healthcare professionals were nurses and physicians working in palliative care and oncology units. Physicians were from oncology, family medicine, surgery, and internal medicine specialisations and general practitioners. Nurses were from oncology and palliative care units. The health professionals' working experiences ranged between 4 and 30 years.

Table 4.1: Patient demographic information for interviews

Characteristics		Number of participants (N=8)
Sex	Female	5
	Male	3
Age	35-45	3
	46-55	2
	56-65	2
	70 -80	1
Diagnosis	Cancer	6
	Cancer and HIV/AIDS	2
Marital status	Married	4
	Widowed	1
	Divorced	3
Religion	Protestant Christian	2
	Muslim	1
	Orthdox Christian	5
Education	Diploma	2
	High school graduate	3
	Less than high school	3
Residence/ location	Addis Ababa	5
	Outside of Addis Ababa	3

Table 4.2: Healthcare professionals' demographic information for interviews

Characteristics		Number of participants (N=12)
Sex	Female	6
	Male	6
Age	25-34	9
	35-44	2
	45-60	1
Profession	Physician	6
	Nurse	6
Marital status	Married	6
	Unmarried	6
Religion	Orthodox Christian	5
	Protestant Christian	3
	Muslim	4
Work experience in years	2-5	9
	6-9	2
	10 and above	1

Table 4.3: Community members' demographic information for interviews

Characteristics		Number of participants (N=5)
Sex	Female	3
	Male	2
Age	25-40	2
	41-55	1
	56-70	2
Marital status	Married	4
	Divorced	1
Religion	Protestant Christian	2
	Orthodox Christian	2
	Muslim	1
Educational level	Diploma and above	4
	High school graduate	1

Table 4.4: Summary of demographic information of all participants for interviews

Characterstics		Number of participants; In-depth interviews (N=25)
Sex	Female	14
	Male	11
Age	25-39	13
	40-54	5
	55-69	6
	70-84	1
Marital status	Married	14
	Single	7
	Divorced	3
	Widowed	1
Professions	Medical doctor	6
	Nurse	5
	Others	14
Educational level	Medical doctorate	6
	Bachelor science	5
	Diploma	4
	High school	4
	Less than high school	6
Religion	Orthodox Christian	14
	Protestant Christian	7
	Muslim	4

Table 4.5: Demographic background of patient participants under observation

Characteristics		The number of participants; Observation (n=26)
Sex	Female	11
	Male	15
Age	35-50	7
	51-65	11
	66-75	8
Religion	Orthodox	10
	Muslim	10
	Protestant	6
Residence/ location	Addis Ababa	12
	Outside Addis Ababa	14

4.3 DATA PRESENTATION

The findings of the study are presented in four phases. Phase one presents themes and sub-themes that emerged from interviews; phase two describes results from observations; phase three proffers combined findings from interviews and observations; and in phase four, the development of guidelines and its components are discussed in Chapter Five. The details are discussed in the subsequent segment.

4.4 PHASE 1: FINDINGS FROM INTERVIEWS WITH PATIENTS, HEALTHCARE PROFESSIONALS AND COMMUNITY MEMBERS

Table 4.6: Themes and sub-themes derived from patients

Themes	Sub-themes
Theme 1. Perceptions about life-threatening illness	1.1. Social values, beliefs and attitudes regarding lifethreatening illness 1.2. Religion, faith, and religious rituals play an important role in conveying bad news
Theme 2. Experiences with life-threatening illness	2.1. Responses to bad news disclosure 2.2. Unmet needs for information on the patients' serious medical conditions 2.3. Benefits of breaking bad news 2.4. Mechanisms for coping with bad news
Theme 3. Preferred ways of breaking badnews	3.1. Individual preferences when breaking bad news 3.2. Culturally acceptable protocols of breaking bad news 3.3. Inappropriate and unacceptable ways of breaking bad news

Theme 1. Perceptions about life-threatening illness

Most of the study participants described that their faith in God, religious beliefs and rituals are invaluable cultural attributes when serious news are discussed. Participants in the study reported that their views of health, and illness were framed by their religious faith and beliefs. Moreover, according to the results of this study, the social values that ought to be maintained when delivering bad news relate to using acceptable and comforting terms to calm the patient. This theme describes the cultural values, beliefs and perceptions regarding breaking bad news and disease under the listed sub-themes.

1.1 Social values, beliefs and attitudes regarding life-threatening illnesses

Suffering is influenced by one's perceptions of health and illness. Most participants in this study perceive illness from their religious belief point of view as described below:

> *“Serious illness belongs to Satan; it is not ours. Because it belongs to demons, it may be taken off from the patient in God’s day. At the time that God permits, it will be taken away. I will be saved. I may get sick, but, I will be saved in God. The doctor’s role is to diagnose the disease.*” (I1P1PT).

Another patient participant from a different religious denomination mentioned her views that disease is a manifestation of testing the person’s belief and that this disease is retribution for committing sin:

> *“…this disease does not mean anything. There is no need to depart from the Creator and to be discouraged by the serious illness. Satan is the one who breaks the spirit… God might allow the illness to strengthen our faith through test….God has given me a serious illness may be because my sins are too great, however, I can find solution from Him by requesting His mercy”* (I3P3PT).

Traditional healers and religious concepts are the first place where patients seek remedy when a serious health condition manifests. Another patient diagnosed with HIV/AIDS and cervical cancer, and was informed of her poor prognosis stated her views:

> *“…At that time, the disease was just level two, and then I stopped chemotherapy in the middle of the treatment and went to traditional healers. I took traditional medicine. Then I went to Tsebel (holy water). Finally, I became too weak, my arms and legs were paralysed, and I went to hospital”* (I4P4PT).

Another patient shared his experience about his friends’ perceptions when he was diagnosed with cancer as follows:

> *“…Having a disease like cancer makes you very isolated. When some of my close friends knew my disease was cancer, they isolated me. They were no longer interested in remaining a friend and visiting and meeting with me. Their perception towards me has changed adversely. They believe that cancer is contagious, a curse and divine punishment”* (I10P10PT).

1.2. Religion, faith, and religious rituals play an important role in conveying bad news.

The Ethiopian community are predominantly Christian and Muslim, and this informs their perceptions on the meaning of life and the values, beliefs and perceptions that they hold about bad news. As a result, they resort to religious practices such as prayers, taking holy water (Tsebel), and other sacred religious creeds while maintaining medical treatments. Using words or reflecting general ideas from holy books like the Bible or the Quran perspective is a common cultural practice when any sad news is communicated, and that is suggested by some participants in the delivery of bad news or serious medical news. The majority of the patients stated that their faith in God and religious rituals are fundamental forstaying encouraged, seeing some meaning in life even amidst the suffering from incurable diseases, and holding onto the hope that things shall improve for the better. As a consequence, they look for solutions to their problems even when they are confronted with life-threatening illness.

Patients were asked what helped them during difficult times when suffering from a lifethreatening illness, and the study participants mentioned that religious beliefs remain a firm source of encouragement, keeping them thankful regardless of the challenges:

> "*I was desperate and stopped taking my medicines, it was through God's encouragement during prayers that I restarted taking the drugs. Nothing will happen in my capacity when I live in this world… You need to have God more than humans. You should praise God; when you thank God, then the blessing of health will be added to you… Whether I am cured from my illness or not, I thank God very much*…" (I1P1PT).

In the same talk, another patient reported how religious beliefs and practices helped them to deal with difficulties and keep hope as following:

> *"Everybody has a religion… I believe in heaven, resurrection, and that the Creator will fulfil my hope. When I am closer to my religion and ask God [for] forgiveness, I get a deep spiritual satisfaction. In addition, when I pray to the*

> *Creator as I am dying to give me mercy, and include me among those to whom you give mercy and I beg you about my health*, *God does reply"* (I3P3PT).

A patient participant stated that she denied the medical report, and believed that her life is determined by God, upon whom she relies and trusts for her life. She was determined on preserving both her religious beliefs and receiving the conventional medical treatments. This also helped her to balance telling the truth and maintaining hope when bad news is delivered:

> *"The doctor told me that the cancer was stage four and that my chances of survival were very low. When he told me this, I did not accept and believe him because life is in God's hands. I will live as long as God allows me. I am taking the medicines properly and pray passionately in my religion. Life belongs to God…" (I4P4PT).*

Patients said that their religious beliefs and values helped to console and overcome the difficult situation, as stated in the following:

> *"Prayers, and hospices are huge supports above anything. I benefited from going to church, worshipping to God. I pray and fast to share my concerns with God, to tell to God what I do not tell my family and all that helped. I believe He has dominion over my problem as He created me"* (I4P4PT).

Theme 2. Experiences with life-threatening illness

Patients with life-threatening illness who took part in this research shared their experiences about breaking bad news. This theme describes how to overcome problems related to life-threatening illness, experiences regarding receiving bad news, and the benefits of knowing the health status based on the patients' experience in the following sub-themes:

2.1. Responses to bad news disclosure

The participants informed the researcher that they had various emotional responses on the occasion of the bad news disclosure such as shock, feeling desperate, running away, feeling upset, feeling blunt, screaming, crying, loss of appetite for food, falling, lack of interest to interact with people, including family members, and transferring anger to family or close friends, or healthcare worker:

> *"I was broken down and in tears when I received the bad news, and I was in panic as I walked to tell my family. The information I had and my perception of cancer were both frightening. When I was informed, I was shocked. I cried, I had not eaten properly, and I withdrew from social life for several weeks. I was furious and vented my rage on my close family and friends. When the doctor informed me of the diagnosis, I said okay and ran away"* (I2P2PT).

The delivery of bad news may affect the patient's behaviour and the repercusions might be serious:

> *"A diagnosis of life-threatening illness causes distress to the patient... When I found myself in the position of having cancer, I felt sad and uncomfortable. I was angry and insulted people. I was terrified and concerned about the disease. My life has been full of frustration; I have lost my attention to social relationships, and I did not get along with people; I have become an easily upsetting person, and I have quarrelled with family and friends for no reason. I also stopped working at that time"* (I1P1PT).

The effect of delivering bad news may last for a long time, with patients who may keep hurting emotionally or psychologically. The way it is presented may help to heal the patient and family and reduce the fears and anxiety. Moreover, the healthcare professionals should ensure the patient is stable, not in pain, and emotionally ready to receive the message only if this could be conveyed effectively. However, there is a dire need to consider that the patient may still exhibit an emotional reaction regardless of the preparation:

> *"When the doctor told me my disease was cancer, I was suspecting it, but I was shocked, I cried, because I have heard it is a serious disease. I could not blame the doctor who told me because his follow up during the process of investigation was good and he prepared me before telling, but I left the room and ran away. When I remember the situation when I was informed of my disease, I still feel sad."* (I2P2PT).

2.2 **Unmet needs** for **information on the patients' serious medical conditions**

The study participants reported that their needs for information and support in breaking bad news are not met:

> *"I really wanted to know about my condition, but I had to ask my doctor about the level of my illness and about the cancer stages. I wanted to know to the smallest details. I requested for explanation on my condition repeatedly… The doctor explained it to me"* (I5P5PT).

One of the patients wanted to know more about her condition, but she did not get enough information, as stated below:

> *"I requested them to explain it to me as I did not have enough information…They did not provide me with enough information. Every time I saw my treating doctor, he provided me with insufficient information and talked to me briefly. They rushed up to see the next patient"* (I10P10PT).

Despite patient's desire to know about their medical state and get support, he did not receive emotional support, and was not informed of his treatment plans, as described below:

> *"…I was told that the disease had not improved. The doctor told me the cancer was in stage four and I had no idea what that meant. He never described it. The way he delivered the bad news hurt me more than the disease itself. Patients I met at the hospital provided me with important information about the side effects of chemotherapy. They also encouraged me and gave me advice on how to proceed with the treatments"* (I10P10PT).

2.3. Benefits of disclosing bad news

The results of this study show that breaking bad news benefits the patient to make informed treatment choices, minimize uncertainties, fulfil the end of life needs, create good rapport between care givers and patient, conduct religious sacred rites, minimize or avoid unnecessary costs, and fix things and finish the unfinished business.

Patients pay for their medical expenses out of their pocket and it is serious burden to the patient and family. Knowing the illness has advantages of avoiding costs on futile treatments, to get the right care and treatment, and reduces psychological pressures. In addition, hiding the truth from the patient may cause anxiety, fear and uncertainty.

Proper breaking bad news can play significant role for the patient to be aware before the surgical intervention. A cancer patient with permanent colostomy stated that the treatment costs for his medication and stoma bag influenced his life negatively:

> "*The cost of both the stoma bag and the medications are too expensive. I regret the surgery, and wish I had not had it, as the disease is not cured and I am economically exhausted. I sometimes think it would be better if I died rather than financially harming and torturing my family and friends*" (I10P10PT).

Patients stated that breaking bad news assists them in reducing stress, making informed decisions, taking medicines, seeking help, and reducing uncertainty:

> "*If the patient is informed of the illness, he can decide what to do by himself. If it is higher stage for cure he will decide on the treatment. It is beneficial to be aware of the consequences of the disease and interventions so that I could make informed decisions*" (I3P3PT).

> "*I am glad I know about my condition. I would have died at home before I saw a doctor, if I were not told. I adhere to the medications and take them as prescribed, and I have no worries because I am aware of my condition*" (I1P1PT).

The religious beliefs and rituals acknowledge ceremonies in the end of life. The significance of knowing serious medical condition allows the patients to get spiritual support, and fulfill their sacred rites in end of life. Furthermore, as people may have perceptions that serious illness is the result of sin, it may help them to confess to God and prepare for the ultimate eventuality according to their religion:

> *"If you know your medical fact, you would beg the Creator for mercy, and you may pray for healing. I will be more committed and look for solutions in my faith, if I am aware of the bad news"* (I3P3PT).

2.4 Breaking bad news enables patients to participate in enacting their medical decisions

Patients want to be involved in their medical decision process. Informing patients of their condition helps to avoid bias from others' opinion on treatment options and uncertainties:

> *"It is beneficial for the patient to be aware of his serious illness and treatment options so that the patient can make informed decisions. If not informed, the patient may not accept his condition and may refuse treatments. People may also tempt him/her to reject conventional treatment and seek out traditional healers and medicines"* (I3P3PT).

If the patient is involved in the process and identifies their wish and choice of care or treatment, that helps them to meet the needs of care. There might be a time twhen the family gets into the dilemma of making treatment choices as the following patient put it:

> *"I have had surgery three times. However, the surgery was opposed by the family. I had to make my own decision. In such a difficult time, it should be up to the patient to make the decision, not the family. Because the family believed they would regret, if they agreed to the surgery and the surgical outcome was bad or I died"* (I4P4PT).

2.5. Coping mechanisms with bad news

Patients described cultural values and beliefs that enable them to accept bad news and overcome challenges associated with a life-threatening illness. Religious rituals and beliefs were promoted as an important support structure. The family, friends and healthcare professionals support and hospice care were useful.

Patients reported that their religious faith and prayers were sources of hope during their hard times:

> *"It is not by my capacity that I overcome my challenges. To be honest, it is God who has helped me in any ways. It is God who has encouraged me; it could not happen in my capacity. God gave me the strength"* (I1P1PT).

Ethiopian culture is attached to family, friends and neighborhood. Patients illustrated that support from family, healthcare workers, friends, neighbours and their personal strength helped them cope with their conditions:

> *"I think, my neighbours care, and support assisted me to survive. Everyone reassured me; the social support makes me stronger and encouraged. Truly speaking the doctor's become my hope and really supported me. I think God has put them (the healthcare professionals) in a good position for me. They were very good. They care for people very much"* (I2P2PT).

Reading scripture or stories from the Bible or the Quran and religious rituals were useful:

> *"I always remember some stories of saints from my religion… I am encouraged by prayers"* (I3P3PT).

Theme 3. Preferred ways of breaking bad-news

This theme explains the preferences of patients regarding breaking bad news and preferred methods for breaking bad news.

3.1. Individual preferences when breaking bad news

Patient participants intimated that they choose to be told of their medical condition by their next of kin in this study. They also want to be involved in their medical decision process. Patients suggested gradual and amiable approaches when breaking bad news.

3.2 Patients want to know about their medical condition

Patients were asked whether they wanted to know their medical condition and how much they wanted to be told. Almost all patients in this study prefer to be informed of their illness in detail:

> *"I would like to know my medical condition in-depth. They have done laboratory tests for me and I took a chemotherapy, and have follow-ups, but I do not know the stage of my illness. I should have been informed, but I was not... Bad news should be told for the patient"* (I3P3PT).

Two participants stated the same desire differently: also said:

> *"I would like to discuss my diseases with my doctor. I would love to know my illness. Knowing my problems will help me to live with realistic hope… I want to understand it so it would be great, if they explain to me like this and that, and describe it in detail"* (I1P1PT).
>
> *"What is the point of going around? The medical condition should be stated clearly for the patient. If the news is hidden, the patient will not be prepared, cured, treated, or given a solution. I do not believe in the perceptions and fears of people; if he hears the bad news, he will be like this and that. I think it would be good, if bad news is not a secret, and be openly told. It would be good if they tell the condition clearly for the patient"* (33P33PT).

As indicated below, a patient participant stated that she preferred to be told and refused the detour of informing family without the patient's consent:

> *"I would rather prefer to be told. I am the sufferer. However, my personal experience with medical care was not good. I would not be pleased to hear through a family member without my consent. The family member may tell me smoothly, but I should be involved when the doctor disclose. I am the one who is suffering"* (I3P3PT).

3.3 Patients want to be accompanied by their family when bad news is delivered

Patients want the presence of their family when bad news is conveyed, and they described their preference as follows:

> *"Bad news should be conveyed with the family. Family should be involved during bad news conversations. The doctor also needs to involve family when planning treatments and treating so that patient can get complete support"* (I1P1PT).

A patient who was informed in the absence of her family said:

> *"I was told alone by chance, but I did not want to be told alone. I wanted to hear it with someone from my family. I think it would be nice to have a family or someone else like close friend or next of kin when bad news is delivered"* (I5P5PT).

Another patient stated that such disclosure should only be shared with close family members if they are available and that family has to be involved as mentioned below:

> *"If the patient has family, it is mandatory to tell them together, because family will be responsible to give care when the patient is very sick, so they should hear. In my experience, I was informed alone because I had no another alternative; I have no family. But the others may have their family. Otherwise, if there is no close relative or friend around, it is not necessary to tell someone else without consent"* (I2P2PT).

3.4. Culturally acceptable manners of breaking bad news

Participants in this study were asked how they would like to be informed according to their cultural preferences. The preferred approaches for breaking bad news that were gradual, amiable, supportive, and delivering in a compassionate manner. Empathetic approach and not intensifying the presentation of the bad news was also emphasised.

3.5 Amicable approach

Patients would want to build a good relationship with their care provider prior to talking about difficult news and preferred amiable approaches when bad news is delivered than very formal approach. When patients asked how they wanted to be told, they replied:

> *"I would like [the news] to be communicated like a family manner with the healthcare providers; friendly approach, with love, not much formal. The health professional needs to be prepared how to approach and explain to the patient like a brother or a sister, provide counselling support and describe the issue with example"* (I4P4PT).

Amiable approach is created by having a good communication, and understanding feelings to support the bearer of bad news. Using open ended question like "How are you today?" allows patients to express thoughts, concerns and feelings freely:

> *"When you get into the examination room, you would appreciate it when the doctor identifies you by name and communicates with you in a friendly manner, as this will help you build a good relationship. It is confronting to know they care about you, call you by name and inquire about your health. The health professional should welcome the patient and be informative person"* (I3P3PT).

Warm greetings is a common culture that reflects humbleness in Ethiopia. Welcomed approach with smile face can open the patient's appetite to communicate with healthcare workers. In addition, the first impression matter to the patient to keep building rapport with healthcare worker:

> *"It gives a pleasure when you receive the word "how are you doing". When the healthcare provider asks concerning my health and greets me, I feel as if somebody is available to help me. That gives me a pleasure"* (I1P1PT).

> *"If he uses positive and good words and be humble, it grasps the patient's heart. This can assist to keep hope and makes the patient pleased and have*

> *a good memory of the conversations, and relationship with the healthcare professional"* (I2P2PT).

3.6 Breaking bad news in a gradual manner

Patients prefer to be told the bad news gradually. This means that small amounts of information should be delivered at once, with a careful and step-by-step approach. The proceeding quote describes the concepts of this sub-theme:

> *"Bad news should be told in roundabout manner and presentation should be light; take a long process by talking about general thing before coming to the point. When explaining, I want to sit down, and receive small information. My doctor informed me abruptly that it was cancer and I have to do surgery, and take chemotherapy… It was hard to hear that way. I wish the doctor told me it was tumor, and explain how it turned into serious illness or cancer"* (I5P5PT).

> *"In my opinion, it would be preferable if the patient is informed indirectly, by using an example of that has happened to someone else, and with appropriate reassurance and emotional support. The issue is that doctors tell you abruptly and immediately. If the patient is told straight, they may commit suicide. Individuals' ability to deal with such bad news varies. When hope is broken and you are dealing with other serious issues, you may become psychologically ill"* (I1P1PT).

A good rapport should be established with healthcare providers during the process of assessment, and doing investigations. This may introduce an opportunity to tell small information every time leading ultimately to the forthcoming bad news in a general manner which helps the patient to be prepared. The gradual approach for conveying bad news allows the patient to be prepared through the discussion process. Patients want to be prepared for that ultimate revelation about their condition:

> *"Hmmm…It was a good thing the doctor asked me if I was prepared to hear the condition at that time. Before he informed me the bad news, he said that*

> *the laboratory results were ready and assessed my level of interest and readiness to hear. I agreed and demonstrated my willingness to hear the bad news. When he said, your disease is cancer, I already have suspected it"* (I2P2PT).

3.7 Breaking bad news sympathetically

Patients want the bad news to be presented embraced with plan of treatments, care and support. When bad news is presented, patients wish to hear not only the bad news, but also what the treatment options are. Sympathy sounded too petty for the patients, understanding their suffering and getting care and support.

Encouraging the patient by reassuring them that there is still something that can be done and the care will continue irrespective of the stage of the illness. Patients wish to be consoled when they receive the bad news:

> *"When you tell bad news, reassure and tell him in a gentle way. Any patient is happy to find a doctor who gives reassurance. I visited different hospitals to see doctors due to my illness. I would consider a good doctor, if they effectively communicate, and gives love"* (I3P3PT).

In preparation for breaking bad news, there should be help for the patient with his medical, emotional, psychological and social adjustments after bad news is delivered. Healthcare professionals, family members and friends play significant roles to overcome the challenges associated with such adjustments:

> *"What helped me is that, first, I go to the church and I read the Bible. It helps me a lot. May God bless my doctor, he is a good doctor. He looked after me, he helped me. My family and children helped me"* (I5P5PT).

Patients do not want their doctor to give up on their situation even if the condition is serious. Patients were asked how messages on incurable disease should be disseminated and one of the participants outlined the following:

> *"Hearing that the diseases is incurable shocks me… That is so shocking. It would be better if they say they will try, we will treat, we will try our best than saying we cannot cure your illness"* (I5P5PT).

3.8 Telling gently using both religious convictions and conventional treatments

Breaking bad news gently by giving small information about the stage or poor outcome of the disease certainly came through as a sensitive approach. Some patients want to be told their serious medical condition gently. A patient with advanced stage of cancer succinctly stated:

> *"The doctor told me that the cancer was at a good stage and I could be cured by faith. He advised me to keep my hope, but I have had cough as my lung was affected…they gave me medicines"* (I2P2PT).

Patients with advanced illness may suspect that their illness is serious throughout their journey, but they may not want to talk about it. In addition, one patient may prefer to be told the prognosis in a tender manner:

> *"When a serious illness is delivered, it should be by giving minimum information on the serious level. The critical stage of the illness should not be mentioned. If I put myself in the place of the professional and tell someone else, I would say, if you take such treatments and solutions, you are more likely to recover from your illness. I would tell by minimizing the severity and telling the possible treatments and care"* (I3P3PT).

Some people reject taking conventional treatments due to misconceptions. Patients want to comply with their religious rituals such as prayers, alongside their medical care. The following vignette shows the patient's experience in getting her to accustom her belief to taking her medicines:

> *"I had received a message in the church and I had stopped taking medicines. But, I could have taken both the prescribed medicines and keep my faith in healing and be cured by either of the two or both. I did not consult*

> *a doctor. I had stopped the anti-epilepsy drugs too, as a result I suffered. But I should not do that"* (I1P1PT).

The word *ayzoh/sh* (take courage) is a normative one often used to encourage and comfort the person when one is in a difficult situation. Moreover, it evinces sympathy for a grieved person and using such a term is traditionally taken as feeling their precarity and enjoining them to persevere. Patient participants mentioned that it would be welcome if the healthcare professionals encouraged the patient by using comforting words like *"ayzoh/sh*" (take courage). Moreover, the way a grieved person takes their ill health could get assuaged if they are reassured by ensuring care and support from the healthcare professional. Patients want their doctor to calm them through empathy, giving them a snapshot, providing adequate information, giving due time for question and answer, presenting small information at a time when bad news is delivered. These ways of communication are reflected by the following quotes:

> "*The doctor should describe me the benefits and plan of the treatment. and reassure me like "Ayzosh". He should calm and tell me the bad news…*" (I3P3PT). Reassurance may be done as mentioned below by one of the patients:
>
> "*If I put myself in the place of the professional telling a patient, I would reassure by saying, we are by your side. When you are sick, when you have worries, when you are in distress, we will stay by your side. If you tell the bad news this way, [the patient] will be reassured*" (I4P4PT).
>
> *"I do not know why the doctor did not call me by name and describe it or calm me. I wish the doctor calmed me and took consent to involve my family and explained the situation. It should not be communicated instantly soon after the diagnosis is set"* (I4P4PT).

Participants informed the researcher that it is appropriate to tell of poor outcome of the disease to the family. When the patient is nearing the end of life, family takes the role to make decisions.

Another patient stated that family members, in collaboration with the healthcare workers, should make the medical decisions in the end of life:

> *"At the end of life, close family members delegated by the patients and the healthcare professional must make the decision. A healthcare worker can assist with medical decisions. The patient's wish might be requested. I believe the immediate family and the health professional communicate and should decide on medical interventions and treatments"* (I10P10PT).

3.10 Inappropriate and unacceptable ways of breaking bad news

Telling prognostication was not accepted by majority of patient participants while poor prognosis is preferred only if told to the family member. Telling prognostication is not culturally acceptable as people believe it is against the religious beliefs as mentioned below:

> *"While it is good to inform bad news, telling estimated time of death is not acceptable as life is in God's hands. I strongly oppose predicting the time of death. The doctor said to my family, she will not survive, she only has one month to live, and I was sent for hospice care, however I lived longer"* (I4P4PT).

One of the patients mentioned that it may help to tell the impending death, however, only to the family as stated below:

> *"I would not oppose to inform a poor prognosis, but rather for the family; the poor outcome of the illness and impending death, as well as what can be fixed. This can be advantageous to be prepared prior to death, and the patient can enjoy the remaining life"* (I4P4PT).

Patients do not accept a direct disclosure of serious news i.e. telling the patient about their serious medical condition without psychological and emotional preparation, adequate information about the illness, reassurance and sympathy, as described below by different patients:

> *"…Doctors tell you abruptly. The problem is that the doctors tell you immediately.*
>
> *But, it would have been good if they take care for your emotions, and if inform you with hope that you can survive and live with others when they tell you the bad news"* (I1P1PT).

Another patient added:

> *"When I was informed of my diagnosis, the doctor's manner of delivery shocked me. I think the healthcare professionals speak abruptly without preparing the patient, and it feels as if something terrible thing has just happened instantly. I never thought it was cancer. I thought it was a tumor. I took it something light, but when he told me it was cancer, I was so shocked"* (I5P5PT).

4.5 EXPERIENCES ON BREAKING BAD NEWS

Patients who participated in this study reported that their experience in breaking bad news was sad and the utterances were upsetting:

> *"When I was first told, his communication hurt me than the disease. He said, you have short life time. You are about to die; the stage of the illness is high. I felt sad very much when I heard… I went to outside of my home to hide myself from my children and family. At that time, I did not expect to survive this much even for a month"* (I4P4PT).

One of the patients reported that her conversation with her doctor was not good and preferred that the doctor use more appropriate language when informing her of bad news:

> *"His discourse was bad; the way he approached and terms he used to inform me were disappointing. He informed me of the problem directly… The approach for telling bad news was disgusting. It is immoral to deliver bad news in an improper way"* (I1P1PT).

A patients' experience confirmed that they had bad experience with doctors when they were informed of their diagnosis. The doctors' method of telling bad news caused shock and left the patient feeling desperate. In addition, communication was disrupted as a result of poor delivery of the bad news:

> *"My wife was informed before me, and my family had a hard time to tell me. Sometimes later, I saw my doctor, and he said, the swelling on the tip of your rectum is cancer without preparing and taking care. I and my family were tuned in and could not believe it. It was tough for me, and I felt desperate as I had not anticipated. I was upset by his method of telling and the news... When the doctor continued speaking to me, I could not listen to him. He said, we are done, but I had not heard well, so I sat down again"* (I10P10PT).

> *"The physician saw the laboratory results and said, we will do surgery, and you will take chemotherapy and radiation therapy. I was lying in the examination coach, so he told me to get up and he started writing up something. I got up, but I have even lost where I kept my clothes due to the shock"* (I5P5PT).

Table 4.7: Themes and sub-themes for Healthcare Professionals

Themes	Sub-themes
Theme 1. Healthcare professionals' experiences about breaking bad news	1.1. Perspectives of healthcare professionals concerning breaking bad news 1.2 How healthcare professionals' perceived by patients and community when delivering bad news 1.3 Family is the first recipient 1.4 Challenges related to breaking bad news
Theme 2. Benefits of breaking bad news	2.1. To fulfil the ordinances of faith, fix unfinished business and avoid unnecessary costs 2.2. To share the burdens, build trust and help the patient understand the situation

Theme 3. Suggested approaches for breaking bad news	3.1. Make comprehensive assessment prior to breaking bad news 3.2. Cultural circumstances that should be considered 3.3. Involve family members 3.4. The practices of breaking bad news

Theme 1. Healthcare professionals' experiences about breaking bad news

This theme outlined the healthcare professionals' experiences related to delivering bad news and their views on who should be be prioritised in disseminating such news.

1.1 Perspectives of healthcare professionals concerning breaking bad news

Healthcare professionals emphasised that patients have the right to know about their medical conditions. They also outlined that the patient should be informed of their illness, and make informed decisions, as far as the patient is an adult and mentally intact:

> *"In my opinion, first the truth should be told to the patient. She/he is primarily responsible for his/her own life. The patient has the right to make decisions on own life as long as he/she more than 18 years old, conscious, and mentally healthy. I think the patient should first be aware of the problem and tell the family or inform both of them together"* (I28P28HCPRN).

> *"Our culture might influence who should be informed, however, hiding or simplifying the facts will eventually backfire on the healthcare professionals, and so the truth should be conveyed as smoothly as possible. It is important to be polite…You should not hide anything even if the culture encourages to hide"* (I25P25HCPDR).

> *"I would be very angry if doctors suggested telling prognostications. It is too unethical and not practical to tell a patient that he/she has one-month left or oneyear left to live as this will cause suffering. Prognostication might be requested due to fear of suffering"* (I11P11HCPDR).

> *"…I believe that bad news should be told to the patient. But sometimes our culture does not give freedom to speak freely so we may need to modify some of them. It is our duty to let the patient know step by step so that it does not break his/her hurt…And I think it is good to be able to communicate in a culturally sensitive, respectful, and in a gradual way"* (I12P12HCPDR).

> *"Delivering bad news is the duty and responsibility of healthcare professionals, but a right for patients and families to know. I think the patient should be asked if he want to know before telling. He has also the right to refuse to hear; if he/she do not want to know, it should be respected. We should not force them to hear"* (I6P6HCPRN).

1.2 How healthcare professionals' perceived by patients and community when delivering bad news

There is a traditional perception amongst the community where illness and telling bad diagnosis or prognosis are taken as an unfortunate telling "Muart." One of the senior healthcare professionals described how breaking bad news related to serious medical illness is culturally perceived:

> *"When you tell the patient he has a serious illness, there are traditional beliefs that discourage the patient to accept the truth. So, there are things that encourage denial. There is a statement called unfortunate telling, "Muart." It is stated as, do not speak unfortunate telling. Unfortunate telling means bad wish or bad speech that, if someone speaks to the other person and the hearer accept it, it will happen. If you deny, it will not happen"* (I9P9HCPDR).

One of the healthcare professional participants shared his experience and described how he was regarded as a bad person whenever he breaks bad news as follows:

> *"In my personal experience, I have been blamed for revealing diagnosis and prognosis. Some patients and family members perceive me as an arrogant doctor because I informed them about their serious condition. Some*

> *patients also complained as if I had insulted them when I informed them of their illness. I believe our culture is not open to discussing such serious medical news"* (I25P25HCPDR).

Another healthcare professional reported how delivering bad news was traditionally considered:

> "*A doctor who tells bad news to the patient that they have an incurable disease can be regarded as "cruel doctor". It feels a somehow uncomfortable and due to this cultural influence, we tell the news to the family member*" (I13P13HCPDR).

Life-threatening illness such as cancer is directly related to death sentence or other traditionally related perceptions as mentioned below by one of the healthcare professionals:

> *"If someone is told that he has cancer, he/she only thinks of death. So, when you tell the patient he/she has cancer, the patient may be afraid of dying and refuse to take treatments. There is also a perception among the society that having cancer is the result of a curse"* (I6P6HCPRN).

A physician mentioned that it is important to maintain cultural sensitivity when breaking bad news that that eventually allows for the provision of palliative care, as follows:

> *"I think we need culture-oriented palliative care. Breaking bad news must be culturally oriented. If we cannot make it so, it is not palliative care, it means that we have not created comfort, we would have lost the philosophy of culturally suitable palliative care. If we fail to convey bad news properly, every aspect of our care will not be acceptable"* (I11P11HCPDR).
>
> *"If you tell prognostications, you would be blamed as if you took the role of God as patient or family might associate such news with religious and cultural views and accuse you as a person and professional. Such news are considered as caused by curse or resulted from Satan…"* (I6P6HCPRN).

1.3 Family is the first recipient

Healthcare professionals reported that family is usually the first point of contact for delivering bad news, especially poor prognosis. Furthermore, the cultural influence to maintain patient autonomy was reported:

> *"We look at the patient's clinical condition and tell the prognosis to the family first. After telling the family, we see how the patient responds"* (I26P26HCPDR).

Another health professional also stated that he prefers telling such bad news to family member:

> *"I prefer bad news be told to the patient caregiver than to the patient because patients are very frustrated when they are informed of their conditions.*
>
> *Especially, it should not be told to the patient who is in the end of life. After they are told of the bad news, they refuse treatment"* (I30P30HCPRN).

One of the health professionals mentioned that he opts for telling bad news to the family member first due to the cultural influences:

> *"I firstly inform to family. Our community culture is different from those abroad. I have learned from my medical education that patients should be fully informed, and it is unethical to tell family members without consent. However, providing the patient with complete information presents culturally numerous challenges. The patients should know, but we tell patients in a smoggy manner due to cultural influences. However, we explain every detail to the family"* (I29P29HCPDR).

In the same talk, a physician stated how much it is difficult to make the balance between patient's autonomy and the culture as follows:

> *"The culture emphasises that we must respect the elderly or who is influential in the family, and doing things in group or collective than individualism. That patient lives in this culture, his behaviour and way of life*

> *is shaped by this culture. I think that individual's autonomy does not usually prevail in our culture. The medical decision might be made by the family. When it comes to ethics, it binds us to respect the patient autonomy, but culturally this approach is forbidden."* (I11P11HCPDR).

A nurse in charge of caring for cancer patients informed the researcher that usually family ask for the information and they often get informed:

> *"It is the patient caregivers who often request to know the condition, the level of the illness, and about the treatments…We inform them when they have requested"* (I27P27HCPRN).

Patient's family may push the healthcare professionals to hide the patient of the fear that the affected patient would immediately lose hope upon the disclosure:

> *"Let me tell you my experience. The patient has had an advanced ovarian cancer with metastasize on the liver and the lung, and did surgery. The patient had expectation for cure despite her serious situations. Her daughter came into the examination room and said, we have not mentioned anything to her including the purpose of the surgery she had done. We know about the disease. If we tell her, she will lose hope and die. So, we do not tell her anything"* (I11P11HCPDR).

1.4 Challenges related to breaking bad news

The results of this study identified various factors hindering breaking bad news. The study participants explained their challenges as lack of skill, lack of protocol, patients' socioeconomic backgrounds, language barrier and healthcare settings.

Healthcare facility, professionals, cultural and patient related challenges were identified factors affecting conveying bad news. The below quotes describe these challenges.

> *"Many people associate telling bad news with traditional beliefs, and misconceptions so that they do not believe the bad news. The patients have low level of awareness about cancer, and most of them deny it. Their level*

> *of understanding and awareness about their disease is low"* (I28P28HCPRN).

Poor hospital setting, shortage of time and workload affect delivering bad news and that it might results in poor practice of breaking bad news as mentioned by healthcare professionals as follow:

> *"I think time and workload are challenging for breaking bad news. I see many new patients and who come for follow up. Some of them need to be informed. Some want psychological and emotional support. Both breaking bad news and counseling require due attention and time, but shortage of time is against this. We do not have also a private examination room; the staff get in and out, there are students… all of these distract you"* (I11P11HCPDR).

In the same talk, another healthcare professional described that lack of training for physicians, language barriers and the settings are challenges affecting breaking bad news as described below:

> *"The hospitals setup is not convenient for conveying bad news. The other thing is the way patients understand when they hear bad news, and the presence of language barrier. I think, the other significant problem is that lack of experiences, training, knowledge and skill for physicians on this subject. I think the lack of skill on breaking bad news is a big problem"* (I12P12HCPDR).

It was reported that the medical training does not involve how to tell bad news. It has also been suggested to incorporate breaking bad news in the medical curricula:

> *"The medical curricula did not cover cultural way of telling bad news. We learned medical jargon and then become confused as to how to explain serious medical diagnosis and prognosis in a way patients and other's understand. We are eventually getting learn from patients. However, I believe that we are lacking in communication skills. I believe that*

> *incorporating teaching communication skills and breaking bad news in medical education would be great"* (I29P29HCPDR).

It was also mentioned how much breaking bad news is a difficult task especially for patients with advanced illness, and that there is no protocol for breaking bad news:

> *"You might find patients taking palliative chemotherapy but not aware the purpose is not for curative intent. It makes me worried how to tell and their level of understanding. If they insist, we tell them the stage and the purpose of the treatment. But it is hard to tell, even you do not get terms to use, it is difficult to find the right words. We often tell them as if they will recover and be better. We do not properly inform and counsel them, because we do not follow any protocol"* (I27P27HCPRN).

Theme 2. Benefits of breaking bad news

2.1 To fulfil the ordinances of faith, fix unfinished business and avoid unnecessary costs

Participants mentioned disclosure of bad news would assist the patient and family for making the right decision, social benefits and avoiding unnecessary costs, as the described under the following quotations:

> *"There are three important advantages for the patient to know about his illness. First, avoid unnecessary costs. The second one is social aspect; you give him the opportunity to write a will, giving him the opportunity to resolve issues with his friends or family. The third benefit is that it aids in the resolution of spiritual issues and needs"* (I25P25HCPDR).

> *"I believe the patient and family save money by avoiding unnecessary expenses. It is expensive to travel here and to stay. They would comply with health educations. They would prioritize improving quality of life over useless treatments. Knowing their conditions also relieves them of excessive anxiety and provides answers uncertainties such as, what kind of*

> *illness do I have, why and what is hidden from me, what kind of serious illness is being withheld from me?"* (I27P27HCPRN).

> *"There are issues that needs decision such as what kind of treatment should they take? Selling a house or not for paying treatment expenses, should they be sent abroad or should they not; does she/he have enough time or not, does she/he have enough money? What is the result of the treatment? …they have to make these decisions, so they need to be explained clearly*" (I9P9HCPDR).

A medical professional agreed with the benefits of breaking bad news to the patient in order to make a will and fulfil the commandments of faith:

> *"The patient may be prepared for death. He/she will do what he/she wants to finish with family, in his religious beliefs, write wills, and makes decisions for himself. Being aware helps to speak to the religious father to repent, and be ready for heaven"* (I31P31HCPRN).

2.2. To share the burdens, build trust and help the patient understand the situation

The disclosure of bad news for both patients and families reduces the emotional and psychological burden and allows to share the burden amongst healthcare professional, patient and family members:

> *"Disclosure of bad news even makes communication easier for us. The patient might tell us we should not worry and he/she will handle the situation. That is to share the burden. The burden would be shared by the patient, the family and the healthcare professional. The burden would not fall on one person… Either the patient bears the burden or the family caregivers, or the doctor bears the burden.*
> *…Whenever the burden is share, there are solutions. These things will make it easier to make decisions"* (I12P12HCPDR).

The following quotes stated breaking bad news facilitate good rapport, build trust and understand about the treatment plans:

> *"It makes for a good relationship between the patient and the doctor. It is important for patients and their families to understand what the disease is, its level, what the treatment is, the side effects and benefits of the treatment at the right time. It helps them decide whether to start a treatment or not. It is good to start with a clear understanding of the pros and cons of treatments and continuing with the process"* (I13P13HCPDR).

> *"I need to collect complete information about the problem and explain to the patient because this builds trust. When the patient asks me a question, I need to explain it. I should not be unfamiliar about basic and important issues because I will lose trust"* (I11P11HCPDR).

Healthcare professional reported that proper bad news delivery helps to maintain hope and promote breaking bad news:

> *"By disclosing bad news in a proper way, we can reconcile these two; delivering the bad news to make patients aware and maintaining their psychological peace. Withholding bad news will not benefit anything. Telling by improper way also may cost more. So, we have to reconcile the two by breaking bad news properly"* (I6P6RN).

Theme 3. Suggested approaches for breaking bad news

3.1 Make comprehensive assessment prior to breaking bad news

Prior to informing the patient of the bad news, the patient's needs and values should be thoroughly assessed. The healthcare professional therefore should evaluate the patient's background including socio-demography, his/her capacity to receive the news, cultural background, level of understanding, educational background, and his circumstances in detail as described below:

The following participant mentioned comprehensive assessment should be taken in to account when assessment is done:

> *"It is necessary to take all round circumstances into consideration such as what kind of patient is, his/her level of education, culture, religion, family status, the level of the disease, the conditions of the treatment and the purpose of the treatment we are planning to give"* (I13P13HCPDR).

The patient, and family may be the source of information for the patient's background:

> *"You should also use the family to tell us better about the patient's circumstances; his behaviour, personality, his favorite methods of communication... In some culture, for example if you tell the family member without the husband's consent, you despise them, you dare them, and then communication breaks down. We do assessments in our own way first, but family also has an important role to give us information*" (I11P11HCPDR).

A physician also said that assessment should be done about the patient before breaking bad news:

> *"You consider and look at the person's general situations like his level of education, age and socio-economic status before you tell. Telling both the diagnosis, and the details is useful, but the way you tell, the terms to use, and how much detail you should tell depend on the individual background"* (I25P25HCPDR).

Before breaking the bad news to a family member, find out the patient's wishes and consent regarding who to involve in medical discussions:

> *"It is necessary to determine who, among family members, should participate in the conversation. We should ask the patient who he/she wants to be involved in the serious conversation and treatment decision. Informing family based on the patient's consent will assist us in giving better treatment and care and soothe communication"* (I12P12HCPDR).

Health professional said that bad news should be conveyed progressively manner, which is small at a time, gradual and in a sensitive manner:

> *"Depending on the stage of the disease and situation; if we tell a small thing today, we will tell small amount next time, and the stage of his illness sometimes later. This method, I think plays an important role, if we build good relationship and trust as that helps making it acceptable. Our culture do not encourage a direct communication, you do not speak straightforward, and gentle way of speaking is appreciated, I believe this is a good tradition, especially for breaking bad news.*
>
> *We also have a culture that telling bad news step by step…"* (I12P12HCPDR).

3.2. Cultural circumstances that should be considered

It was suggested that we should learn from the cultural norms for informing the death of family member *(Merdo)* that selects an appropriate time and place for the conveyance of the bad news:

> *"When it comes to cultural values, it is good to learn from some of the features of traditional bad news telling method, "Merdo". Some values that I see are telling bad news is taken seriously and it is delivered curiously. For example, bad news are reported in the morning, and not at night, because the person is going to cry all night, no one else is going to sleep all night, he will not get adequate rest and the other person is not going to rest, if told at night"* (I9P9HCPDR).

Cultural values play an important role in communicating bad news. Generally acceptable manners and ethics such as privacy, and dignity of patient should be maintainedas confirmed by one of the study participants:

> *"Everyone should do things like giving time, privacy, and in a way that respects our culture. Things like showing due respect and regards are considered as a feature of a good person in our culture. Thus, I believe it is appropriate to deliver bad news in this manner. And in our culture, it is very disgraceful to speak in public about something bad news. Telling serious*

> *thing in front of other people is considered disgraceful. …it is our great tradition to adopt oneself and honor one another”* (I12P12HCPDR).

Healthcare professionals believe that bad news should be delivered in a way that acknowledges the role of God, affirm the patient’s belief in God and that miracles or healings happen through God as most of patients hold religious beliefs. It is worthy to mention that the bad news is confirmed through the test results and it is good to maintain hope in God:

> *“I think first of all, build a trust and create a good rapport. The doctor should not speak so suddenly, but first listen to their expectations about their illness outcome, ask what they already know and their opinion carefully and then listen to them.*
> *Then, you should tell without contradicting the religion matters. And reassure like God knows the outcome, God can heal…”* (I28P28HCPRN).

It was also reported that bad news disclosure should consider cultural beliefs. When asked how bad news should be disclosed, one of the healthcare professionals mentioned the following:

> *“Bad news should be conveyed in a way that does not contradict with the patient’s culture, and religion; you may say, according to this evidence, she/he has this illness. When we tell bad news, we should not challenge the patient's religious faith, and cultural values”* (I6P6RN).

While telling the diagnosis of a life-threatening illness or prognosis, the physician should also focus on helping the patient. Hence, palliative care can be provided as alternative care and treatment:

> *“One of my patients had fainted when I told him the diagnosis in my first time experience. I had to report it gradually... We must allow them to take their time and become acquainted gradually as there is a widespread misconception about cancer as a death sentence. We should also ensure*

> *that we care for them, provide treatments, and pain relief; when we do so, we saw that they are reassured and comforted"* (I29P29HCPDR).

3.3. Involve family members

Patient family should be involved in breaking bad news, in the process of the care and treatments. It was suggested to inform and discuss the situation with the family member before telling the patient.

Healthcare professionals suggested a progressive approach for breaking bad news. The following submissions describe the role of family member and suggested methods.

> *"According to my practice and our culture, first it should be discussed with the family. Because, in our culture it is a next of kin who takes care of the patient even in the hospital setting. As a result, most of the time, the basic nursing care is on the shoulders of family. Thus, discussion should be done with family members before informing the patient"* (I9P9DR).

In the same talk, another healthcare participant stated how family plays an important role in the following:

> *"The role of the family is significant in our community…many medical decisions are made by the family, and the role of the family is paramount. It is good to talk to someone who is a family to the patient"* (I13P13HCPDR).

> *"I often tell the patient, but I confirm whether he/she wants to know or not. Nevertheless, if I see a poor performance, there is no point to tell the patient. When seriously sick patient comes, I would ask the family to take the patient out of the room, and ask the family to discuss without patient. …I tell to family, and we talk about the problem, because it is the family that give the care…"* (26P26HCPDR).

3.4. The practices of breaking bad news

Healthcare professionals shared their experiences on breaking bad news and how bad news is being delivered in practice. It was reported both the good and poor practice of breaking bad news.

The following vignette shows how a trained physician roke the news in palliative care practice:

> *"I first choose a conducive place, I collect evidence to learn on the illness. I greet and introduce myself before serious conversation. I assess the medical needs, and I use open ended questions as, "How are you today?" "Do you want me to tell you about your condition?" Then, when the patient is willing and ready, I would further ask questions such as "What did you know about your illness?" "How much do you want to know?" "What do you want me to tell you today?" Would you want your family to be with you?" When I tell the bad news, I would say the laboratory results show... according to the results of… I would explain to him what it means. Then I ask if he understands, any questions and then I summarize it"* (I12P12HCPDR).

The following healthcare professional's experience demonstrated poor practice of breaking bad news where patient's needs are not assessed, and the patient is excluded from medical decisions and consent as described below:

> *"From my experience, the patients' need is not evaluated; what does he want and know about the condition? How much does he want to know? Rather, the physician dictates him; "I know for you," and it is not done procedurally. I saw patients who were hidden their medical diagnosis, but did surgery*" (I11P11HCPDR).

> *"We inform without preparing, the way we deliver the bad news is sudden. …If the illness is life-threatening condition, it is very difficult to tell, and we do not usually tell the patient, rather we often tell family"* (I9P9HCPDR).

The following couple of quotes outline the lack of knowledge on delivering bad news properly and that breaking bad news is delivered ineffectively:

> "*Breaking bad news is a big deal and the issue is huge. I think it needs to get proper attention, especially the way we disclose bad news is poor. I do not know if there is a guideline, I do not know how bad news should be disclosed. I do not know how to approach patients properly. Effective communication skill is needed*" (I30P30HCPRN).

> *"…We deliver bad news inappropriately and in the wrong way. We disclose in a way that does not consider the patient's psychological well-being. That may have a lot of consequences including experiencing unwanted treatment failure* (I6P6HCPRN).

It was also stated that the task of breaking bad news task could be assigned to other staff. Training in the etiquette could certainly improve the skill:

> *"Whenever possible, I would not inform or I would rather give the responsibility to someone else. Because telling someone that sad news thing is a very serious responsibility. I was scared to tell, because I know that the way I tell is very important to the person. I did not like to do it, I wanted to avoid confrontation, and not tell as much as I could. I just had to tell the patient as, "It is beyond our level, no cure and stay in home" because I did not have the skill and knowledge how to deliver. But, now with training… I am not afraid to tell"* (I1212HCPDR).

Table 4.8: Themes and sub-themes for Community Members

Themes	Sub-themes
Theme 1. Community members perspectives concerning breaking bad news	1.1. Approaches for conveying bad news 1.2. Preferences on who ought to be informed the bad news

Theme 1. Community members' perspectives concerning breaking bad news

Community members' including patient family were asked their views regarding how to inform, who should be told around breaking bad news and issues about end of life care. This theme outlined the preferences of community members when delivering bad news and discussed under the following sub-themes.

1.1 Approaches for conveying bad news

The following traditional ways of conveying bad news was preferred as showing sympathy, and encouraging the patient as mentioned below:

> *"It would be gratefully received if expressions like, "God can work miracles," "you can live longer than the estimated time, who knows" "A healthy person may die while a sick person continues to live" "everyone who is ill will not die very soon" were used when breaking bad news. Such kinds of traditionally used phrases are important and healing when informing bad news"* (I8P8COM).

The study participants amongst community members concurred with the idea of gradually telling bad news and described how:

> *"It is better not to tell suddenly. I think it is good to tell gradually. It is better to tell little by little every time…"* (I8P8COM).

Another participant mentioned that it is not suitable for Ethiopian culture to tell how long a time one has left to live. The community member reported that telling a patient how long they have left to live is not culturally acceptable. This does not help the patient or family; rather it adds psychological and emotional scarring:

> *"…Telling bad news should not discourage the patient to live. The patient should not give up on hearing the time of his death and just count the days of his death.*
>
> *It is certainly not appropriate to tell prognostications as it causes distress"* (I7P7COM).

A holistic approach was recommended as illustrated below:

> *"I think it is better to take care of the patient as much as possible when delivering bad news. The care and support should include spiritual and psychological dimensions"* (I7P7COM).

1.2 Preferences on who ought to be informed the bad news

Family members have chosen to withhold bad news from the patient to guard from perceived harm. A patient's family mentioned the following when she was asked who should be told bad news:

> *"Who should be told other than the family? The family should know first. I was told lately after we spent many times for treatments. I would have appreciate it if I was told earlier. The doctor asked the patient if he wants to know, but I did not want him to hear. I would prefer, if he told to me only. Because, I wanted to carry the burden, encourage and care for him"* (I35P35FM).

A patient's family who has been informed of the bad news with the patient mentioned her preference as follows:

> *"The doctor informed the bad news for me and the patient together. Fortunately, my mum had no idea about cancer, so that she did not understand what the doctor said to her. However, I and my family would be pleased if we have heard of it without her (the patient) at that time"* (I37P37FM).

It was preferred to disclose disease diagnosis to the patient and family, however, withhold prognosis:

> *"I think, it is not good to tell the level of their situation directly to the patient. I would advise that the close family should be informed so that they can be prepared. The patient should know his illness at some level, but when it is the illness is serious it should be disclosed to the family caregivers as it causes stress to the patient" (I38P38FM).*

> *"We talk openly with the health professional as the level of the illness is not too bad. However, when the disease get worse, it would be better to tell to the family caregivers, not to the patient. "… I would not oppose to tell the condition to the family caregivers in detail, I would rather think that is good. I mean, when you are the caregiver, you see the change and the situation every time, so that it would be good not to hide from family caregivers, and discuss what is going on with health professionals in detail"* (I38P38FM).

Patient may want the conversations of the bad news omit to discussing bad news or the details of the prognosis and focus on the positive aspects of the situation where there is something that can be done than the sad aspects. One of the study participants from community member mentioned as below:

> *"I do not think it is necessary to explain the unfortunate part of news in-detail. I think it is important to think only of about the good things. It is important to convey in a way that does not affect the person. The patient should not spend the rest of his time worrying, he should not give up, and spend the rest of his time worrying"* (I7P7COM).

Family members also have vital role in the disclosure of bad news and to give support to the patient in palliative care. The community member said the family should take a decision-making role when the patient is seriously ill and at the end of life as described below:

> *"If the patient is in the final stages that has to be communicated to the family. Let his family take care of him for the rest of his life; or he may be able to relax and have a good time. It is up to the family to decide on various issues. I think the family should know that because he cannot do anything on its own, the family asks for many things, and the care is on the family shoulder"* (I7P7COM).

4.6 PHASE 2: FINDINGS FROM OBSERVATION

As a second data collection method, field work was undertaken through observation. The researcher watched when physicians conveyed bad news to patient and/or their families at different times. The findings from conversations between patients and healthcare professionals when physicians deliver bad news to the patient or family, nonverbal cues, and study setting are presented in this section.

This research established that the hospital physical setting is inconvenient for the requiste privacy. According to the physical observation of the study area, the cancer treatment out-patient unit has three rooms. The rooms are furnished with a chair for patient and doctor, and one couch. The space is estimated to be eight square metres and there is no window. The surgical out-patient unit has four chairs and four tables furnished with desktop computer for patient examination in one and an open examination room. Physicians share one patient examination couch when they do a physical examination on the patient. They use a bedside screen when they perform physical examination, despite the screen being old and it does not fully maintain privacy. It was observed that the setting is uncomfortable and distracting to communicate with the patient. During interviews with patients, two or three physicians see patients in the same examination room so that one can hear the other's story. The voice from the information desk generates another noise.

Patients and their family stay in the waiting room for their turn to see the doctor and they talk loudly in the waiting area. The proportion of patients staying in the waiting room exceeds the number of healthcare professionals. Those who have seen their doctor leave the room and may talk to the nurse for further information and help at the information desk, and the nurses also talk to patients to allocate appointments and give other support. All these happen in the waiting room and it is distracting. The noise was a barrier and complicated how to communicate with patient, deliver bad news, and hear each other. The examination door is kept open often, colleagues get in and out even while a patient is under observation by a doctor, and this disrupts communication. To this end, the noise from the waiting area is apparently distractive for breaking bad news. The out-patient units setting is not conducive to maintain privacy and keep confidentially when making serious conversation.

During the field work, it was noticed that breaking bad news is common but tough task, often resulting in emotional and psychological scars to the healthcare provider and patient. After conveying bad news, it was noticed that the healthcare professionals were distressed. This was observed from the health professionals' facial expression and body language. They express their feelings by leaning down their head, rubbing eyes for tears, and appearing very sad after the difficult conversations.

The patients' background equally affects how they receive the bad news. They take time to reconcile the news with the effects on appreciating a lifetime of debilitating illness. Patients from urban settings are literate and they communicate better with healthcare professionals. The bad news communication process was better for physicians when the patients were aware of their conditions, and they could discuss the plan of care. Furthermore, patients were told the plan and purpose of treatment briefly (FN02). One of the patients who was aware of her illness discussed with her physician and reflected her choices following the following vignette:

> "*I refused to do further CT (computer tomography) scan investigation for my brain. I think it is sometimes better to live without exploring the progress every time as it is pointless to know*" (FN08).

The field work showed a gap in how, to whom and how much bad news could be delivered, as well as inappropriate approaches. It was noticed that the healthcare professionals do not prepare the patient or family before conversations about bad news in terms of time. Patients were not asked whether they wanted to know and how much they wanted to know. Adequate time was not given for the patients to reflect their needs, ask questions and share their concerns. Adequate information was not provided and no open discussion occured before ordering laboratory tests and treatment. Furthermore, paternalistic approaches were evident when making medical decisions. The following quote illustrates how the physician communicated to a patient with breast cancer. The patient was not involved in the decision; there was no invitation to the patient and no discussion on potential options for treatment other than the surgery:

> *“The laboratory result has shown that the mass did not spread out, so surgery should be done. We will remove the breast by operation*” (FN15).

In addition, the field observations verified that patients were not given adequate information on their serious situation. The following quotes are based a conversations between physician and patient’s family. The physician asked the family and patient if they had been informed. They replied that they had not been given sufficient information and had not been notified on the patient condition at the appropriate time:

> *"We had seen several doctors, but none of them had informed us the condition.*
>
> *We were recently told by a surgeon that his disease is pancreatic cancer”* (FN06).

During another conversations a patient mentioned the following to the physician:

> “*I was not given adequate information and informed of my medical situation even before I did a surgery*” (O23P23).

The patient’s emotional reactions should be observed and supported after telling bad news. Nevertheless, it was noticed that most of healthcare providers do not recognise and pay due attention for the emotional pain and reactions of the patient following disclosure. It would have been great if patients were given a chance to express feelings, and get support accordingly. Bad news modify the view of life of the patient and family.

Field observation in the study area revealed that the majority of patients presented at the hospital with their family. Moreover, patients are told about their medical condition such as diagnosis in the presence of their family while family is informed of poor prognosis. In most of bad news conversations, it was noticed that healthcare providers use comforting words such as “Take courage *(Ayzoh)*”, “May God be with you” “God can heal you, we are an agent of God” to reassure and console. Physicians deliver poor prognosis and treatment failure to the family. Patients were kept out of the examination room when the health provider communicated with the family. The following quote illustrates how a physician disclosed the patient's poor prognosis and impending death to the patient family:

> *"You have worked tirelessly to assist and care for your wife, and we have done much to treat her disease. God knows when a person will die, but I think she is nearing the end of her life*" (O16P16).

The family requested the physician to confirm if the patient was clinically fit for life prolonging treatments. The healthcare professional stated that the problem was advanced and could not be reversed, and he advised and reassured the family:

> *"Her cancer treatment has not been effective. Her liver has failed, and we are unable to change the situation and stop the progress. She is not capable to receive chemotherapy, however the symptoms should be managed"* (O16P16).

The family has accepted the advice and stated that the situation is determined by the Creator or God so that it is not reversible and cannot be fixed by human being. Furthermore, patients were not involved during disclosure of poor prognosis and physician and family withhold the bad news:

> *"…As a family, you have done everything you could for her. Even if it is tough, it is necessary to accept the situation and a poor outcome. …You must prepare yourself for the inevitable death. However, do not tell her anything about the progress. Do what she wants. You will have no regrets after her death if you do this"* (O16P16).

Most of the time bad news is delivered without following the preparation and principles for communicating bad news. Open-ended questions should be used to assess the needs of the patients. However, during bad news disclosure, closed-ended query are often used. Patients are not asked whether they would prefer disclosure and who they would want to present the news. The following conversation between patient and physician demonstrates how bad news is delivered with no thorough assessment of the patient's needs, poor communication and without asking whether the patients want to know at that time:

> *Doctor: Have you been told that your laboratory result shows cancer in your pancreas?*

> *Patient: No, I did not know. I am hearing it just right now as you are mentioning it.*
>
> *Doctor:* "…*Your CT-scan result shows cancer of pancreas. It was not possible to do the surgery because the mass was not operable as it might cause excessive bleeding. So you are referred to this unit for chemotherapy"* (O19P19).

The delivery of bad news were not performed systematically. During field work, it was observed that healthcare workers do not follow protocol or step-wise method when breaking bad news. It was noticed that bad news is delivered abruptly. Patients were shocked and benumbed when bad news delivered without proper assessment and preparation. The following quote shows how commonly bad news is delivered:

> "*The aim of chemotherapy is to reduce the symptoms. It is difficult to cure the disease. Did we not tell you there is no cure for this?"* (O24P24).

The physician explained more about the purpose of the treatment when the patient replied he was not as aware:

> *"Oh… I thought we told you that the medicine we give you now does not cure the disease. The treatment can reduce unwanted symptoms that make you wake up at night, and makes you rush to toilet, but it is not possible to completely cure the disease*" (O24P24).

Often, when bad news is delivered, the objective of treatments is conveyed to the patient and family, whether it is for palliative or curative intent in an unpalatable manner. There was no time given for question and answer. Healthcare providers do not distinguish between palliative and curative treatment. When divulging bad news, both local terms and medical jargon are conflated without interpreting or discussing the meanings.

Terminally ill patients might not understand the meanings and implications of the stages of life-threatening illness unless these are sensitively explained.

> "… *Your disease is cancer of the stomach. When we look at the level of the illness, it shows a spread to the other parts of the body…So, the main*

> *purpose of the chemotherapy is not to cure the disease, because the stage of the disease is stage three”* (O14P14).
>
> “*I was told that my disease is a tumor. When I signed consent for chemotherapy, I was informed that I had cancer*” (O24P24).

In the same talk, patients might not have an interest in talking about the bad news. One patient was informed of the poor prognosis and purpose of the treatment. However, the patient wanted to focus on his current status and the clinical responses from the treatment when the physician talked about the poor prognosis of the disease:

> “*To be honest, I feel [a] lot better since I began chemotherapy. I was quite ill, weak, and unable to walk, but I am now feeling much better. I believe the medicine is assisting to treat the disease”* (O14P14).

Based on one of the field observations with patient and physician conversations conveying bad news, the doctor invited the patient to take a seat and greeted the patient who looked quite relaxed to talk with the doctor. This illustrates that general communication principles such as greeting when the patient comes into the examination room, welcoming the patient by calling their name and asking them to take a seat, followed by a courteous self-introduction are fundamental to facilitate effective delivery of bad news. These basic protocols reflect sympathy, humility and kindness. Patients who were greeted and welcomed by doctors felt more at ease and relaxed to ask questions and talk. Nevertheless, this kind of approach was not commonly performed.

When reassuring and counselling patients or someone who is sad, it is common cultural practice to use the everyday religious terminology. Similarly, healthcare workers are encouraged to use such religious terms when communicating bad news:

> *“The physician said to the patient, God can heal using people. What people say will not happen, rather what the Creator's says; take a courage "Ayizosh”. You will return to this hospital, if it is God's will. May God heal you”* (O16P16).

4.7 PHASE 3: TRIANGULATION OF FINDINGS FROM INTERVIEWS AND OBSERVATION

According to the results of interviews, patients reported a desire to get detailed information regarding their health condition and treatment options. The results also showed that access to this information informs medical decisions, minimises uncertainties, avoids unnecessary costs on futile treatments, it helps them to make religious, social and economic decisions. Similarly, health professionals outlined that disclosure of bad news has advantages of sharing burdens, building good rapport between health workers and patients. However, patients pointed out that they did not get enough information on the occasion of disclosure of serious illness.

Patients, health professionals and community members agreed that bad news should be conveyed progressively, giving small doses of information at a time, telling the bad news gradually and in a sensitive manner. Patients choose to be told bad news after adequate psychological preparation. Therefore, breaking bad news has to be done when patients are sensitised to the gravity of the disclosure. Health professionals also reported that holistic assessment of the patients' situation and needs should be applied and with sufficient time allowed for such disclosure of bad news.

The telling bad news observed during field work confirmed that the practice fails to allow sufficient space to the patients' needs, and insufficient information was disclosed while the communication was short. In addition, observational findings confirmed that patients were not well-informed about their disease. The conversations between the patients and physicians were brief, with insufficient time allocated to listening sensitively to the patients' concerns. Moreover, the patients' needs on receiving bad news were not properly identified; either the patient or family were not prepared prior to telling the bad news and end of life conversations. Furthermore, patients were not asked whether they wanted to know, how much they wanted to know, if they were ready to hear, or when they wanted to hear.

Receiving bad news has an impact on patients and their family. Field observation verified that the delivery of bad news did not get due attention, and patients were not involved in treatment plans and the decision processes. There is little opportunity, if any, provided for the patient to ask questions or discuss potential treatment options.

The patient participants stated that doctors follow inappropriate approaches in delivering bad news, quite often abruptly without preparing the patients psychologically. The patients' experiences with receiving bad news were dissatisfying as this was disclosed plainly, which is shocking to hear.

Patients chose to receive bad news and this was similar to the healthcare professionals reporting that patients have the right to know their medical condition. During observations in the study area, it was noticed that most of patients are accompanied by their family. Patients indicated that they want their families to be present when they receive bad news. In line with this, it was observed that disease diagnosis is divulged to patients in the presence of family while poor prognosis was delivered more often to the family. The patient family reported that they would rather withhold bad news to protect the patients.

Physical environment, workload, and patient-related circumstances influence the delivery of bad news. The findings from interviews with healthcare professionals and patients confirmed that traditional misconceptions regarding telling bad news, the hospital setting, lack of training and skill in breaking bad news, and patient's level of understanding were factors affecting the delivery of bad news. This result aligns with the field work results confirming that those factors influence how bad news is conveyed. During fieldwork, it was observed that patient age, educational background, and area of residence (urban vs rural) all had an impact on how patients receive information on bad news. Furthermore, insufficient time owing to workload, poor infrastructure, and inadequate skill are barriers for breaking bad news effectively. All these factors affect the quality of bad news conversations between patients and health professionals.

The community's perceived understanding and cultural views regarding life-threatening illness, telling bad news and prognosis of an illness were underpinned by religious beliefs. Furthermore, culture and religious beliefs influence a patient's outlook on life and the search for a religious solution when life-threatening illness is diagnosed. As a result, similar to the patient participants' perspectives, a healthcare professional mentioned that religious values must be integrated when delivering bad news. Field observation affirmed that the way of comforting patients were aligned with using spiritual or religious terms and acceptable phrases such as "take courage", "May God help you" "God Patients mentioned that it is worthwhile to call the patient by name when conversations on the serious ailments commences. Effective communication skills are essential for conveying bad news and ensuring that the patient understands the information to cope and retain faith in the efficacy of care. A welcoming approach, accompanied by a smile may open the patient's appetite to communicate with healthcare workers. In addition, first impressions matter to the patient in building rapport with healthcare workers. Patient participants mentioned that they prefer warm greetings before beginning hard conversations that ease the bad news communication and build good rapport.

4.8 ISCUSSION OF THE STUDY FINDINGS

4.8.1 Introduction

This chapter discusses the research results presented as themes and subthemes in the previous chapter in detail. The results are interpreted and discussed with the support of other published research for developing the guidelines.

4.8.2 Domains of breaking bad news

The practice of disclosure of serious diagnosis generally applies in all medical fields that disclose diagnosis, organ failure, prognosis, poor treatment outcome, treatment failure or the death of a patient. In general, diagnostic disclosure of chronic illness can be shocking compared to acute and treatable infectious illness because such illness requires taking medicine for a lifetime and such illness is incurable and life-threatening. Furthermore, acute illness or any case that has poor outcome or that is life-threatening and impending death constitute bad news that is invariably shocking for the hearer.

People have a low level of awareness about life-threatening illnesses and a misunderstanding of health and illness tied to religious beliefs. The available screening programme and treatment for cancer is limited and it is expensive for most people as healthcare costs are covered out of pocket in Ethiopia (Mesafint et al 2018:113; Reid et al 2018:626; Workneh et al 2018:8). Furthermore, cancer patients usually present to hospital with late stages of the cancer (Abebe & Abebe 2017:257). Serious diseases such as cancer are perceived as ultimate death sentences with prolonged suffering (Haileselassie, Mulugeta, Tigeneh, Kaba & Labisso, 2019:35). As a result, breaking bad news related to life-threatening illness such as diagnosis or prognosis or disease spread is taken seriously and the approach requires due attention in offering hope is.

This research was conducted with patients with life-threatening illness, healthcare professionals in palliative care settings, and field observation was in oncology and surgical out-patient clinic. The domains of bad news in this context include diagnosis of life-threatening illness, recurrence of illness, informing poor prognosis or spread of disease and treatment failure. Conveying such bad news for the patient or family is considered traumatic.

4.8.3 Cultural values and beliefs regarding breaking bad news

Ethiopians have deep religious faith with the majority believing in God, and an afterlife in hell or heaven. Accordingly, the major religions comprise Orthodox 43.8%, Muslim 31.3%, and Protestant 22.8% (CIA.gov:2022). The collective tone of Ethiopian culture is rooted in religious beliefs and collective life, and religion informs most people’s worldviews. One of the community members mentioned that people are raised in an orthodox manner: *"In terms of our culture, of course, the culture in which we grew up, the religious system is very strict and shapes our worldview"* (I8P8COM). In the community, acknowledgment of the Lord or God are valued in many facets, and the traditional view of what is right and wrong is informed by suc religious perspectives. It is also widely believed that judgment on one's life is made by God. This study confirmed that religious beliefs, values and rituals are invaluable in breaking bad news. Patients mentioned that their religious beliefs and religious ceremonies are foundational for their hope and meaning in life. In line with this, a study by Chiatti (2019:344) confirms that religious beliefs, values and rituals are vital cultural constructs in the Ethiopian community (Chiatti, 2019:344).

The holistic approach of palliative care encompasses the spiritual dimensions of the patient and family. As far as culture is concerned in breaking bad news, most Ethiopians are religious and perceive illness from this perspective. Most people believe that God created man, and God grants life and health. In Ethiopia, there is a belief amongst patients that their illness is a result of punishment from God or evil spirit or a curse (Mesafint et al 2018:113; Gebremariam et al 2019:6)

This study reached the conclusion that there are patients who believe that life-threatening illness such as cancer are caused by divination. They also have beliefss that miracles can occur and that God can heal their illnesses. Moreover, this study confirmed that patients cope with their challenges and difficult times related to receiving bad news and their serious illness with their religious beliefs and rituals. According to a study conducted in Ethiopia, participants perceive health as a gift from God (Kahissay et al 2020:951).

People believe that the utmost helper and the utmost decision maker on the lives of human being is God. People perceive healthcare professionals as agents of God who have a vital role in healthcare as God cures patients through these professionals. Moreover, it is commonly believed that God alone has the power to determine human existence and life span. Sometimes, healthcare professionals who deliver bad news are perceived as bad people because of various perceptions related to this obligation. This study verified that patients prefer to be told their medical condition in accordance with religious values and spiritual terms. A study by Aminiahidashti et al (2016:35) also showed similar preference that patients want healthcare workers to consider their religious belief when breaking bad news (Aminiahidashti, h 2016:35).

Talking about a serious medical illness or telling bad news is taken seriously in the community. The majority of the time, serious medical decisions are made through joint family discussions or with close friends. Relationship and building trust is highly valued in these serious conversations. It is culturally discouraged to tell serious diagnosis directly to the patient. Ubuntu similarly prescribes the interconnection among people at the core of its philosophical foundation (Nare 2016:57).

Furthermore, when delivering bad news and discussing end of life care, it is also culturally unacceptable to inform patients of prognostication.

In Ethiopian culture, social norms are anchored upon welcoming each other, participation in religious ceremonies, and diligent performance of religious rites, social relationships, and active participation in the cultural rituals such as. Moreover, sharing resources, supporting economically disadvantaged people, participating in social charity, visiting the sick and feeding the hungry are cultural dimensions of being a good person. In addition, good social interaction and active participation are important criteria by which a healthy life can be measured in the society. If a person has an individualistic life, it might not be taken positively. According to Ubuntu philosophy, being human is viewed as moral superiority of people anchored in empathy and forgiveness and the social relationship between people (Gade 2012:487). The ethos of being collaborative, collective and interconnectedness are the essence of Ubuntu (Gade 2012:492).

The Ethiopian culture emphasises values religious leaders, traditional foods, collective life, hospitality and patriotism. The collective life and socialisation culture of the Ethiopian community is displayed through various norms and values. The coffee ceremony, local community-based associations such as "*Iddir", "Mahiber*", "religious unions", "neighbourhood", "*Lekso"* (social support during loss of family), perceptions and values for kinship all are predominant constructs of the Ethiopian community. In addition, showing respect, empathetic approach and humility are culturally valued before their therapeutic effect (Chiatti 2019:345). One of the common values in Ethiopian culture is warm greetings that reflect a concern for someone's life, respect and attention paid to the relationship. Participants in this study stated that telling bad news abruptly is inappropriate and shocking.

People usually go to cultural places to find solutions for their ill health. Using holy water and prayers are the most common cultural remedies taken before visiting a doctor (Gebremariam et al 2019:6). Because most people are religious, and they trust that God could heals, cures, or helps by using any opportunity, it is not culturally appropriate to tell the estimated survival time for a patient in Ethiopia. It is believed that God has the power to determine how long a person lives. Thus, it is culturally inappropriate to tell prognostications or patients may not prefer to be told how long they have left to live. A study in Ethiopia confirmed that patients prefer poor prognosis to be told to family member rather than directly to them (Woldemariam et al 2021:1344).

The traditional way of divulging the death of a family member, “Merdo,” is taken seriously in Ethiopian culture. The bad news is delivered sensitively and it is delivered by elders or religious leaders in a group with due care for the family as well as selecting the right time. The person who delivers the bad news has to go in person and choose the appropriate words. Family members, neighbours and friends are commonly called upon to comfort the bereaved family.

4.8.4 Preferences and information needs regarding breaking bad news

A study conducted in Ethiopia showed that patients with life-threatening illness wish to know about their illness (Fisseha et al 2020). Similarly, the results of this study found that patients want to be told of their illness and condition including what caused their illness in detail. Patients also wanted healthcare professionals to provide them some information about the illness, treatment options and discuss the causes or factors that contributed to the disease. This helps them to address their uncertainties and involvement in the medical decisions.

Most of participants in this study mentioned that patients should be supported to be calm, and reassured emotionally when delivering bad news. Empathetic approach and humility were voiced as fundamental ethical practicesr when breaking bad news. Delivering bad news in a culturally appropriate and supportive way facilitate maintaining hope while dealing with seriously ill health. This study also found that religious support plays a significant role in maintaining hope when telling bad news and challenges related to lifethreatening illness. The word *“Ayzoh/sh”,* encouraging and comforting words and affirmative words are much appreciated in the consolation of participants in this study.

Evidence shows that family prefer withholding the bad news to protect the patient (Abebe et al 2019:697; Liu et al 2018:2176). This research found that patient family want to know about their loved one’s condition in depth. In line with this, the results from field observation confirmed that family needs detailed information.

Most patients in this study want to be told of their diagnosis or prognosis in the company of their family. This finding is consistent with those of a study done in Ethiopian, which found that patients desired to discuss their medical conditions in the presence of family members (Fisseha 2020:1021). In line with this, observations in the study area verified that the majority of patients come to the hospital with their next of kin. A study by Abebe and Abebe (2017:258), shows that patients come to hospital with their children, siblings, spouse or cousin. This comes from relationships enacted through traditional association, religious unity, mourning ceremony, and various communal traditions exhibiting communal social norms and values in Ethiopia. Family and/or friends are directly involved in collective decisions on serious issues. Often times, a family member is delegated to deal with a healthcare professional about serious medical conditions and if needed, to organise a meeting with family members and/or the patient for further dialogue and decision making (Kebede et al 2020:8)..

It is difficult task to divulge the failure of curative treatment and communicate about death with the patient and family for healthcare professionals (Pereira et al 2016:45). It is culturally inappropriate to tell directly to the patient about his poor prognosis and talk about his imminent death. The result of this study show that the patient's family and community members prefer not to inform the patient of poor prognosis and impending death. According to a study conducted in Ethiopia, patients prefer to delegate dealing with their illness's prognosis to their family (Woldemariam et al 2021:1344). It has also been suggested that it is better to tell poor prognosis to the patient’s family first and then the patient with family. However, some patients want to be the first to receive such news.

It is not common practice to plan in advance and document patients’ preferences in Ethiopian medical ethics. This may put healthcare workers in an ethical dilemma on medical decisions: who to talk and with whom to make the decision. In this study, patients want their family to make decisions on their behalf for lack of capacity or competence in serious conditions.

This study has shown that breaking bad news has many advantages for the patient, family and healthcare professionals. The benefits of being informed of her illness helps the patient in making informed medical decisions, reducing distress, and completing the unfinished business. Patients travel long distances to referral hospitals for seeking curative treatment. For such commitments, patients and family sell their properties to cover medical costs (Haileselassie, Mulugeta, Tigeneh & Labisso, 2019:36).

Furthermore, patients present to healthcare facility with late stages of their illness (Abebe & Abebe 2017:257). Hence, knowing the conditions and the objectives of serious treatments may help the patient to avoid costs on futile treatments and make the right decisions. Breaking bad news also allows discussion of emotional issues, psychological pain, distress, fears, and seeking help. When family and healthcare professionals share the bad news with the patient and involve him in treatment decisions, it reduces the psychological and emotional burden on them. Furthermore, this study discovered that patients benefit from religious rituals that are performed in the end of life. These findings are supported by other studies that revealed breaking bad news reduces unnecessary costs, emotional burdensand treatment plans involving the patients in the medical decision (Alzahrani et al 2018:1661-1663; Lewis et al 2018:507; Sobczak et al 2016:175; Zielińska et al 2017:104)

Individuals may have conflicting choices and perceptions towards who should be told the bad news. According to the results of this study, patients' family and community members have different options on whether the patient should be told of his illness or diagnosis. Some of the family members understand the benefits and the right of the patient to be informed of his condition, and want the patient to be told. Conversely, other family and community members prefer to withhold the bad news and protect their loved one, leaving them to carry the burden of caring for the patient.

This study found that culturally sensitive protocols in breaking bad news guidelines enable healthcare professionals to perform the chores more successfully than on the occasions where such a scaffold is absent. Furthermore, most of healthcare professionals who participated in this study stated that they are obliged to deliver bad news to the patient even though it is difficult for them to accommodate the family's need to know before the patient, and to withhold the news while maintaining the patient's right and confidentiality. In line with this, the literature showed that breaking bad news is a difficult task. In this regard, culturally adapted breaking bad news guidelines ought to be made available (Borjalilu et al 2018:18; Ganca Gwyther, Harding & Meiring 2016:942; Hahned et al 2020:288; Silveiral et al 2017:325).

4.8.5 Preferred methods for breaking bad news

Evidence suggests that bad news should be delivered at the patient's discretion (IbañezMasero et al 2019:5). Patient preferences and the level of comprehension of the information may be influenced by life experiences, demography and emotional state. The literacy rate in Ethiopia is low and the result of this research disclosed that the patients' demographic status, level of understanding, educational level and socio-cultural background should be thoroughly evaluated prior to the delivery of bad news. This enables the health professional to figure out the patient's preferences, as well as how much detail to provide. The health professional should ask the patient whether they prefer knowing and how they seek to know about the illness. In addition, family may be a source of information on the patient's cultural backgroundand behaviour.

This study identified preferred methods of breaking bad news where rapport between the patient and healthcare professional is a basic requirement. Establishing rapport fosters trust and dispels uncertainties that both pave way for patient-centred care (Hashim 2017:30). Both the patient and community participants mentioned that patients should be prepared psychologically before breaking bad news. The chosen approaches for breaking bad news are telling gradually, giving small doses of information indirectly (going roundabout) to show caution. This is consistent with a study done in Ethiopia that showed patients should be consulted on how much they should be informed of their condition progressively (Fisseha et al 2020:1021). Furthermore, health professionals also prefer to break bad news gradually. This is supported by evidence of similar results on health professional preferences (Alshammary et al 2017:69).

4.8.6 Challenges in breaking bad news in Ethiopia

The diagnosis of a life-threatening or terminal disease or prognosis is one of the most shocking times for the patient and family that affect their views of life in the future. Despite the painful truth, it should be communicated to the patient and family in the best interests of the patient. This research distinguished major challenges related to healthcare professionals, patient/family, the hospital setting, workload and lack of culturally suitable guidelines. Research in Ethiopia revealed that lack of privacy to talk about serious and sensitive issues, language barriers and lack of time are among challenges affecting the delivery of bad news (Kebede et al 2020:6).

The culture influences that healthcare professionals compromise the patient's autonomy when delivering a prognosis of a life-threatening illness. As a result, patients’ family are the first contact for communicating bad news in end of life. The family members wish to withhold bad news, often compelling healthcare professionals to avoid breaking bad news to the patient. Some healthcare professionals seek a balance by informing both the patient and the family, whereas some others inform the family only. Making the balance between respecting the patient autonomy and cultural preferences can challenge health professionals to break bad news. Health professionals’ fear of their own death was also another issue that influences delivery of bad news in this study.

Evidence shows that lack of training in breaking bad news impedes the process (Gan et al 2018:1460). According to healthcare professionals who participated in this study, patients need to be informed of their serious medical bad news, however lack of skill is one of the hurdles in the delivery. Similarly, evidence illustrates that health professional break bad news without adequate training and skills (Messerotti et al 2020:7; Sarwar et al 2019:697).

The available guidelines are developed in their cultural context (Abazari et al 2017:2-5; Brown et al 2017:6). This research reported that there is no culturally adapted guidelines available for breaking bad news that support healthcare professionals in Ethiopia. Similarly, research indicates that when delivering bad news, health professionals do not follow a systematic approach (Pereira et al 2016:46). Moreover, in this study, healthcare professionals reported that they have heavy workloads such that they spend less time with terminally ill patients.

4.9. SUMMARY

This chapter discussed the study findings in detail. It outlined the participants’ cultural preferences, values and beliefs regarding breaking bad news. The preferred approaches for breaking bad news, the benefits of breaking bad news, the experiences of healthcare professionals and patients concerning breaking bad news were elaborated. The results were also discussed by consolidating previous findings in published articles. The following chapter focuses on the development of culturally sensitive guidelines for breaking bad news.

CHAPTER FIVE

DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS

5.1 INTRODUCTION

This chapter outlines the components of culturally sensitive guidelines for breaking bad news and how these guidelines were developed. The guidelines was developed based on the results of this research and literature review. The WHO Handbook for Guideline Development (WHO 2014) was used in this undertaking. The chapter also outlines the steps that ought to be followed when breaking bad news, the scope, purpose and audience for the guidelines. Furthermore, 2the chapter offers a discussion on the validation of the guidelines.

5.2 JUSTIFICATION FOR DEVELOPING THE GUIDELINE

The rise of non-communicable disease urge making palliative care available and accessible. Evidence demonstrates that life-threatening such as cancer, cardio-vascular diseases and diabetes are the leading causes of death in Ethiopia (Bigna & Noubiap, 2019:1295). Palliative care reduces the medical costs that patients afflicted by terminal illness are likely to incur (Kremenova, Svancara, Kralova, Moravec, Hanouskova, Knizek and Bonatto, 2022:1092). Patients might not benefit from palliative care services and maynot make the right choices if they are not informed of their medical conditions. Nevertheless, divulging bad news is a difficult task that requires training and strategies for effective delivery. Breaking bad news in an inappropriate manner diminishes the patient's and family's hope, disrupts emotions and psychology, affects rapport, and reduces adherence to treatment and patient satisfaction with palliative care provided.

Patients diagnosed with life-threatening illness have the right to be informed of their illness. Furthermore, patients and their family need information on the patient’s medical conditions. However, patients might not be informed of their serious medical conditions and involved in decision making. Lack of training and culturally appropriate guidelines are part of the reasons for withholding serious medical news. Health professionals have not had formal training on breaking bad news in Ethiopia and this calls for intervention

(Pereira et al 2016:45). Evidence verified that culture influences the ways in which bad news is conveyed. The current guidelines for breaking bad news are limited for application in communities that have diverse cultures. In addition, the current and available guidelines for breaking bad news seem quite limited for the Ethiopian cultural context.

5.3 DEFINITIONS OF GUIDELINES, BAD NEWS AND BREAKING BAD NEWS

A culturally sensitive guidelines is defined in this context as principles, information, suggestions and steps developed that are based on cultural values, beliefs and patient preferences pertaining to the delivery of bad news.

In this study, bad news is described by healthcare professionals as a diagnosis of serious illness, of the limitations pertaining to treatment and the likelihood of loss of life (Muneer et al 2018:3; Nasrabadi et al 2020:3). Thus, bad news is defined as diagnosis of a life-threatening or terminal disease or a poor prognosis that affects the patient's views on life and directions for the future. The delivery of bad news as well as conversations concerning poor prognosis or cessation of disease modifying treatment to patients or family members is therefore understood as breaking bad news (Messerotti et al., 2020:4).

5.4 SCOPE OF THE GUIDELINES FOR BREAKING BAD NEWS

The following steps were taken during the scoping of the guidelines: defining the scope, identifying the parties involved, refining the list of priority topics (key issues identified), searching the literature, sharpening the focus, and formulating key questions, reviewing and reconsidering the disclosure.

Defining the scope: The guidelines is intended for implementation in a facility that cares for patients with life-threatening illnesses such as cancer. The purpose of the guidelines is to assist healthcare professionals in the sensitive delivery of bad news. The guidelines is derived from research results obtained from patients with life-threatening illnesses, community members and healthcare professionals.

The guidelines is primarily designed for use in palliative care settings and ought to be applied at hospitals or palliative care institutions by physicians or nurses or clinical officers. This guideline anticipates divulging diagnosis, prognosis or treatment failure for patients with life-threatening illnesses in a culturally sensitive manner. It promotes serious conversations on the delivery of bad news or serious medical news between healthcare professionals and the patient. Furthermore, it facilitates the relay of information on serious or terminal medical conditions in accordance with the cultures of the patients concerned, and the decisions pertaining to how far the patients could be involved in the medical decisions. However, this guideline is not a “one-size-fits-all” prescript. There should be a recognition of the diversity of cultures in Ethiopia.

5.5 THE PROCESSES TAKEN IN DEVELOPING THE GUIDELINES

The development of guidelines was primarily decided in the research proposal. The study specifically set out to develop a culturally sensitive guidelines based on the results of a qualitative study and literature review. The procedures for this development were detailed in the research proposal, and one of the objectives was to use the *WHO Handbook for Guidelines Development* (WHO 2014:15-18). The following four steps were deployed in the development of the guidelines:

Step 1: The data generated for this study were combined, analysed and themes and subthemes developed and interrogated for cohesion and coherence. The patient preferences and cultural preferences regarding disclosure of bad news were amplified and interrogated. The WHO handbook for developing guidelines provided the directions and issues were explored for full consideration in the development process (WHO 2014). The scope, purpose, audience, implementers and plan of dissemination were repurposed for the ultimate development of the guidelines.

Step 2: The components of the guidelines for breaking bad news were derived from research findings, literature review and existing guidelines. Relevant information was identified and used after reviewing published articles on breaking bad news. The draft guidelines were sent to the supervisors of this study, experts, as well as community members to validate and feedback was incorporated into the final product.

Step 3: The guidelines was tested on a group of healthcare professionals in a purposively selected area. The participants were purposively sampled and orientation was given on the draft guidelines. The participants were subsequently asked to use it in their clinical practice in delivering bad news. Furthermore, the guidelines were disseminated to experts, and community members and feedback was collated by the researcher.

Step 4: The final guidelines was developed after integrating feedback from the experts and community members.

The following diagram summarize the steps taken to develop the guideline (Figure1:1).

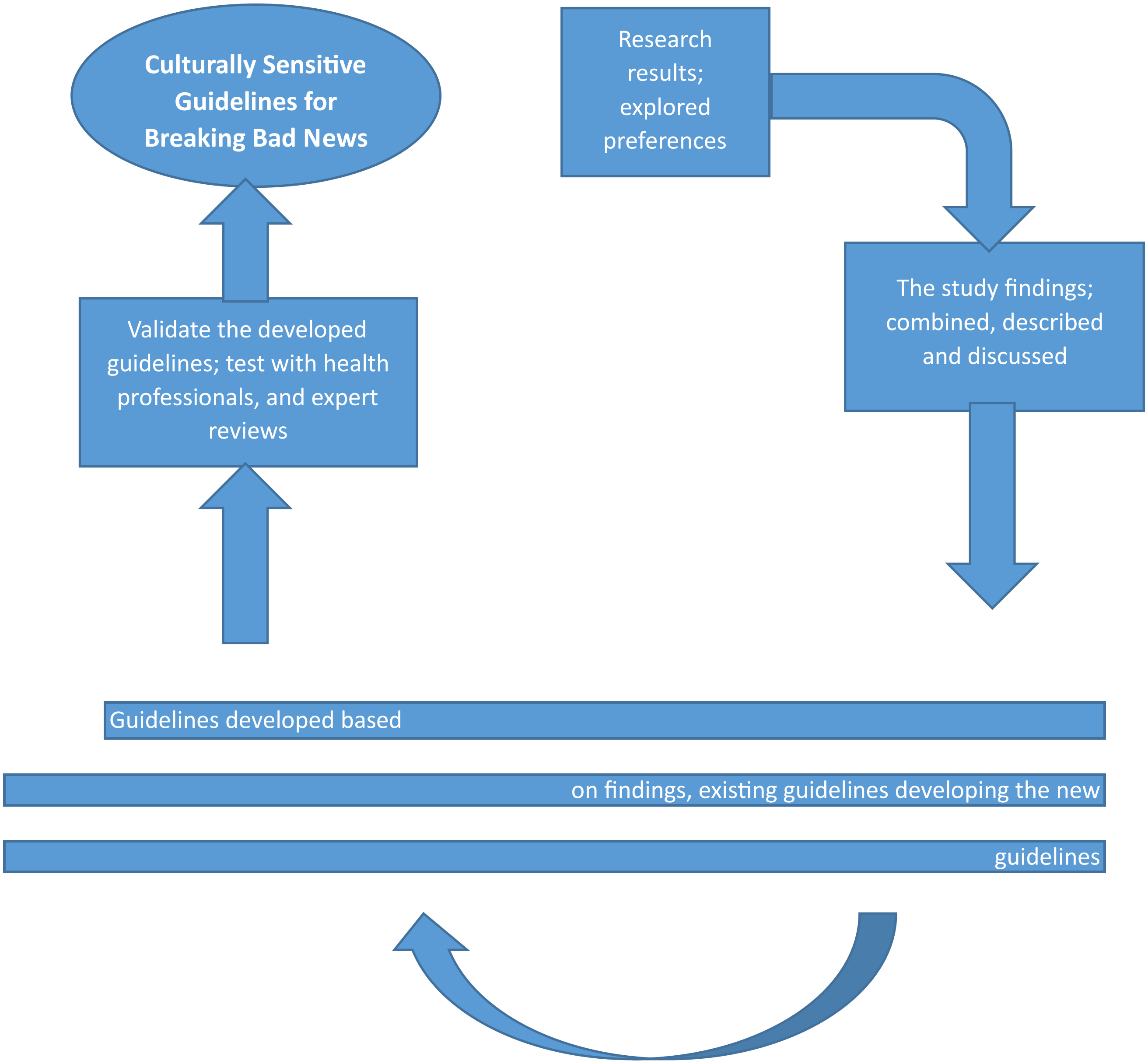


Figure 5.1: The methodological process followed to develop the guidelines

5.6 ISSUES CONSIDERED IN DEVELOPING THE GUIDELINES

The preceding issues were considered based on the WHO Handbook for Developing Guidelines (WHO 2014). The target audience of the guidelines are healthcare professionals such as physicians, nurses and clinical officers working in palliative care settings. These are implementers of the guidelines as they disclose bad news to patients and their families. Patients diagnosed with life-threatening illnesses and their family are the recipients of bad news and therefore comprise the logical targets of the recommended guidelines.

The guideline is designed for dissemination to and implementation at hospitals and palliative care service facilities. The Ethiopian Ministry of Health has developed a 5-year strategic plan for palliative care which entails integrating and expansion and this has been implemented in the hospitals offering palliative care services. This guideline is designed to augment the ministerial ones and further assist in improving the palliative care services already on offer.

The guideline should be printed on glossy and tri-fold brochure paper. Most health professionals can read English and the preferred language for the print version is also in English. The extended recommendation is that the guidelines be translated into the local language, Amharic to enable portability in one's pocket for easy use at work in hospitals and other organisations that provide palliative care. This would also enhance the practical applicability of the guidelines. The brochure should be distributed to respective department heads and healthcare professionals.

Provided that funding is available, the guideline will be printed on a glossy and tri-fold brochure. A short video demonstrating how to break bad news according to the guidelines should be prepared for training.

During the development process of the guidelines, academic supervisors and experts were involved. The guideline was disseminated to the experts for their review and feedback and their feedback was incorporated into the development of the final guideline.

Questions answered in the guidelines:

Questions are useful for establishing a framework for guidelines recommendations (WHO 2014:77). Thus, the following questions were formulated in developing these guidelines.

Background questions:

What is bad news? How common is the task of breaking bad news? What are the perceptions regarding divulging bad news? How is bad news currently communicated?

What are the challenges related to breaking bad news? What are the practices and challenges of breaking bad news?

Key questions:

What are the benefits of culturally sensitive breaking guidelines?

What are the preferences of patients regarding breaking bad news when diagnosed with life-threatening illness?

What information do stakeholders need for breaking bad news when patients are diagnosed with life-threatening illness?

How would prefer to be told about your medical condition?

Who do you think should be the first to receive news regarding your medical condition?

What cultural perspectives should doctors and nurses take into account during disclosure of bad news?

What would you consider the most sensitive constructs for consideration in delivering the bad news to patients?

How much detail would you like to know?

What matters would you prefer not be told?

What are the specific challenges in breaking bad news?

The purpose of the guidelines

The purpose of the guideline is to enhance culturally sensitive practices related to breaking bad news by health professionals in palliative care settings. The guidelines are designed to promote communication with patients when they have to be informed of their illness and prognosis. By consulting the patients and eliciting their preferences, the guidelines incorporate patients' preferences in the dissemination of such messages. This takes into consideration the wellbeing of patients, maintaining patient autonomy and reducing unnecessary costs for patients and their family.

Major objectives of the guideline

The availability of the new guidelines has the following main objectives specifically crafted to:

Promote the delivery of bad news in culturally appropriate way.

Assess the needs of patients and collect information.

Provide care and support for the patients and their families based on their needs.

Assist patients in making informed decisions and reducing their unnecessary costs.

Allow patients to understand complex information about their medical complications.

Help patients and their families make better medical decisions.

Minimise the emotional and psychological pain arising from bad news disclosure through culturally insensitive ways.

Build rapport and improve patients' satisfaction in palliative care and bad news conversations.

Assist health professionals in the process of breaking bad news.

5.7 VALIDATION OF THE GUIDELINES

The guidelines were shared with experts, community members, and academic supervisors for validation. Participants were selected purposively based on their expertise and experience in the field of palliative care and guideline development. A total of nine people were involved for validating the guideline comprising two community members, two nurses and four physicians trained and working in palliative care settings in a public hospital and palliative care organisation, and one physician working for the Ministry of Health and in palliative care.

The guidelines was sent to the experts who were requested to review critically and send feedback on its feasibility, cultural sensitivity and applicability. Moreover, two of the healthcare professionals applied the guidelines to test in their palliative care practice. Their feedback, criticism and suggestions were received and incorporated in reviewing the guidelines. In addition to written feedback, debriefing was made with five of them for further opinions and elaboration on their feedback. The guidelines were accepted and its significance was underlined by the experts. In addition, important criticisms were also provided for improving its sensitivity. Some of the main suggestions emphasised learning from traditional ways of informing about death of a family member, where “Merdo” was recommended - the presence of a religious father when possible, using mnemonics to remember the steps, adding additional examples of phrases and questions to assess patient needs, emphasis on the family role, using the local language directly, specifically terms such as *“Emnet”* rather than the English term, “*Ash”,* and listing the common emotional reactions when bad news is communicated.

Table 5.1: Biographic background of experts and people who validated the guidelines

Professional background	Service year	Area of expertise	Remark
Physician	30 years	Internal medicine, researcher and trained in palliative care. Involved in developing various national guidelines and manuals including palliative care, pain, and noncommunicable disease. Trainer of healthcare professionals in palliative care. Working closely with the Ministry of Health.	
Physician	5 years	Family medicine, trained and working in palliative care. Teaching staff at college, and trainer of healthcare professionals in palliative care	
Physician	6 years	General practitioner. Involved in developing national palliative care and pain management guidelines, and train healthcare professionals in palliative care. Working closely with the Ministry of Health.	
Physician	8 years	General practitioner. Involved in developing national palliative care and pain management guidelines and manuals, train healthcare professionals in palliative care. Working for the Ministry of Health.	
Physician	6 years	Oncologist, trained on palliative care.	

Nurse (BSc)	8 years	Trained and working on palliative care setting. Teaching staff at University. Involved in developing national palliative care and pain management guidelines, and train healthcare professionals in palliative care.	
Nurse (BSc)	7 years	Trained and working on palliative care setting.	
Accountant	16 years	Volunteer with charity and actively participate in his village as a volunteer committee.	Community member
Project coordinator	30 years	Member of church elder, and Iddir	Community member

5.8 CULTURALLY SENSITIVE GUIDELINES FOR DELIVERING BAD NEWS

Background

Informing patients of their medical results, the illness and treatment outcomes are the task of health professionals, regardless of the difficulties. Medical ethics and principles of biomedical ethics prescribe how patients must be treated with respect that recognises their unique identities (Healthcare Ethics and Law, 2021). Full disclosure of serious medical news to the patient is a standard practice in the Northern Hemisphere, as one of the ethical principles is the patient's right to choose treatment and make informed decisions about their own health or life (Varkey 2021:20).

Ethical principles, however, can be influenced by cultures. The collective life is predominant culture within the Ethiopian community. Healthcare professionals may encounter a dilemma of cultural influence and maintaining the medical ethics of patient autonomy. Understanding the cultural needs and how to approach the divulging of bad news is paramount to customize ethics with the patient needs. Virtually all of the patient participants reported that they preferred disclosure of their illness in this study. Similarly, multiple evidence suggests that in Ethiopia, the majority of patients prefer to be notified of their serious medical conditions (Fisseha et al 2020:1021; Woldemariam et al 2021:1344). Nevertheless, current practice is that serious medical news is concealed from patients (Kebede et al 2020:8). Similarly, this study revealed verified that patients did not get adequate information on their medical condition.

Withholding the bad news and poor communication of bad news exert an adverse impact on both the patient and family. The benefits of being informed of her illness helps the patient in making informed medical decisions, reduce distress, and complete the unfinished business. In addition, disclosure has the advantage of minimising or avoiding costs on futile treatments. Evidence suggests that integrating palliative care into hospital care reduces medical costs (Kremenova et al., 2022:1092). This cannot be achieved without conversations on bad news with patients and their families. Breaking bad news also opens the door to discuss emotional issues, psychological pain, distress, fears, and the procedures in getting help. When family and healthcare professionals share the bad news with the patient and involve them in treatment decisions, such an approach reduces the psychological and emotional burden of family and health workers as well: *"The burden would be shared by the patient, the caregiver and the doctor" (I12P12HCPDR).* Furthermore, this study discovered that patients benefit from religious rituals that are supposed to be performed near the end of life.

Despite a majority of healthcare professionals believing that patients have the right to know their illness, they do not apply it. Lack of skill, culturally adaptive guidelines and training are among the barriers in the proper disclosure of bad news (Gan et al 2018:1460). In addition, healthcare professionals disclose bad news without having adequate training and most of them learn about the disclosure of bad news through observation when their seniors or others do it (Messerotti et al 2020:7; Sarwar et al 2019:697). The need for locally adapted protocols relating to bad news disclosure is apparent and evidence calls for urgent availability of culturally sensitive guidelines for breaking bad news (Abazari et al 2017; Pereira et al 2016).

The following guidelines were devised on the basis of the results of this research that strove to understand cultural preferences concerning disclosure of bad news, and literature review. The structure of the guidelines was informed by the study results. There are guidelines for breaking bad news that are published in different journals (Abazari et al 2017; Baig et al 2018; Buckman 2005; Holmes and Illing 2020; Pereira et al 2016). These articles were reviewed in the process of developing the new guidelines for the Ethiopian context.

The presented guidelines pertain to information, principles and suggested stepwise approaches for breaking bad news. It emphasizes planning, making thorough assessment about the circumstances of the patient and needs, preparing the patient before breaking the bad news and delivering bad news as a process. Building an amiable relationship and therapeutic communication is paramount for the disclosure. A roundabout, gradual, sympathetic and sensitive approach that is culturally nuanced suggested methods of telling bad news. There are lessons to learn from the "Merdo", creed and the traditional way of telling the family about death. Using comforting words, culturally suitable phrases, reassurance and encouraging the religious rituals to keep faith in their Creator/God are central to maintaining hope and cultural values when telling bad news. The common emotional reaction and the suggested supportive care are also discussed within the guidelines. The guidelines has six steps and can be memorized through a simple mnemonics - PAPDAS - by taking the first letter of each of the steps (See Table 10). This guideline recommends divulging bad news step-by-step and considering the serious nature of the conversations.

Table 5.2: Six steps for delivering bad news as mnemonics – PAPDAS

PAPDAS	
P	Planning for delivering bad news
A	Assess the needs and other circumstances
P	Preparing the patient
D	Disclose the bad news
A	Alleviate emotional pain
S	Summary and set up follow-up visits

Step one:
Planning for delivering bad news

Before breaking bad news, healthcare professionals should plan ahead of time. Do not break bad news because you have to do it or because it is your job, but with due attention, carefully and sensitively (Mannix, 2021:38). Effective communication can be affected by poor physical setting, noise, emotions, level of relationship and perceptions. Bear in mind how most people perceive about life-threatening illness such as cancer and traditional views of telling bad news.

Planning and implementing breaking bad news guidelines may be deterred by poor setting and workload. The physical setting and the time of disclosure should also be worked out beforehand. While the medical investigation is underway, plans for a better time, place, and situation can be made. Ensure there are chairs for patient and family members to sit comfortably. The physical setting may be a challenge to emotional reactions, so to overcome these, a bed side screen may be prepared. Moreover, a quiet environment should be created to avoid excessive sound outside of the examination room. A sign notifying people to reduce their noise could be posted in the waiting area. Most health professionals have a heavy workload such that this phase assists in identifying a suitable time to communicate bad news. It is important to identify and plan who should be involved; which family member and professionals should be there. It is recommended to disclose bad news as integrated part of the work with good skill.

Preparation includes gathering evidence to confirm the medical diagnosis and stages of the disease. Bad news can be unpleasant and causes sadness not only for the patient or family, but also to the deliverer. When bad news is delivered, the health professional may experience emotional and psychological trauma. It is therefore important to be prepared psychologically and emotionally. Self-awareness is also important to understand one's character, beliefs, and how to respond to sad reactions and anticipate reactions that influence your emotions in dealing with intense conversations directed at helping the patient.

The attending healthcare professional is supposed to build a good rapport with the patient and the family. This step may begin at the time of meeting with the patient and involving them during the processing of setting the diagnosis or prognosis.

The traditional approach for telling bad news such as the death of family member, “Merdo” is performed sensitively, sympathetically and with due care for the family member. The bad news should be disclosed during the daytime. It is usually done in a group. The tellers might be elders or respected persons. They discuss how to tell and they select a convenient place. They also ensure that a close family is present and the recipient is sat down to avoid physical injury, should they be shocked. They go around before actually telling the bad news i.e., the death. They could commence by saying, “As it is known, people live and die when the due time comes. What can we do if the day comes?” They select appropriate terms to minimize the emotional shock. They use words suggesting that the person has moved into a higher realm rather than that the person is dead. They also share the grief and give care and support the bereaved family.

Tips for checking planning

Set the aim of delivery of bad news. It is critical to ensure the physical setting conducive, there is a chair for the patient and family members, there is tissue paper ready and that the room for such disclosure is available. There is need to consider carefully the time of disclosure, who should be involved from the medical cohort and the multidisciplinary approach involving a nurse or social worker or mental health professional. There must medical evidence collated to link the current patient’s case to previous medical experiences in case there is neeed to reassure the patient. The team must be ready for blunt questions from the patient and they should be prepared for reasonable responses.

Step two

Assess the needs and other circumstances

This second step assists the healthcare professional in gathering pertinent information about the patient's cultural beliefs and preferences, deciding who to tell; patient or family first or together and how much information to provide. Evaluation should be done regarding what information the patient has been told by other health workers, the patient’s level of understanding information, attitude about illness, religious beliefs, educational background, general behaviour, person's family status, cultural background and residency whether urban or rural. There is also a need to assess how the patient and family perceive health, and serious medical illness such as cancer.

The literacy rate in Ethiopia is low, and access to mass media is limited in the rural part of the country. Thus, patients who come from the rural areas of the nation might not have sufficient information or understanding of life-threatening illness. Illiterate persons might take longer time to understand information. They may want their family or healthcare professional support to make informed decisions. If the patient is from a rural locale, the possibility of understanding the problem fully is low, so the patient should be asked to delegate a family member to get involved. When any information regarding the patient is needed the accompanying family could be the source of information.

Understanding the patient's need is important to provide person-centred care. Despite the fact that patients with life-threatening illness come to hospital when they are already at an advanced stage of illness in Ethiopia, (Tesfaw, Demis, Munye & Ashuro 2020:1396), the patient may come in the full hope and expectation of a cure. If this is the first visit to hospital, it can make the delivery of bad news difficult, or even striking a balance between telling the bad news and achieving the patient's expectation or wish for cure. If the patient has already seen a couple of physicians after having some kind of treatment or interventions, they may present with either partial information or misinformation on their disease diagnosis and/ or progress of their illness or in denial. Patients may also know the diagnosis, but not the poor prognosis.

Patients commonly present to hospitals with a family member or friends, so it would be beneficial to inquire about the relationship. Furthermore, the patient should be asked who would present with him when talking about the results of medical investigations, medical conditions, treatment plans and any serious conversations. The patient's and family's needs for information should also be assessed as most patients may not ask any probing questions related to their illness.

Thorough assessment on the need for information, the amount of information and the timeliness of disclosure should be concluded before the moment of disclosure.

Religious belief informs the sense of meaning in life and is a source of hope for a community like Ethiopia (Hussein 2016:34). People believe that bad spirits or other religious factors can cause illness and they hope to be cured by following their religious convictions and rituals (Gebremariam et al 2019:6). This belief should be respected. It is worthwhile to assess the expectation from the treatment as many patients prefer focusing on favourable outcomes. Assess if the patient has unrealistic hopeful thinking that can affect the patient plan. A patient with advanced illness, but who has not been informed of the condition might shop hospitals or plans for treatment abroad. Patients in denial or adhering to their religious beliefs and faith may want to see the favourable side of the situation and even full cure.

Find out what the patient does or relies on in terms of religious convictions to overcome challenges associated his disease. Often, patients try religious rituals such as prayers, "Tsebel", "Emnet", Kibakidus" or visit traditional healers prior to conventional medical treatments. This might assist to know their perceptions, expectations, wishes and behaviour. Therefore, careful assessment allows the health professional to learn about the patient's and family's circumstances and views. You can look for any sign for religious beliefs such as cross with black thread is a sign for Orthodox Christian, Hijab for Muslim female head covering or ask to which religion they subscribe. Explain the reason for asking and mention that your intention is to integrate their religious belief into the provision of care and support.

There is insufficient documentation of serious conversations between the health professional and the patient and family. However, a written note should be used when delivering bad news. This also helps to communicate among colleagues, prevent repeating questions and upsetting the patient.

An amiable approach is preferred in establishing a good rapport and trust between the patient, family and healthcare professional. Most patients prefer healthcare professionals who are easily approachable according to the findings of this study.

This consolidates the findings of an Australian research that reported friendly approach of health workers created therapeutic rapport (Bradshaw, Siddiqui, Greenfield & Sharma 2022:3). Health professionals should take the initiative to build a good relationship and the following suggestions create conducive communication process:

Identify and talk about the patient and family about their main concerns and expectations; while taking care of the patient, be involved and connected to the situation of the patient and the family; the relationship can be developed through care, interactions and sharing of ideas and information; being too formal might be a barrier to sharing feelings and thoughts. It is crucial to establish good relationship through giving optimum time for interaction and listening to the patient and family to understand their concerns. This allows them to feel at ease and share their thoughts or concerns or feelings. Respect, honesty, care, sympathy listening, asking for preferences, responding to complaints, and not being judgmental are essential attributes for the occasion of reporting bad news to patients and family.

Tips for needs assessment

Ask the patient what they have been told or understood of earlier given information.

Would you like to get all your laboratory results?

Who would you like be present when we talk about your medical condition or the laboratory test results?

How much information would you prefer to be disclosed on your illness?
What information would you prefer not to be disclosed for you? Is there anybody you would prefer delegating if you are personally intimidated of the diagnosis?

When would be a suitable time to talk about your condition and treatment plan?

Step three

Preparing the patient

Patients should be psychologically prepared throughout the care, treatment, and divulging process for the bad news. The previous steps and procedures play a role in preparing the patients and their families. If the patient has requested to know or already saw other physicians that could be an indicator of partial preparation on the part of the patient.

The preparation can begin by telling the reason for doing tests, for example x-ray or laboratory tests or MRI or CT scan. It is advisable to provide information on what you are suspecting when you send for serious laboratory tests or imaging as that confirms a serious diagnosis or prognosis, and this should be done sensitively. Once the evidence is collected about the illness, sensitize the patient. There may be a general talk such as if they have knowledge of other sick persons and if the patient suspects any chronic illness. Give warning information in the early stages of breaking bad news that helps to reduce the emotional shock of such disclosure (Brown et al 2017:6). This should be done empathetically by using euphemism such as “tumor.” Tell the patient and family that the test results could be either bad or fairly good. You may say “the result shows you have tumor, but it seems it has changed to something bad. We will need to investigate further and discuss sometimes later.” You might ask if the patient has already been given any information by other physicians; what they have been told by previous doctors and then proceed to skip to step four and divulge the bad news, if the patient is ready to know the situation at this stage. All the above-mentioned actions and this step facilitate to minimize the load of information and distress when bad news is ultimately disclosed.

Accommodation of family needs

There are ethical and cultural dilemmas when news is disclosed to the family member. First, there is a need to breach patient autonomy, if the patient hears first the cultural preferences may not be maintained and you breach family trust. This is the common challenge that healthcare professionals encounter in breaking bad news.

Family care givers play a fundamental role in the decision process as well as caring for patients in the Ethiopian context. It requires due attention when breaking bad news to them. Mostly, family want to withhold the bad news from the patient and it is a challenging time for health professionals who would then have to balance the family wish with the patient’s right.

Family member might receive the bad news first and help to convey this to the patient. If they refuse, the medical practitioner would need to ascertain why the reservation: "Why do you want the patient not to be informed of the bad news?" Often, family members want to withhold information because they are afraid of the patient losing hope, experiencing shock, aggravating the illness, and experiencing emotional (Ayers et al 2017:4). If they want to take time, allow and ask them to review their decision. Negotiate with the family; take the time to discuss the benefits of telling the patient to accommodate their needs as well as customize the culture. Healthcare professionals should help family to see the benefits of full disclosure to the patient.

This could be done by assuring how much you care for the patient when you tell and the use of acceptable approaches. Inform that mostly patients want to hear of their illness, and that you break bad news if the patient is willing to receive such. It is also useful to disclose the downsides of hiding information from the patient including the patient's right to know, causing distress, feeling of loneliness and uncertainty.

It is advisable to inform the patient of the need to fulfill his sacred rituals such as, “Nuzaze”, (writing a will) “Neseha” (confession), “Erk” (expression of regret), “Mekureb” (communion), rituals that address their concerns, fears and worries. As medical practitioner, there is need to ensure that there is a plan to help, if there are any issues arising and you involve them to help the patient. Inform them that the benefit of telling the patient also include reducing the burden from the family member as they may make serious decisions on behalf of the patient. This can put them in a dilemma what to choose, and regret their decision if the patient's needs are not well identified. Involving the patient in the care and decision reduce the patient's distress and assure that he maintains his dignity. You should tell them that family and healthcare professionals should work to meet the patient needs and preferences. Questions like “Should we do what the patient wants or what we want?” “Should we satisfy our wishes or the patient's?” could all suffice to maintain the hopes in the patient.

This approach for breaking bad news takes into account the family through an evaluation of the patient needs and consent. A patient can be asked whether they would personally want to be involved or who else they would prefer at the moment of disclosure of the medical condition or serious conversations. The team could ask: “We need to discuss about the results of your medical investigations and your conditions. In this case, would you like one of your family to be involved? If yes, who do you want to be involved? Who would be the best person for you to talk with us? Would you give us the name and introduce them? This consent can be done either verbally or written. A brief written note on this delegation of responsibility on the patient chart in the local language and signed by the patient should suffice for the ethical conduct regarding accountability of confidentiality and autonomy while maintaining the cultural needs.

When the family agrees, the patient should be informed in the presence of the designated family member. However, there could be a challenge if the family still insists on withholding the truth or refuse telling the patient of the ultimate diagnosis. As such condition, the patient’s right to know or autonomy should be respected. The following steps should be followed in the disclosure to the patient.

Step four

Disclose the bad news

This study verified that patients want to receive bad news in the company of their families. Fisseha et al (2020:1021); Krieger, Salm, Dresen & Cecon (2022:5) and Woldemariam et al (2021:1344) reached similar conclusions. When possible and applicable, the presence of a chaplain is culturally preferred. Some patients may not want to know their condition or they may want to delegate their family member. If the patient has expressed an interest in knowing, it makes bad news disclosure easier. Commonly patient inquiries range from: "What is my problem? What exactly is my disease? Why am I not making good progress? I was wondering if I could see a doctor who would tell me the exact problem.” All of these queries relate to a patient who is eager to clarify and know their status.

It is critical to decide how much to tell while delivering bad news, and the fact that hope needs to be maintained. Both the health workers and the patient and family should sit down when divulging bad news. Ask the patient whether they are ready for conversations on their medical condition, who he wants to be with him or whether he wants to make it another time. If the patient is keen to know or ready and the family is present, share small information of the bad news. This study confirmed that patients want to be informed step by step. This is similar to findings in a study by Brown et al (2017:6) who identified the need for incremental information on the patient’s medical condition. There is ultimately a need to give space for the patient to reflect after disclosure of the bad news.

There are times that the patient has to consent before administrating therapy, but they may be interested in knowing the situation. If the patient refuses to discuss their condition, it is advisable to respect their choice. Meanwhile, it becomes critical to inform the patient of the possible benefits and giving them time to think about it. Make sure you are accessible and glad to discuss the next time they are ready or has altered his/her mind. If the patient continues to refuse to hear the bad news, request to delegate and inform a family member.

Be aware that the medical information is not only bad but new and unexpected information. Use phrases like “Your test result shows that your illness is like a cancer”, for example instead of blurting the exact medical condition. If it is the first time for the patient to hear, tell only the diagnosis and postpone talking on prognosis. However, this could be changed according to the patient’s situation, needs of information, urgency of the treatment and other social factors. Most patients and family want to get more information on the diagnosis, the illness and possible treatments. A portion of information may be given on the treatment options. It is important not to give too much information at the first time of disclosure unless otherwise requested. Patients get shocked and experience other distressful emotional feelings in the face of the bad news (Krieger et al 2022:5).

The person's beliefs, values, and attitude all influence how they convey the message. According to the preferred approaches, going around the problem, using religious phrases, and telling sensitively should be taken into account when telling the truth. It is always advisable to use an amenable approach, and not burst it out straightway. Make sure distressing symptoms are managed and the patient is not in pain. While delivering bad news, it is helpful for the patient to use generally religious sounding phrases; God knows what is going on… All things are possible with God as there is nothing beyond Him… Despite the medical results, the disease is XXX. Suggest that the patient continue with religious rituals such as prayers, using holy water or going to church or the Mosque in tandem with their prescribed medical treatment.

Check if the message delivered is fully understood. Help the patient to understand what the diagnosed disease means and give time for the patient to reflect. If the patient and/or family is in a significant emotional shock, another time may be set for detailed discussion. Some of the patients showed that they have received treatments without understanding its advantages and disadvantages. Giving time for the patient to recover from emotional shock could facilitate to remember the information and involve the patient in the decision process and make the right decision.

When delivering bad news, the conversation may either open or close the patient's appetite to the bad news conversation. Furthermore, if the conversation at the start is done correctly, it helps to prepare and open the floor for consecutive conversations (Mannix, 2021:24). Start your conversation by greeting and by standing to show respect.

Cultural phrases for greetings such as "*Tena yistelegn" "Selam lerso yihun*" (peace be up on you) *"Endet aderu/ Endet walu"* (greetings during morning or afternoon) should be used. Effective communication requires addressing the patient by name and selfintroduction (Custer et al 2019:3). Call the patient by name and give warm greetings as this bestows some respect. Ask general questions: "How the night", "was How the day was?" "How are you dealing with issues?" "How the family is is doing". This could be a bridge to conversations on medical complications. Use words that evince respect such as "Antu" "Erso" during such conversations. Introduce yourself, the team and explain your team's responsibility, allowing the patient also to introduce themselves. The basic demographic information such as name, age, sex and residence could be extracted from the patient chart. Open-ended questions have the advantage of eliciting detailed information and provide the patient some opportunity to express feelings and emotions freely (Mannix 2021:56). Using open-ended questions provides space and opportunity to explore other aspects of background such as educational level, religion, culture and so forth. An example of a question would be: "What is your highest educational achievement?" Where were you born and raised?" "What is your profession and what do you do for a living?" "Tell me about your family."

In summary, the following principles, questions and suggestions should be followed when divulging bad news to a patient:

i) Do not divulge bad news abruptly; you need to break the ice or give a snapshot by initiating a conversation: "You might be aware that every person gets unwell and some diseases could be quite complex. This happens to any of us…" The conversation leads below might be used for further dialogue:

What would you think if we discussed the possible consequences of your disease now?

Would you like to know what your illness means from this point onwards?

I would like to talk to you about your illness now, would this be the right time for you?

Are you ready to talk about your medical condition today?

If the patient is ready, then you could deliver the bad news clearly and concisely:

"According to the test results, there is a serious complication in your liver". You could proceed further and hint at the truth by using the right medical term of the disease. It is necessary to give the patient some space after divulging the bad news. You would need to explain what the prognosis means briefly and give space for the patient to reflect and take in the ramifications. It is advisable not overload either the patient or the family with excessive information. When presenting the diagnosis, you could present possibilities that you can "cure" the disease, or that you are prepared to offer the best to control the patient's "tumour or cancer." Such conversations on stopping the spread of the tumour certainly livens the patient, offering some hope that the problem could be brought under control, difficult though this could be.

ii) Active listening is vital in understanding the patient's needs and their position; it is a therapeutic response to emotional pain as well (Bradshaw et al., 2022:4). Medical practitioners should:

- Anticipate and pay attention to the emotional reactions of the patients. It is advised to follow step five in alleviating the emotional pain.

- Use comforting words to reassure; “Ayzoh/sh” and align with general faith-based terms such as God knows the future; God give you the strength and courage. It is my prayer that God assist you. A diagnosis of this nature does not mean a death sentence: be hopeful.

iii) Ask if the diagnosis and its implications are fully understood before commencing with treatment. It is advisable to be cautious in further communication following the disclosure of bad news. Literature demonstrates that non-essential and ineffective messages may not be remembered by a patient under the duress of disclosure (Krieger et al 2022:5). It is recommended to avoid medical jargon, and any language other than what the patient understands. Questions to check for understanding ought to be actively pursued, such as rephrasing and asking whether the patient understands the message. In most cases, there could be need to repeat instructions and messages.

iv) Illustrate and discuss the treatment options and plans if the patient is ready. Do not push decisions immediately unless emergency intervention is needed. If any other factors determine decisions on some issues at the same time, give the patient time to recover from the emotional shock arising from disclosure, and allow for clarification questions that could arise.

Telling poor prognosis or the advanced stage of an illness calls for diligent attention and some patients may prefer handing over the conversation on decisions and future plans to their family. Poor prognosis or transition from curative treatments to end-of-life care should be discussed progressively with family members. Individual preferences should be considered and consent to tell family should be taken. However, a patient might be asked if they have questions or matters that they would want to know about their current ailment. Based on the needs, the patient might be informed of the poor prognosis or further information on the medical condition. From the results of this study, talking about prognostication is culturally sensitive, and the preferenc lies in telling the family, even though individual preferences might differ. A study in Ethiopia confirmed that the majority of patients are not keen to know poor prognosis of their illness but would rather have their family informed of the disease prognostication (Woldemariam et al 2021:1344). Medical practitioners are advised to desist from pronouncing that the disease affecting the patient is lethal. Both patients and family are never ready to hear how much time the patient stll has before the terminal end. Thus, prognostications could be disclosed to the family. When medical practitioners talk about prognostication, they may tell how long some other patients survived with the same illness based on evidence, if only requested.

Death and dying should not be openly communicated with patients who have life threatening illness. Treatment failure, poor prognosis or turning the focus on end-of-life care is preferably communicated with family that the results in this study suggest that telling prognostication is not culturally acceptable. However, if the patient inquires into their status, then the suggestion is that family could convey such prognosis with acute sensitivity.

The recommendation is to begin with questioning when telling the family would be warranted; considering what you think about the patient's condition and whether you ever disclosed the level of the illness to other patients in the past. It is crucial to keep in mind that, culturally, most patients do not wish to be told when they are likely to die.

It is advised to specify the level of the disease concisely, indicating that the disease at this stage cannot be medically treated. When telling the prognosis, commonly used and culturally acceptable ways that maintain hope, encouragement and reassurance should be utilised:

The Creator heals in miracles. Maintain your hope in God. We ought not to give up on the Creator.

It is advisable to encourage the patient to use both conventional treatments and religious rituals or remedies simultaneously.

The patient's family might be informed first as they provide care for the patient or they might have been informed prior to disclosure to the patient. Depending on the situation, disclosure might be done with family members first, convincing them to tell the bad news to the patient, and then with the patient and family. It is pertinent to query why why the family would prefer withholding disclosure. It becomes necessary to assure the family that bad news must be disclosed in so far as it benefits the patient. The benefits include information on medical treatment, psychological distress and uncertainty. It is important to allay the anxiety of the patient as disclosure prepares them for time to fulfill his sacred rites. Furthermore, ensure the medical professionals must not push for disclosure should the patient be unwilling to get the bleak prognosis.

Step five

Alleviate emotional pain

Religious convictions and faith, family, neighbours, the support of friends and healthcare professionals collectively assist in overcoming the effects following the disclosure of bad news in this study. Evidence shows that a lack of sufficient emotional support is linked to depression and a low quality of life. Thus, emotional help should be provided to improve the quality of life and overcome the psychological impact.

The patient should be provided with adequate time to recover from the emotional shock prior to commencing on treatment. Emotional reactions need to receive due attention. Listening is a vital communication skill in rejuvenating the patient from the sadness and possible depression induced by disclosure. Medical professionals should be wary of the common emotional reactions such as silence. Should these be manifest, then urgent reassurance and emmpathy are important responses to alleviate emotional pain. Use generally culturally accepted phrases and comforting words. Emotional support could be delivered through sympathy, validating the feelings, reassurance, encouragement, listening and nonverbal facial expression and gentle caressing (Healthline, 2023).

The following are the common emotional reactions that patients reported in this study:

Shock, desperation, feeling upset, feeling numb, loss of appetite, falling, lack of interest to interact with people including family members, and transferring anger to family or close friends, or healthcare workers. A study by Krieger et al (2022:5) revealed that shock, disbelief, depression, anger, fear, denial and helplessness were emotional responses of patients upon reception of bad news. There is a call to assist in maintaining hope while facing the difficult situation. Professionals must give full attention, listening and encouraging to facilitate hope. Therapeutic communication is fundamental for the emotional care of patients. Patient may be helped to keep doing routine functional activities while managing the manifest symptoms. Palliative care does not merely help to relieve the patient's suffering but also facilitates in the relief from emotional worries and distress. This also builds rapport.

Patients cope with their problems differently. Denial should be accepted as a normal coping mechanism and unique for the individual journey. Patients may blame the devil or rely on the delusion that they could be healed by prayer or some religious rituals. Denial is a normal coping mechanism among patients as reaction to the unexpected serious news or terminal illness.

Effective and culturally sensitive communication influences the uptake of information and coping with the disease. These constructs of communication offer emotional support to patients and their families. Establishing a harmonious relationship and trust are crucial in assisting patients physically, psychologically and emotionally towards the ultimate goal of recuperation and mere coping (Bradshaw et al 2022:3). Hence, providing the necessary information, clinical care and support, good communication with patient and family would help to build trust between patient, family caregiver and health care provider. This approach is therapeutic and aligns with emotional healing and the sense of being valued (Bradshaw et al 2022:3). Furthermore, respect, honesty, sympathy, asking for cultural and religious preferences and responding to concerns and being non-judgmental are much appreciated (Chiatti 2019:345) and can be the means to developing good rapport and trust. This social support scaffolds mental health through therapeutic counseling.

Tips to care for emotional pain

Listening provides emotional and psychological support in as much as it generates good rapport. Emotional support can be offered through social relationships and peer group assistance. A friendly approach is therapeutic for sad emotions.

Patients should be encouraged to maintain religious faith and keep hope in God and sacred rites. In this regard, support from religious organisations is important. The study recommends the following:

- Ask the patient to share feelings, thoughts or nay worries.

- Encourage patients not to give up on God. The Creator knows the future. Moreover, it is appropriate to mention that the disease did not occur due to the patient's curse or sin and could afflict anybody.
- Show your empathy: I am sorry for telling this bad news, I can see this news will affect you, but disclosure helps you in many ways. The medical professional might further explain the benefits of knowing the condition.
- Commonly used phrases in the culture help qin healing the emotional pains and provide support: Everyone lives as far as God allows. Human life is in the hands of God. Having a diagnosis of a life-threatening condition does not necessarily imply immediate death.
- Your non-verbal response is important in garnering emotional support.

Reassure the patient through religious views; God can heal, we are the reason for that.

Advise the patient to take courage - "Ayizosh.". God can work miracles, who knows. Ensure treatment and care are consistent. Hence, inform that comfort, relief from distressing symptoms and suffering and support are provided in spite of the serious illness or poor prognosis. Use comforting words like "Ayzoh" (take a courage).

Ask if there is any thought or worry to share. You may ask how the news feels and allow the patient to reflect feelings. Validate the worldview of the patient by acknowledging the patient's distress and feelings and appreciating the patient's concern. Medical professionals must not evade the fact that the news could be upsetting and hurtful.

Step six

Summary and set up follow-up visits

At the end of any bad news conversation there should be some time to summarize the narrative, ensuring that the patient has understood the disclosure and plans for alternative treatment or care. In this research, patients reported that they appreciated it if their doctor disclosed the bad news intandem with suggesting possible solutions. When bad news is delivered, providing knowledge on treatment possibilities assists patients in overcoming challenges and making informed decisions (Krieger et al 2022:5). Palliative care can be compulsory in case of diagnosis of life-threatening illness. This should be discussed clearly, highlighting the processes recommended for alleviating suffering and anxiety.

It is helpful to fix an appointment for further discussion on treatment options, palliative care and clarify any issues. Even though this might have been done on the occasion of first time disclosure, information provided may not be recalled well, hence the need for reinforcement. Disclosure of such bad news could be shocking and calling for sufficient time to recover. There are circumstances such as the patient’s residence or distance, clinical situation or financial issues that could influence whether to set up another time for further discussion, especially if the patient is unable to return for consultation. Telephone communication and home care visit are options for where applicable.

To this end, bad news disclosure is not a once-off task. It is rather a continuous process to assist patients emotionally and psychologically and answer questions. All information provided on the first day might not be remembered. Detailed information must be provided, uncertainties addressed and patients in denial supported through a series of subsequent conversations. It is important to realise that denial is a normal coping mechanism for some patients. As the disease progresses, there might be a need for solid conversations dedicated to assisting the patient in overcoming the emotional and psychological impact of the news.

5.9. SUMMARY

This chapter explained the rationale for the development of the guidelines for breaking bad news. The scope as well as the validation process were described. Finally, a guidelines for breaking bad news was presented and elaborated, recommending a stepby-step approach for this protocol in the Ethiopian cultural context.

CHAPTER SIX

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

6.1 INTRODUCTION

This chapter terminates the study by proffering a discussion of the research results and recommendations derived from the research questions and results. It presents the limitations, applicability and transferability of the study results.

6.2 CONCLUSION

This research aimed to understand the cultural preferences of Ethiopian community for breaking bad news when diagnosed with a life-threatening illness. Bad news is withheld from the patients as culturally family want to protect the patients from emotional hurt and of the fear of losing hope (Abebe & Abebe 2017:258; Ayers et al 2017:4). However, the results of this study showed that patients with life-threatening illness wish to be informed of their serious medical diagnosis and prognosis, though they have unmet information needs (Fisseha et al 2020:1021). The majority of patients' preferred to be told of their serious medical report in the full company of family and they prefer getting involved in making decisions relating to their serious medical problems. Using holy water, prayers and social support were found to be important cultural values and beliefs. Perceived health and life-threatening illness and cultural values are rooted in religious beliefs. Thus, patients expressed the desire that their religious beliefs be taken into account within the process of breaking bad news. The study also showed breaking bad news is a tough task and undertaking for healthcare professionals. In addition, breaking bad news has the advantages of getting the patient involved in making informed medical decisions on health, fulfilling the patient's needs, respecting their values, reducing unnecessary costs and distress, and sharing the burden. It assists and promotes healthcare professionals in telling serious medical reports by reducing the distinction between medical ethics and cultural preferences, and assisting how to do it. Furthermore, the study confirmed that telling bad news has an advantage of minimizing and avoiding costs on futile treatments in palliative care settings.

Healthcare professionals should follow amiable and gentle approaches when breaking bad news to patients diagnosed with life-threatening illnesses. Furthermore, the incremental, roundabout and sympathetic approaches are the preferred methods of breaking bad news. To this end, based on the study findings, a culturally sensitive guidelines for breaking bad news was developed in an Ethiopian context. The guidelines suggest six steps; planning, assessing patient's needs, preparing the patient, disclosure of bad news, assisting with emotional response and follow-up in palliative care settings (PAPDAF).

6.3 RECOMMENDATIONS

For healthcare professionals

Despite being a tough undertaking, breaking bad news cannot be avoided. The entire process requires training for the ultimate development of effective and culturally sensitive communication skills. The skills should be anchored on an approach that must be personalised and fully contextualised. Breaking bad news should be done empathetically, sensitively and in accordance with the patient's values and choices. The process should begin as early as possible so that the preferred incremental and roundabout approaches are sensitively applied. The stepwise approach is recommended in the delivery of bad news. The phrases recommended in the guidelines need to be used according to the cultural values of the patient. The role of family is central and should be integrated so that they are involved when bad news is disclosed with the consent of the patients. Family could help the patient financially, physically, emotionallyand psychologically.

For the Ministry of health and the Ministry of education

The occasion of breaking bad news should be foregrounded within the health facility. The training on protocols for breaking bad news should be integrated into the pre-service medical curriculum for the training of physicians, nurses and health officers. A short course on these protocols should be compulsory for all those involved in treating and caring for patients with life-threatening illness.

6.4 CONTRIBUTION OF THE STUDY

This research contributes new knowledge in the medical field, specifically on treating and caring for patients with life-threatening illness. This study extends knowledge on how patients and the community prefer communication related to disclosure when a lifethreatening illness is diagnosed in a palliative care setting in Ethiopia. The findings provide an essential scaffold for hospitals and healthcare professionals to garner insight into the cultural preferences regarding breaking bad news. Furthermore, this study contributes to the care of patients with life-threatening illness in its introduction of new scientific knowledge about the preferences and needs of patients, healthcare professionals and the community around breaking bad news.

The findings from this study have been used to develop a culturally sensitive guidelines for breaking bad news in an Ethiopian context. The guidelines is the first of its kind in Ethiopia, benefitting people diagnosed with life-threatening illness, and healthcare professionals. Moreover, the guideline assists health care professionals in delivering bad news when a life-threatening illness is diagnosed and illness prognosis is considerably bleak. The patient can make informed choice of treatment, and minimize needless costs on futile treatment by allowing them to make informed decisions. Data triangulation was also accomplished through the use of interviews and observations, which enhanced the trustworthiness of the findings.

6.5 LIMITATIONS OF THE STUDY

The study used qualitative research approach to explore cultural issues on the conundrum of breaking bad news. The study recruited small numbers of participants who have sufficient knowledge and experience. Since the sample size is small and purposive sampling was applied, it is not possible to generalise the findings to other contexts and populations. However, trustworthiness of the study was enhanced by maintaining the credibility, dependability, transferability and conformability.

The study was time-consuming and exhibits some bias towards a non-probability purposive sampling technique, which has the inherent disadvantage of subjectivity. In order to circumvent these limitations, the researcher used reflexivity technique, and spent a long time in the field as recommended by Merriam & Grenier (2019:27). Moreover, the researcher triangulated the data collection, described the findings in detail, and member checking methods in tandem with expert reviews for validation of the guidelines (Merriam & Grenier 2019:26).

6.6 SUMMARY

This chapter summarised the choices of patients and community members regarding the protocols in disclosing bad news. These include the desires of the patients to be informed of all serious medical information, and that they be involved in making medically informed decisions. In addition, cultural values, beliefs and protocols of disclosing bad news were outlined. The six-step wise guidelines for disclosing bad news were summarised and recommendations for healthcare professionals and reinstitutes were proffered.

REFERENCES

Abate, A.T., Amdie, F.Z., Bayu, N.H., Gebeyehu, D., & Mariam, T. 2019. Knowledge, attitude and associated factors towards end of life care among nurses working in Amhara referral hospitals, Northwest Ethiopia: A cross-sectional study. *BMC Research Notes,* 12(521): 1-8.

Abathun, E., Mamo, Y., & Reid, E. 2020. Dignified communication in a time of crisis: COVID-19 and the role of palliative care in Ethiopia. *Ethiopian Medical Journal,* 58(4): 377-378.

Abazari, P., Taleghani, F., Header, S., Malekian, A., Mokarian, F., Hakimian, S.M.R., & Ehsani M. 2017. Breaking bad news protocol for cancer disclosure: An Iranian version. *Journal of Medical Ethics and History of Medicine*. 10:1-7.

Abebe, E., & Abebe, H. 2017. Types of cancers diagnosed and the preference of families of adult patients with cancer about disclosing diagnosis to the patient. *J Health Sci*. 27(3):255-262.

Addis Ababa University College of Health Science. http://www.aau.edu.et/chs/tikuranbessa-specialized-hospital/background-of-tikur-anbessa-hospital/ (Accessed 11 November 2020).

African Palliative Care Association. 2021. What is palliative care? African Palliative Care Association: What is palliative care? (Accessed 26th June 2021).

Alemayehu, M., & Meskele, M., 2017. Healthcare decision making autonomy of women from rural districts of Southern Ethiopia: A community based cross-sectional study. *International Journal of Women's Health,* 9:213–221.

Alshami, A., Douedi, S., Avila-Ariyoshi, A., Alazzawi, M., Patel, S., Einav, S., Surani, S., & Varon, J. 2020. Breaking bad news, a pertinent yet still an overlooked skill: An international survey study. *Healthcare*, 8(4): 1-8.

Alzahrani, A.S., Alqahtani, A., Alhazmi, M., Gaafar, R., Bajabir, D., Alharbi, I.M., Alharbi, A.M.F., Kheshaifaty, G., & Alzahrani, A. 2018. Attitudes of cancer patients and their families toward disclosure of cancer diagnosis in Saudi Arabia: A Middle Eastern population example. *Patient Preference and Adherence,* 12: 1659-1666.

Aminiahidashti, H., Mousavi, S.J., & Darzi M.M. 2016. Patients' attitudes toward breaking bad news: A brief report. *Emergency*, 4(1):34-37.

Anderson, B. 2019. Reflecting on the communication process in health care. Part 1: Clinical practice - breaking bad news. *British Journal of Nursing*, 28 (13):858-863.

Anteneh, S., Kassa, H., Demeke, T., & Guadu, T. 2016. Assessment of nurses' knowledge, attitude, practice and associated factors towards palliative care: The case of Amhara region hospitals. *Advances in Biological Research*, 10(2): 110-123.

Anuk, D., & Bahadir, G. 2020. A Challenging Issue for both Patients and Physicians: Breaking Bad News in Oncology. *Turkish Journal of Oncology*, 35(1):114–118.

Arabyat, R., BPharm, & Raisch, D. 2019. Relationships between Social/Emotional Support and Quality of Life, Depression and Disability in Patients with Chronic Obstructive Pulmonary Disease: An Analysis Based on Propensity Score Matching. *Ann. Behav. Med*. 53:918–927.

Arrey, A.E., Bilsen, J., Lacor, P., Deschepper, R. 2016. Spirituality/Religiosity: A Cultural and Psychological Resource among Sub-Saharan African Migrant Women with HIV/AIDS in Belgium. *PlosOne,* 11(7):1-22.

Ayers, N.E, Vydelingum, V., & Arber, A. 2017. An ethnography of managing emotions when talking about life-threatening illness. *International Nursing Review*, 64(4):1-8.

Baig, L., Tanzil, S., Ali, S.K., Shaikh, S., Jamali, S., & Khan, M. 2018. Breaking bad news: A contextual model for Pakistan. *Pak J Med Sci*. 34(6):1336-1340.

Bain, M.G., Lian, C.W., & Thon, C.C. 2020. Breaking bad news of cancer diagnosis – Perception of the cancer patients in a rural community in Malaysia. *South Asian Journal of Cancer,* 3(2):116-121.

Bairagi, V., & Munot, M.V. 2019. *Research Methodology: A Practical and Scientific Approach*. New York. Taylor & Francis Group.

Balboni, T.A., & Balboni, M.J. 2018. The Spiritual Event of Serious Illness. *Journal of Pain and Symptom Management,* 56(5), 816-822.

Banerjeea, S.C., Mannaa, R., Coylea, N., Shena, M.J., Pehrsona, C., Zaidera, T., Hammondsa, S., Kruegera, C.A., Parkera, P.A., & Bylunda, C.L. 2016. Oncology nurses' communication challenges with patients and families: A qualitative study. *Nurse Educ Pract.* 16(1):2-19.

Batten, M., Nguyen, B., Burke, B., Harryanto, H., Mitchell, I., & Davis, A. 2018. End-of-life care of oncology inpatients: Are we getting it right? *Asia-Pacific Journal of Clinical Oncology*, *14*(5), e528-e534.

Be´Langer, E., Rodri´guez, C., Groleau, D., Gare´ F.L., Macdonald, M.E., & Marchand, R. 2016. Patient participation in palliative care decisions: An ethnographic discourse analysis. *International Journal of Qualitative Studies on Health and Well-being*, 11:1-15.

Belay, H.T. 2021. The value of death: Death and dying in Ethiopia. From: Death and dying in Ethiopia – The Value of Death (wordpress.com) (Accessed 21 May 2021).

Berhane, A. 2016. Understanding patient satisfaction: Preferences, expectations and patient rights of practice in public hospital settings for Amhara regional state, Ethiopia. A Dissertation submitted to the School of Graduate Studies of Addis Ababa University in partial fulfillment of the requirements for the Degree of Doctor of Philosophy (Ph.D.) in Public Health. Addis Ababa University.

Berhane, A., & Enquselassie, F. 2016. The lived experiences of patients regarding patients' rights practice at hospitals in Amhara Region, northern Ethiopia. *Patient Intelligence*, 8: 47–55.

Bernard, M., Strasser, F., Gamondi, C., Braunschweig, G., Forster, M., Kaspers-Elekes, K., Veri, S.W., Borasio, G.D., & the SMILE consortium team. 2017. Relationship between Spirituality, Meaning in Life, Psychological Distress, Wish for Hastened Death, and their Influence on Quality of Life in Palliative Care Patients. *Journal of Pain and Symptom Management,* 54(4): 514-522.

Bhattacharya, K. 2017. *Fundamentals of qualitative research*. 1st edition. New York. Routledge.

Biazar, G., Delpasand, K., Farzi, F., Sedighinejad, A., Mirmansouri, A., & Atrkarroushan, Z. 2019. Breaking Bad News: A Valid Concern among Clinicians. *Iran J Psychiatry*, 14(3):198-202.

Bigna, J.J., & Noubiap, J.J. 2019. The rising burden of non-communicable diseases in sub-Saharan Africa. *The Lancet Global Health*, 7(10): 1295-1296. DOI https://doi.org/10.1016/S2214-109X(19)30370-5 (accessed 24th 2020).

Biyazin, T., Yetwale, A., & Fenta, B. 2020. Mode of decision-making in surgical procedures at Jimma medical centre, Jimma, Ethiopia. *J Eval Clin Pract*. 1-7. From: Mode of decision making's approach in surgical procedures at Jimma Medical Centre, Jimma, Ethiopia (wiley.com) (Accessed 4 September 2021).

Bongelli, R., Bertolazzi, A., Piccioni, L., & Burro, R. 2021. Italian onco-haematological patients' preferences in bad news communication: A preliminary investigation. *BMC Cancer*, 21(555):1-19.

Borjalilu, S., Karbakhsh, M., Hosseini, M., Sadighi, S., Kavian, A. 2018. Clinicians' practice and perception of disclosure model for breaking bad news to breast cancer patients. *Archives of Breast Cancer*. 5(1): 15-25.

Bovero, A., Gottardo, F., Botto, R., Tosi, C., Selvatico, M., & Torta, R. 2019. Definition of a good death, attitudes toward death, and feelings of interconnectedness among people taking care of terminally ill patients with cancer: An exploratory study. *American Journal of Hospice & Palliative Medicine*, *37*(5): 343-349.

Bradshaw, J., Siddiqui, N., Greenfield, D., & Sharma, A. 2022. Kindness, Listening, and Connection: Patient and Clinician Key Requirements for Emotional Support in Chronic and Complex Care. *Journal of Patient Experience*, 9: 1-7.

Brink, H., van der Walt, C., & van Rensburg, G. H. 2018. *Fundamentals of research methodology for healthcare professionals.* 4th edition. Juta and Company [Pty] Ltd. https://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=1647445&site=eho st-live&scope=site (Accessed 5 October 2021).

Brown, O., Goliath, V., Rooyen, D.R.M., Aldous, C., & Marais, L.C. 2018. Cultural factors that influence the treatment of osteosarcoma in Zulu patients: Healthcare professionals' perspectives and strategies. *Health SA Gesondheid*, 23(0):2-7.

Buckman, R.A. 2005. Breaking bad news: The S-P-I-K-E-S strategy. Community Oncology. 2(2):138-142.

Burke, P.J. & Soffa, S.J. 2018. *The Elements of Inquiry Research and Methods for a Quality Dissertation.* 2nd edition. New York. Routledge.

Buss, M.K., Rock, L.K., & McCarthy, E.P. 2017. Understanding Palliative Care and Hospice: A review for primary care providers. *Mayo Clin Proc*. 92(2):280-286.

Byrne, C.M., & Morgan, D.D. 2020. Patterns of religiosity, death anxiety, and hope in a population of community dwelling palliative care patients in New Zealand—What gives hope if religion can't? *American Journal of Hospice & Palliative Medicine*, *37*(5), 377-384.

Campbell, J., Buyinza, N., & Hauser, J. 2018. Perspective on care at the end of life at Hospice Africa Uganda. *Journal of Palliative Medicine, 21*(7), 901-906.

Canadian Hospice Palliative Care Association. 2021. Hospice Palliative Care. From: Hospice Palliative Care - Canadian Hospice Palliative Care Association (chpca.ca) (Accessed 26 June 2021).

Cao, W., Qi, X., Yao, T., Han, X., & Feng, X. 2017. How doctors communicate the initial diagnosis of cancer matters: Cancer disclosure and its relationship with patients' hope and trust. *Psycho-Oncology 26:640–648*.

Carduff, E., Kendall, M., & Murray, S.A. 2018. Living and dying with metastatic bowel cancer: Serial in-depth interviews with patients. *European Journal of Cancer Care,* 27(1), e12653.

Centre to Advance Palliative Care. About palliative care. From: Palliative Care Definition | What is Palliative Care | Center to Advance Palliative Care (capc.org) (Accessed 30 June 2021).

Chan, C.M.H., Blanch-Hartigan, D., Taib, N.A., Wee, L.H., Krupat, E., & Meyer, F. 2020. Preferences for patient-centred care among cancer survivors 5 years post-diagnosis. *Patient Education and Counseling*, 103:1601-1605.

Chane, W., Birhanu, B., & Suga, Y. 2020. Quality of informed consent among patients who underwent major surgical procedure in a tertiary care hospital, Addis Ababa, Ethiopia. *Open Access Surgery*.13: 27–33.

Chen, Q., Flaherty, J.H., Guo, J.H., Zhou, Y., Zhang, X.M., & Hu, X.Y. 2017. Attitudes of older Chinese patients toward death and dying. *Journal of Palliative Medicine*, *20*(12), 1389-1394.

Cheng, H.W.B., Chan, O.M.I., Chan, C.H.R., Chan, W.H., Fung, K.S., & Wong, K.Y. 2018. End-of-life characteristics and palliative care provision for patients with motor neuron disease. *American Journal of Hospice & Palliative Medicine*, *35*(6), 847-851.

Chessa, F., & Moreno, F. 2019. Ethical and legal considerations in end-of-life care. *Prim Care Clin Office Pract*. 46:387–398.

Chiatti, B.D. 2019. Culture Care Beliefs and Practices of Ethiopian Immigrants. *Journal of Transcultural Nursing*, *30*(4), 340-349.

CIA.gov. July 2022. From: https://www.cia.gov/the-world-factbook/countries/ethiopia/ (Accessed 1 August 2022).

Ciesielska, M., & Jemielniak, D. 2018. *Qualitative methodologies in organisation studies:* Corey, V.R., & Gwyn, P.G. 2016. Experiences of nurse practitioners in communicating bad news to cancer patients. *Journal of the Advanced Practitioner in Oncology,* 7(5): 485494.

Collins, A., McLachlan, S., & Philip, J. 2017. Communication about palliative care: A phenomenological study exploring patient views and responses to its discussion. Palliative Medicine, 32(1): 133-142.

Court, D. 2018. *Qualitative research and intercultural understanding: Conducting Qualitative Research in Multicultural Settings*. 1st edition. New York. Routledge.

Custer, A., Rein, L., Nguyen, D., Wentworth, K., & Dhamoon A. 2019. Development of a real-time physician– patient communication data collection tool. *BMJ Open Quality,* 8:1-5. Dafallah, M.A., Ragab, E.A., Salih, M.H., Osman, W.N., Mohammed, R.O., Osman, M., Taha, M., & Ahmed, M.H. 2020. Breaking bad news: Awareness and practice among Sudanese doctors. *AIMS Public Health*, 7(4): 758-768.

Dalal, S., & Bruera, E. 2017. End-of-Life Care Matters: Palliative cancer care results in better care and lower costs. *The Oncologist,* 22:1–8.

Definitions.net. Bad news. 2023. From: https://www.definitions.net/definition/bad+news (Accessed 7 August 2023).

Definitions.net. Expert. 2021. From: https://www.definitions.net/definition/expert (Accessed 17 October 2021).

Denzin, N.K., & Lincoln, Y.S. 2018. *Handbook of qualitative research*. 5th edition. London: SAGE.

Dzierżanowski, T., & Kozlowski, M. 2022. Personal fear of their own death and determination of philosophy of life affects the breaking of bad news by internal medicine and palliative care clinicians. *Archives of Medical Science*, *18*(6): 1505-1512.

Engeser, P., Leutgeb, R., Glassman, J., Szecseniy, J., & Laux, G. 2020. Identifying palliative patients in general practice: Focusing on the place of death and the vital role of specialized home palliative care: An observational study. *Journal of Palliative Medicine*, 1-5.

Epstein, R.M., Duberstein, P.R., Fenton, J.J., Fiscella, K., Hoerger, M., Tancredi, D.J., Xing, G., Gramling, R., Mohile, S., Franks, P., Kaesberg, P., Plumb, S., Cipri, C.S., Street R.L, Shields, C.G., Back, A.L., Butow, P., Walczak, A., Tattersall, M., Venuti, A., Sullivan, P., Robinson, M., Hoh, B., Lewis, L., & Kravitz, R.L. 2018. Effect of a Patient-Centred Communication Intervention on Oncologist-Patient Communication, Quality of Life, and Health Care Utilisation in Advanced Cancer: The VOICE Randomised Clinical Trial. *JAMA Oncol*. 3(1): 92-100.

Etafa, W., Wakuma, B., Fetensa, G., Tsegaye, R., Abdisa, E., Oluma, A., Tolossa, T., Mulisa, D., & Takele, T. 2020. Nurses' knowledge about palliative care and attitude towards end- of-life care in public hospitals in Wollega zones: A multicentre crosssectional study. *PlosOne* 15(10): 1-14.

European Association for Palliative Care. What is Palliative Care? From: What We Do – European Association for Palliative Care, EAPC (eapcnet.eu) (Accessed 24 June 2021).

Fan, S., & Hsieh, J. 2020.The experience of do-not-resuscitate orders and end-of-life care discussions among physicians. *International Journal of Environmental Research and Public Health*. 17(18):1-10.

Federal HIV/AIDS Prevention Control Office From: Factsheet | Federal HIV/AIDS Prevention and Control Office (hapco.gov.et) (Accessed 22 November 2021).

Federal Negarit Gazette of the federal democratic republic of Ethiopia. 2014. 20th year. No.11. http://efmhaca.hcmisonline.org/wp-content/uploads/2019/02/Food-Medicine-and-Healthcare-Administration-and-Control-Councils-of-Ministers-Regulation-No-299-2013.pdf (Accessed 7 Augus 2023)

Ferrell, B., Chung, V., Koczywas, M., Borneman, T., Irish, T.L., Ruel, N.H., Azad, N.S., Cooper, R.S., & Smith, T.J. 2020. Spirituality in cancer patients on phase 1 clinical trials Betty. *Psycho-Oncology, 29*(6):1077-1083.

Ferrell, B.R., Temel, J.S., Temin, S., Alesi, E.R., Balboni, T.A., Basch, E.M., Firn, J.I., Paice, J.A., Peppercorn, J.M., Phillips, T., Stovall, E.L., Zimmermann, C., & Smith, T.J. 2017. Integration of palliative care into standard oncology care: American society of clinical oncology clinical practice guideline update. *Journal of Clinical Oncology,* 35(1):96112.

Fisseha, H., Mulugeta, W., Kassu, R.A., Geleta, T., & Desalegn, H. 2020. Perspectives of protocol based breaking bad news among medical patients and physicians in a teaching hospital, Ethiopia. *Ethiop J Health Sci*. 30(6):1017-1026.

Flick, U. 2018. *The SAGE handbook of qualitative data collection*. SAGE Publications Ltd. https://0-www-doi-org.oasis.unisa.ac.za/10.4135/9781526416070 .

Frunză, A., & Sandu, A. 2017. Values grounding the informed consent in medical practice: Theory and practice. *SAGE Open,* 7(4):1-14.

Gade, C.B.N. 2012. What is Ubuntu? Different Interpretations among South Africans of African Descent. *S. Afr. J, Philos.* 31(3):485-503.

Gan, Y., Zheng, L., Yu, N.X., Zhou, G., Miao, M., & Lu, Q. 2018. Why do oncologists hide the truth? Disclosure of cancer diagnoses to patients in China: A multisource assessment using mixed methods. *Psycho-Oncology,* 27(5):1457-1463.

Ganca, L.L., Gwyther, L., Harding, R., & Meiring, M. 2016. What are the communication skills and needs of doctors when communicating a poor prognosis to patients and their families? A qualitative study from South Africa. *South African Medical Journal,* 106(9):940-944.

Gebremariam, A., Addissie, A., Worku, A., Assefa, M., Kantelhardt, E.J., & Jema, A. 2019. Perspectives of patients, family members, and health care providers on late diagnosis of breast cancer in Ethiopia: A qualitative study. *PlosOne,* 14(8):1-14.

Getachew, S., Tesfaw, A., Kaba, M., Wienke, A., Taylor, L., Kantelhardt, E.J., & Addissie, A. 2020. Perceived barriers to early diagnosis of breast cancer in south and southwestern Ethiopia: A qualitative study. *BMC Women's Health,* 20(38):1-8.

Gonc¸alves, J.A.F., Almeida, C., Amorim, J., Baltasar, R., Batista, J., Borrero, Y., Fallé, J.P., Faria, I., Henriques, M., Maia, H., Fernandes, T., Moreira, M., Moreira, S., Neves, C., Ribeiro, A., Santos, A., Silva, F., Soares, S., Sousa, C., Vicente, J., & Xavier, R. 2017. Family physicians' opinions on and difficulties with breaking bad news. *Porto Biomedical Journal,* 2(6): 277-281.

Gorniewicza, J., Floyda, M., Krishnanb, K., Bishopa, T.W., Tudivera, F., & Lang, F. 2017. Breaking bad news to patients with cancer: A randomised control trial of a brief communication skills training module incorporating the stories and preferences of actual patients. *Patient Education and Counseling,* 100: 655–666.

Gramling, R., Stanek, S., Han, P. K. J., Duberstein, P., Quill, T. E., Temel, J. S., Alexander, S. C., Anderson, W. G., Ladwig, S., & Norton, S. A. 2018. Distress due to Prognostic Uncertainty in Palliative Care: Frequency, Distribution, and Outcomes among Hospitalised Patients with Advanced Cancer. *Journal of Palliative Medicine*, *21*(3):315– 321.

Green, J., & Thorogood, N. 2018. Qualitative methods for health research. 4th edition. London:SAGE. https://books.google.com.et/books?hl=en&lr=&id=HUhLDwAAQBAJ&oi=fnd&pg=PP1&dq=Thorogood+%26+Green+2018+&ots=quK4VPOb_M&sig=1Hbg4X6AY7Km_O4Nvyvrrr0VC4g&redir_esc=y#v=onepage&q=Thorogood%20%26%20Green%202018&f=false (accessed 20 June 2020).

Hahne, J., Liang, T., Khoshnood, K., Wang, X., & Li, X. 2020. Breaking bad news about cancer in China: Concerns and conflicts faced by doctors deciding whether to inform patients. *Patient Education and Counseling,* 103. 286–291.

Haileselassie, W., Mulugeta, T., Tigeneh, W., Kaba, M., Labisso, W.L. 2019. The situation of cancer treatment in Ethiopia: Challenges and opportunities. *Journal of Cancer Prevention*, 24(1):33-42.

Hashim, M.J. 2017. Patient-Centred Communication: Basic Skills. *American Family Physicians,* 95(1):29-34.

Healthcare Ethics and Law. 2022. From: *The Four Principles of Biomedical Ethics — Healthcare Ethics and Law* (Accessed 23 August 2022).

Healthline. How to Be Emotionally Supportive. From: Emotional Attraction: 16 FAQs, Signs, and Tips (healthline.com) (Accessed 28 January 2023).

Hennink, M., Hutter, I., & Bailey, A. 2020. *Qualitative research methods*. 2nd edition. London: SAGE.

Higginson, I.J., Daveson, B.A., Morrison, R.S., Yi, D., Meier, D., Smith, M., Ryan, K., McQuillan, R., Johnston, B.M., Normand, C., & BuildCARE. 2017. Social and clinical determinants of preferences and their achievement at the end of life: Prospective cohort study of older adults receiving palliative care in three countries. *BMC Geriatrics,* 17(1):1-14.

Hilário A.P. 2019. Preferences around the disclosure of dying: A vision from Portuguese society. *Palliative and Supportive Care,* 1–6.

Holloway, I., & Galvin, K. 2017. *Qualitative research in nursing and healthcare*. 4th edition. West Sussex: John Wiley.

Holmes, S.N, & Illing, J. 2021. Breaking bad news - Tackling cultural dilemmas. *BMJ Supportive and Palliative Care,* 11. 128–132.

Hospice Ethiopia. 2022. From: https://hospiceethiopia.com/about-us/ (Accessed 9 August 2022).

https://books.google.com.et/books?hl=en&lr=&id=aOK_DwAAQBAJ&oi=fnd&pg=PP13&dq=qualitative+Research+interview+ebooks&ots=hXT_GWMBnG&sig=o9JmnrTnm9Bk06HKaILGyP1LfI&redir_esc=y#v=onepage&q&f=false (Accessed 22 July 2020).

https://www.bing.com/images/search?q=map+of+addis+ababa+city&id=B0F29ABA8F1 BCEF8BE324352CECFFECEEF9962D9&form=IQFRBA&first=1&tsc=ImageHover Title (Accessed 31 August 2022).

https://www.merriam-webster.com/dictionary/health%20care (Accessed 17 October 2021).

https://www.merriam-webster.com/dictionary/life-threatening (Accessed 17 October 2021).

Hussein, J.W. 2016. The social–psychological and phenomenological constructs of spirituality in the culture of dhikr in Eastern Ethiopia. *Culture & Psychology, 24*(1), 26-48.

Ibañez-Masero, O., Carmona-Rega, I.M., Ruiz-Fernández, M.D., Ortiz-Amo, R., CabreraTroya, R., & Ortega-Galán, A.M. 2019. Communicating Health Information at the End of Life: The Caregivers' Perspectives. *Int. J. Environ. Res. Public Health,* 16. 1-11.

International Agency for Research on Cancer. World Health Organisation: Ethiopia. 2021

Jie, B., Feng, Z., Qiu, Y., & Zhang, Y. 2019. Association between sociodemographic factors, coping style, illness perceptions and preference for disclosure/non-disclosure of diagnosis in Chinese patients with hepatocellular carcinoma. *Journal of Health Psychology, 24*(11): 1473-1483.

Jóhannesdóttir, S., & Hjörleifsdóttir, E. 2018. Communication is more than just a conversation: Family members' satisfaction with end-of-life care. *International Journal of Palliative Nursing,* 24(10):483-491.

Kahissay, M.H., Fenta, T.G., & Boon, H. 2020. Religion, Spirits, Human Agents and Healing: A Conceptual Understanding from a Sociocultural Study of Tehuledere Community, Northeastern Ethiopia. *Journal of Religion and Health,* (59):946–960.

Kasahun, G.G., Gebretekle, G.B., Gecho, Y.H., Woldemariam, A.A., & Fenta, T.G. 2020. Catastrophic healthcare expenditure and coping strategies among patients attending cancer treatment services in Addis Ababa, Ethiopia. *BMC Public Health,* 20(1):1-19.

Kassirera, S., Levineb, E.E., & Gaertig, C. 2020. Decisional autonomy undermines advisees' judgments of experts in medicine and in life. *Proceedings of the National Academy of Sciences of the United States of America,* 117(21): 11368–11378.

Kastbom, L., Milberg, A., & Karlsson, M. 2017. A good death from the perspective of palliative cancer patients. *Support Care* ogistics*Cancer,* 25(3): 933–939.

Kebede, B.G., Abraha, A., Andersson, R., Munthe, C., Linderholm, M., Linderholm, B., Lindstro¨m, N.B. 2020. Communicative challenges among physicians, patients, and family caregivers in cancer care: An exploratory qualitative study in Ethiopia. *PlosOne,* 15(3): 1-16.

Kim, G.M., Kim, S.J., Song, S.K., Kim, H.R., Kang, B.D., Noh, S.H., Chung, H.C., Kim, K.R., & Rha, S.Y. 2017. Prevalence and prognostic implications of psychological distress in patients with gastric cancer. *BMC Cancer,* ogistics 17:283:1-8.

Kim, J.S., Kim, J., & Gelegjamts, D. 2020. Knowledge, attitude and self-efficacy towards palliative care among nurses in Mongolia: A cross-sectional descriptive study. *PlosOne,* 15(7):1-15.

Kirby, E., Lwin, Z., Kenny, K., Broom, A., Birman, H., & Good, P. 2018. "It doesn't exist…": negotiating palliative care from a culturally and linguistically diverse patient and caregiver perspective. *BMC Palliative Care,* 17(90):1-10.

Knaul, F.M., Bhadelia, A., Rodriguez, N.M., Arreola-Ornelas, H., & Zimmermann, C. 2018. The Lancet Commission on Palliative Care and Pain Relief: Findings, recommendations, and future directions. *The Lancet Global Health,* 6:5-6.

Ko, E., & Fuentes, D. 2020. End-of-life communication between providers and family caregivers of home hospice patients in a rural US-Mexico border community: Caregivers' retrospective perspectives. *American Journal of Hospice & Palliative Medicine, 37*(5), 329-335.

Kpanake, L., Igier, V., & Sastre, M.T. 2019. Cultural differences in perceived appropriateness of breaking bad news to patients: A direct comparison of Togo and France. *Universitas Psychologica,* 18(2):2-7.

Kpanake, L., Sorumb, P.C., & Mulletc, E. 2016. Breaking bad news to Togolese patients. *Health Communication,* 31(11):1311–1317.

Krause, F., & Boldt, J. 2018. *Care in healthcare: Reflections on theory and practice*. Cham: Springer Nature.

Kremenova Z., Svancara, J., Kralova, P., Moravec, M., Hanouskova, K., & KnizekBonatto, M. 2022. *Journal of Palliative Medicine*, 25(7): 1088-1094.

Krieger, T., Salm, S., Dresen, A., & Cecon, N. 2022. Cancer patients' experiences and preferences when receiving bad news: A qualitative study. *Journal of Cancer Research and Clinical Oncology,* 2022: 1-12.

Leavy, P. 2017. *Research design: Quantitative, qualitative, mixed methods, arts-based, and community-based participatory research approaches*. New York: The Guilford Press.

Lee, E.S., Suh, S., LeBlanc, T.W., Himchack, S.H., Lee, S.S., Kim, Y., & Ahn, H. 2019. Korean physicians' perspectives on prognostication in palliative care: A qualitative study. *American Journal of Hospice & Palliative Medicine, 36*(6), 500-506.

Lewis, E.G., Oates, L.L., Rogathi, J., Dunmaijer, A., Shayo, A., Meguro, S., Bakari, B., Dewhurst, F., Walker, D.W., Dewhurst, M., & Urasa, S. 2018. "We never speak about death": Healthcare professionals' views on palliative care for inpatients in Tanzania: A qualitative study. *Palliative and Supportive Care, 16*(5), 566-579.

Liamputtong, P. 2020. *Qualitative Research Methods*. 5th edition. Dockland: Oxford University Press.

Lim, R.B.L. 2016. End-of-life care in patients with advanced lung cancer. *Therapeutic Advances in Respiratory Disease,* 10(5):455-467.

Liu, Y., Yang, J., Huo, D., Fan, H., & Gao, Y. 2018. Disclosure of cancer diagnosis in China: The incidence, patients' situation, and different preferences between patients and their family members and related influence factors. *Cancer Management and Research,* 10: 2173–2181.

MacArtney, J.I., Broom, A., Kirby, E., Good, P., & Wootton, J. 2017. The liminal and the parallax: Living and dying at the end of life. *Qualitative Health Research, 27*(5), 623-633.

Madden, R. 2017. *Being ethnographic: A guide to the theory and practice of ethnography*. 2nd edition. London: SAGE.

Maltoni, M., Scarpi, E., Dall'Agata, M., Zagonel, V., Berte`, R., Ferrari, D., Broglia, C.M., Bortolussi, R., Trentin, L., Valgiusti, M., Pini, S., Farolfi, A., Gardini, A.C., Nanni, O., & Amadori. D. 2016. Systematic versus on-demand early palliative care: Results from a multicentre, randomised clinical trial. *European Journal of Cancer,* 65(2016), 61-68.

Mannix, K. 2021. *Listen: How to Find the Words for Tender Conversations*. 1st edition. London: William Collins.

Map of Ethiopia and Addis Ababa. 2022.

Marschollek, P., Bąkowska, K., Bąkowski, W., Marschollek, K., & Tarkowski, R. 2018. Oncologists and breaking bad news - From the informed patient's point of view. The evaluation of the SPIKES protocol implementation. *Journal of Cancer Education,* 34:375– 380.

MedlinePlus. 2020. Do-not-resuscitate order. From: Do-not-resuscitate order: MedlinePlus Medical Encyclopedia (Accessed 1 July 2021).

Merriam, S.B., & Grenier, R.S. 2019. *Qualitative research in practice: Examples for discussion and analysis*. 2nd edition. San Francisco: Jossey-Bass.

Merriam, S.B., & Tisdel, E.J. 2016. *Qualitative research: A guide to design and implementation*. 4th edition. San Francisco: Jossey-Bass.

Merriam-Webster.com Dictionary*,* Merriam-Webster. Health care.

Merriam-Webster.com Dictionary*,* Merriam-Webster. Life-threatening.

Mesafint, Z., Berhane, Y., & Desalegn, D. 2018. Health seeking behaviour of patients diagnosed with cervical cancer in Addis Ababa, Ethiopia. *Ethiop. J Health Sci.* 28(2):111116.

Messerotti, A., Banchelli, F., Ferrari, S., Barbieri, E., Bettelli, F., Bandieri, E., Giusti, D., Catellani, H., Borelli, E., Colaci, E., Pioli, V., Morselli, M., Forghieri, F., Galeazzi, G.M., Marasca, R., Bigi, S., D'Amico, R., Martin, P., Efficace, F., Luppi, M., & Potenza, L. 2020. Investigating the association between physicians self-efficacy regarding communication skills and risk of "burnout". *Health and Quality of Life Outcomes,* 18(1): 1-12.

Miljeteig, I., Defaye, F., Desalegn, D., & Danis, M. 2019. Clinical ethics dilemmas in a low-income setting - A national survey among physicians in Ethiopia. *BMC Medical Ethics,* 20(63):1-13.

Ministry of Health - Ethiopia. 2016. National palliative care guideline.

Ministry of Health - Ethiopia. 2021. Palliative care service participant manual.

Ministry of Health New Zealand. 2016. Palliative care. From: Palliative care | Ministry of Health NZ (Accessed 24 June 2021).

Mirza, R.D., Ren, M., Agarwal, A., & Guyatt, G.H. 2019. Assessing Patient Perspectives on Receiving Bad News: A Survey of 1337 Patients with Life-Changing Diagnoses. *AJOB Empirical Bioethics,* 10(1): 36-43.

Monden, K. R., Gentry, L., & Cox, T.R. 2016. Delivering Bad News to Patients. Baylor University Medical Center Proceedings, 29(1):101-102.

Moosavia, S., Rohanib, C., Borhanic, F., & Akbari, M.E. 2021. Spiritual care experiences by cancer patients, their family caregivers and healthcare team members in oncology practice settings: A qualitative study. *Explore,* 17(5):1-8.

Morse J.M. 2016. *Qualitative health research: Creating a new discipline*. New York: Routledge.

Mugumbate, J., & Chereni A. 2019. Using African Ubuntu theory in social work with children in Zimbuabe. *African Journal of Social Work*. 9(1):27-34.

Muneer, M.S., Elhassan, A.E., Osman, A.M., Abdalla, A.A., Abdelrahim, M.A., Ali, S.M., & Abdalrahman, I.B. 2018. Breaking bad news from the doctors' perspective in a paternalistic society: The case of Sudan. *Tropical Doctor,* 48(4): 340-344.

Nare, N.E. 2016. Conceptualization of African primal health care in mental health. Master's of Science Thesis. North-West University.

Nasrabadi, A.N., Joolaee, S., Navab, E., Esmaeili, M., & Shali, M. 2020. White lie during patient care: A qualitative study of nurses' perspectives. *BMC Medical Ethics,* 21(1):1-7.

National Health Service UK. 2018. What end of life care involves: End of life care. From: What end of life care involves - NHS (www.nhs.uk) (Accessed 26 June 2021).

Ntizimira, C.R., Ngizwenayo, S., Krakauer, E.L., Dunne, M.L., & Esmaili, E. 2016. Addressing end-of-life care in cancer patients through Ubuntu: Lessons learned from Rwanda in global health perspective of humanity. *Current Obstetrics and Gynecology Reports,* 5(4): 273-278.

Oviawe, J.O. 2016. How to rediscover the Ubuntu paradigm in education. *Int Rev Educ*. 62:1–10.

Oxford Learner's Dictionaries. Community. 2021. From: community noun - Definition, pictures, pronunciation and usage notes | Oxford Advanced American Dictionary at OxfordLearnersDictionaries.com (Accessed 17 October 2021).

Oxford Learner's Dictionaries. Culture. 2023. From: https://www.oxfordlearnersdictionaries.com/definition/english/culture_1?q=culture (Accessed 7 August 2023).

Oxford Learner's Dictionaries. Guideline. 2023. From: guideline noun - Definition, pictures, pronunciation and usage notes | Oxford Advanced Learner's Dictionary at OxfordLearnersDictionaries.com (Accessed 7 August 2023).

Oxford Learner's Dictionaries. Next of kin. 2021. From: next-of-kin noun - Definition, pictures, pronunciation and usage notes | Oxford Advanced American Dictionary at OxfordLearnersDictionaries.com (Accessed 17 October 2021).

Oxford Learner's Dictionaries. Patient. 2023. From: https://www.oxfordlearnersdictionaries.com/definition/english/patient_1?q=patient (Accessed 7 August 2023).

Ozyemisci-Taskiran, O., Coskun, O., Budakoglu, I.I., & Demirsoy, N. 2018. Breaking bad news in spinal cord injury: A qualitative study assessing the perspective of spinal cord injury survivors in Turkey. *The Journal of Spinal Cord Medicine,* 41(3):347-354.

Palliative Care Australia. What is palliative care? From: What is palliative care? - Palliative Care (Accessed 24 June 2021).

Palma, R.D., Fortuna, D., Hegarty, S.E., Louis, D.Z., Melotti, R.M., & Moro, M.L. 2018. Effectiveness of palliative care services: A population-based study of end-of-life care for cancer patients. *Palliative Medicine, 32*(8):1344-1352.

Patten, M.L., & Newhart, M. 2017. *Understanding Research Methods: An Overview of the Essentials Account.* 10th edition. New York. Routledge. From: https://0-doiorg.oasis.unisa.ac.za/10.4324/9781315213033 (Accessed 30th Nov 2020)

Pereira, C.R., CalôNego, M.A., Lemonica, L., & De Barros, G.A. 2017. The P-A-C-I-E-NT-E Protocol: An instrument for breaking bad news adapted to the Brazilian medical reality. *Revista da Associacao Medica Brasileira,* 63(1):43-49.

Pope, C., & Mays, N. 2020. Qualitative Research in Health Care Account. Hoboken. Wiley-Blackwell.

Porensky, E.K., & Carpenter, B.D. 2016. Breaking bad news: Effects of forecasting diagnosis and framing prognosis. *Patient Education and Counseling,* 99:68–76.

Price, D.M., Strodtman, L.K., Montagnini, M., Smith, H.M., & Ghosh, B. 2019. Health professionals perceived concerns and challenges in providing palliative and end-of-life care: A qualitative analysis. *American Journal of Hospice and Palliative Medicine,* 36(4):308-315.

Radbruch, L., Lima, L.d., Knaul, F., Wenk, R., Ali, Z., Bhatnaghar, S., Blanchard, C., Bruera, E., Buitrago, R., Burla, C., Callaway, M., Munyoro, E.C., Centeno, C., Cleary, J., Connor, S., Davaasuren, O., Downing, J., Foley, J., Goh, C., Gomez-Garcia, W., Harding, R., Khan, Q.T., Larkin, P., Leng, M., Luyirika, E., Marston, J., Moine, S., Osman, H., Pettus, K., Puchalski, C., Rajagopal, M.R., Spence, D., Spruijt, O., Venkateswaran, C., Wee, B., Woodruff, R., Yong, J., & Pastrana, T. 2020. Redefining palliative care -A new consensus-based definition. *Journal of Pain and Symptom Management,* 60(4):754-764.

Rainsford, S., Phillips, C.B., Glasgow, N.J., MacLeod, R.D., & Wiles. R.B. 2018. The 'safe death': An ethnographic study exploring the perspectives of rural palliative care patients and family caregivers. *Palliative Medicine, 32*(10), 1575-1583.

Rajasooriyar, C., Kelly, J., Sivakumar, T., Navanesan, G., Nadarasa, S., Sriskandarajah, M.H., & Sabesan S. 2017. Breaking bad news in ethnic settings: Perspectives of patients and families in northern Sri Lanka. *Journal of Global Oncology,* 3(3):1-7.

Rao, A., Sunil, B., Ekstrand, M., Heylen, E., Raju, G., & Shet, A. 2016. Breaking bad news: Patient preferences and the role of family members when delivering a cancer diagnosis. *Asian Pacific Journal of Cancer Prevention,* 17(4):1779-1784.

Reid, E., Abathun, E., Diribi, J., Mamo, Y., Hall, P., Fallon, M., Wondemagegnhu, T., & Grant, L. 2020. Rationale and study design: A randomised controlled trial of early palliative care in newly diagnosed cancer patients in Addis Ababa, Ethiopia. *Contemporary Clinical Trials Communications,* 18: 1-5.

Reid, E.A., Gudina, E.K., Ayers, N., Tigineh, W., & Azmera, Y.M. 2018. Caring for lifelimiting illness in Ethiopia: A mixed-methods assessment of outpatient palliative care needs. *Journal of Palliative Medicine, 21*(5):622-630.

Rizo, J.L., & Levitt, H.M. 2021. Qualitative research. In A. Goldberg, & G. Beemyn (Eds.). *The SAGE Encyclopedia of Trans Studies*. Thousand Oaks. https://0-www-doiorg.oasis.unisa.ac.za/10.4135/9781544393858.n225 .

Roots Ethiopia. 2022. From: Mourning Practices in Rural Ethiopia (rootsethiopia.org) (Accessed 1 August 2022).

Saini, G., Sampson, E.L., Davis, S., Kupeli, N., Harrington, J., Leavey, G., Nazareth, I., Jones, L., & Moore, K.J. 2016. An ethnographic study of strategies to support discussions with family members on end-of-life care for people with advanced dementia in nursing homes. *BMC Palliative Care,* 15(55):1-12.

Sarwar, M.Z., Rehman, F., Fatima, S.M., Suhail, M., & Naqi, S.A. 2019. Breaking bad news skill of postgraduate residents of tertiary care hospital of Lahore, Pakistan: A crosssectional survey. *J Pak Med Assoc*. 69(5): 695-699.

Schreier, U. 2018. *The SAGE handbook of qualitative data collection*. London: SAGE Publications Ltd.

Sedhom, R., & Baril, D. 2016. Discussing Goals of Care with Families Using the Four Steps. *Gerontology and Geriatric Medicine,* 2:1-2.

Shiferaw, F., Letebo, M., Misganaw, A., Feleke, Y., Gelibo, T., Getachew, T., Defar, A., Abebayehu, A., Abebe, B., Amenu, K., Teklie, H., Tadele, T., Taye, G., Getnet, M., Gonfa, G., Bekele, A., Kebede, T., Yadeta, D., GebreMichael, M., Challa, F., Girma, Y., Mudie, K., Guta, M., & Tadesse, Y. 2018. Non-communicable diseases in Ethiopia: Disease burden, gaps in health care delivery and strategic directions'. *Ethiopian Journal of Health Development,* 32(3):1-11.

SilveiraI, F.J.F., BotelhoII, C.C., & Valadão, C.C. 2017. Breaking bad news: Doctors' skills in communicating with patients. *Sao Paulo Med J*. 135(4):323-31.

Sleeman, K.E., Gomes, B., Brito, M.J., Shamieh, O., & Harding, R. 2021. The burden of serious health-related suffering among cancer decedents: Global projections study to 2060. *Palliative Medicine,* 35(1):231–235.

Sloan, D., BrintzenhofeSzoc, K., Kichline, T., Baker, K., Pinzon, J., Tafe, C., Li. L., Cheng, M., & Berger, A. 2017. An assessment of meaning in life-threatening illness: Development of the Healing Experience in All Life Stressors (HEALS). *Patient Related Outcome Measures,* 8:15–21.

Julia, P., Renée, S., & Jill, W. (2014). Philosophical approaches to qualitative research. The Oxford Handbook of Qualitative Research.

Sobczak, K., Pawłowski, L., Pietrzykowska, M., & Spola, N. 2016. Delivering bad news by physicians – Polish reality check. *Journal of Medical Science,* 85(3):172-177.

St. Paul's Hospital Millennium Medical College. 2022. From: About – Saint Paul's Millennium Medical College (sphmmc.edu.et) (Accessed 9 August 2022).

Syed, J.Z., & Karim, M. 2016. Breaking bad news to patients with cancer: A comprehensive perspective of patients, their relatives, and the public - Example from a Middle Eastern country. *Journal of Global Oncology,* 2(5):268-274.

Tang, W., Hong, J., Rau, K., Wang, C., Juang, Y., Lai, S., Fujimori, M., Fang, C. 2017. Truth telling in Taiwanese cancer care: Patients' and families' preferences and their experiences of doctors' practices. *Psycho-Oncology, 26*(7): 999-1005.

Taylor, S.J., Bogdan, R., & DeVault, M. 2016. *Introduction to qualitative research methods: A guidebook and resource*. 4th edition. Hoboken, New Jersey: WILEY.

Tesfaw, A., Demis, S., Munye, T. & Ashuro, Z. 2020. Patient Delay and Contributing Factors among Breast Cancer Patients at Two Cancer Referral Centres in Ethiopia: A Cross-Sectional Study. *Journal of Multidisciplinary Healthcare,* 13: 1391–1401.

Tesfaye, T., Anbessie, Y., & Gizaw, A.B. 2018. Palliative care practice and associated factors among nurses working in Jimma University medical centre South-West Ethiopia, 2017. *Palliat Med Care,* 5(3): 1-8.

Thomas, H., Best, M., & Mitchell, G. 2020. Whole-person care in general practice: The doctor–patient relationship. *AJGP*. 49(3):139-144.

Tiruneh, M.A., & Ayele, B.T., 2018. Practice of code of ethics and associated factors among medical doctors in Addis Ababa, Ethiopia. *PlosOne,* 13(8):1-16.

Trant, A.A., Szekely, B., Mougalian, S.S., DiGiovanna, M.P., Sanft, T., Hofstatter, E., Silber, A., Adelson, K.B., Chagpar, A., Killelea, B., Horowitz, N., Lannin, D., Park, T., Corso, M., Abraham, G., Pollard-Murphy, K., Sturrock, T., Knill-Selby, E., Western, A., Servodidio, C., Tasoulis, M.K., Healy, B., Hatzis, C., Pusztai, L. 2019. The impact of communication style on patient satisfaction. *Breast Cancer Research and Treatment,* 176:349–356.

U.S. Department of Health and Human Services. 2021. End of life: What Are Palliative Care and Hospice Care? From: What Are Palliative Care and Hospice Care? | National Institute on Aging (nih.gov) (Accessed 26 June 2021).

Vanbutsele, G., Pardon, K., Belle, S.V., Surmont, V., Laat, M.D., Colman, R., Eecloo, K., Cocquyt,V., Geboes, K., & Deliens, L. 2018. Effect of early and systematic integration of palliative care in patients with advanced cancer: A randomised controlled trial. *The Lancet Oncology,* 19(3): 394-404.

Waterman, M.W., Pilver, C., Smith, D., Ersek, M., Lipsitz, S.R., & Keating, N.L. 2016. Quality of end-of-life care provided to patients with different serious illnesses. *JAMA Intern Med*. 176(8):1095-102.

Westmoreland, K.D., Banda, F.M., Steenhoff, A.P., Lowenthal, E.D., Isaksson, E., & Fassl, B.A. 2019. A standardised low-cost peer role-playing training intervention improves medical student competency in communicating bad news to patients in Botswana. *Palliative and Supportive Care,* 17(1):60–65.

Woldemariam, A.A., Andersson, R., Munthe, C., Linderholm, B., & Lindstrom, N.B. 2021. Breaking bad news in cancer care: Ethiopian patients want more information than what family and the public want them to have. *JCO Global Oncol*. (7):1341-1348.

Workneh, T., Emirie, G., Kaba, M., Mekonnen, Y., & Kloos, H. 2018. Perceptions of health and illness among the Konso people of southwestern Ethiopia: Persistence and change. *Journal of Ethnobiology and Ethnomedicine,* 14(18):1-9.

World Health Organisation. 2014. *WHO handbook for guideline development*. 2nd edition.

World Health Organisation. 2020. Palliative care. From: Palliative Care (who.int) (Accessed 24 June 2021).

World Health Organisation. International Agency for Research on Cancer. From: https://gco.iarc.fr/today/data/factsheets/populations/231-ethiopia-fact-sheets.pdf (Accessed 22 November 2021)

World Health Organisation. Noncommunicable Diseases Country Profiles. 2018.

World Health Organisation. WHOQOL: Measuring Quality of Life. From: WHOQOL - Measuring Quality of Life| The World Health Organisation (Accessed 13 September 2021).

World Health Organization. 2023. From: https://www.who.int/health-topics/health-equity#tab=tab_1 (Accessed 15 August 2023).

Zadeh, R.S., Eshelman, P., Setla, J., & Sadatsafavi, H. 2018. Strategies to improve quality of life at the end of life: Interdisciplinary team perspectives. *Am J Hosp Palliat Care,* 35(3): 411–416.

Zekri, J., & Karim, S.M. 2016. Breaking cancer bad news to patients with cancer: A comprehensive perspective of patients, their relatives, and the public – Example from a Middle Eastern country. *Journal of Global Oncology,* 2(5):268-274.

Zeru, T., Berihu, H., Gerensea, H., Teklay, G., Teklu, T., Gebrehiwot, H., & Wubayu, T. 2020. Assessment of knowledge and attitude towards palliative care and associated factors among nurses working in selected Tigray hospitals, northern Ethiopia: A crosssectional study. *Pan African Medical Journal,* 35(121):1-12.

Zheng, Y., Lei, F., & Liu, B. 2019. Cancer Diagnosis Disclosure and Quality of Life in Elderly Cancer Patients. *Healthcare,* 7(163): 1-8.

Ziegler, L.E., Craigs, C.L., West, R.M., Carder, P., Hurlow, A., Millares-Martin, P., Hall, G., Bennett, M.I. 2018. Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study. *BMJ Open, 8*(1):1-9.

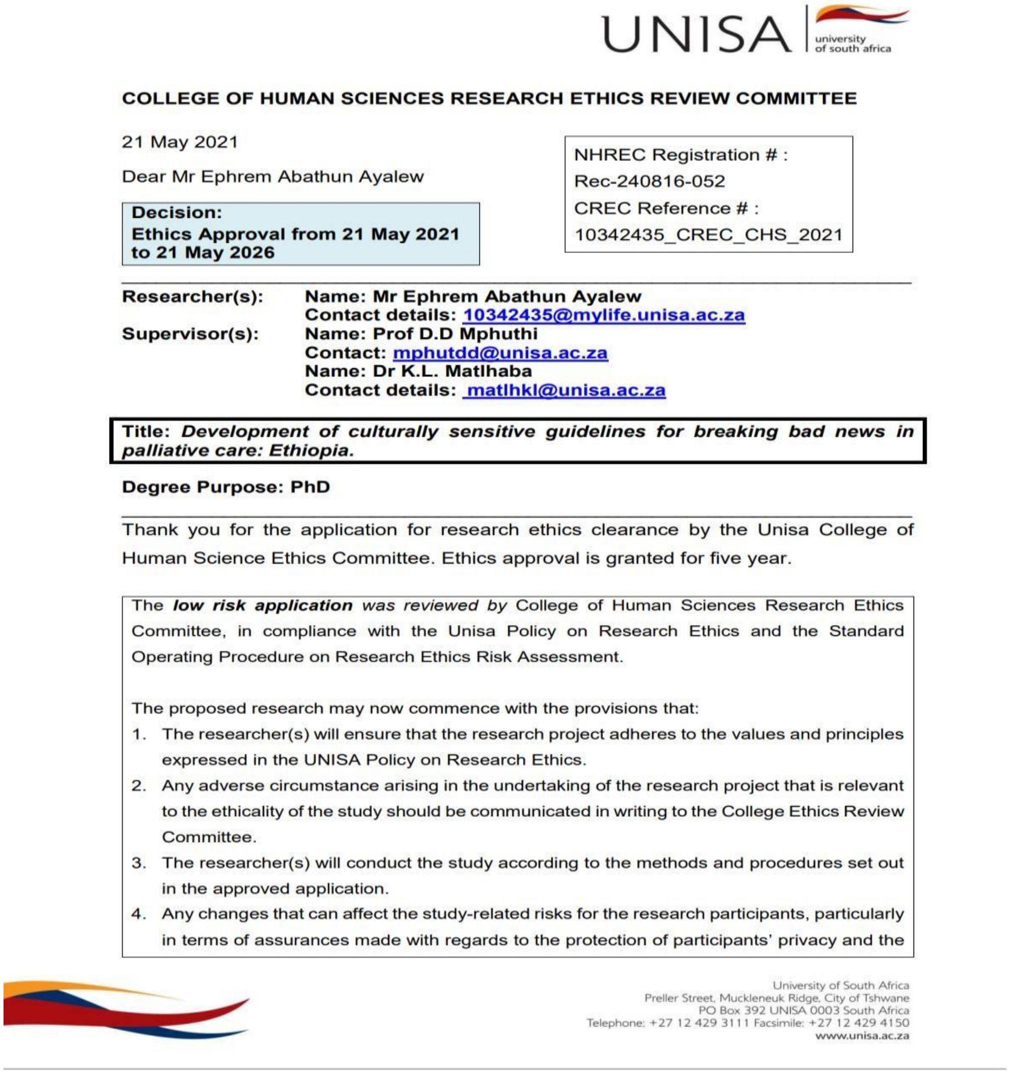
Zielińska, P., Jarosz, M., Kwiecińska, A., & Bętkowska-Korpała, B. 2017. Main communication barriers in the process of delivering bad news to oncological patients — Medical perspective. *Folia medica Cracoviensia,* 57(3):101–112.

Zwingmann, J., Baile, W.F., Schmier, J.W., Bernhard, J., & Kelle, M. 2017. Effects of patient-centred communication on anxiety, negative affect, and trust in the physician in delivering a cancer diagnosis: A randomised, experimental study. *Wiley Online Library,* 123(16):3167-3175.

ANNEXURES

Annexure one:

Ethics approval letter from the University of South Africa



UNISA
university
of south africa

COLLEGE OF HUMAN SCIENCES RESEARCH ETHICS REVIEW COMMITTEE

21 May 2021

Dear Mr Ephrem Abathun Ayalew

Decision:
Ethics Approval from 21 May 2021 to 21 May 2026

NHREC Registration # :
Rec-240816-052
CREC Reference # :
10342435_CREC_CHS_2021

Researcher(s):	**Name: Mr Ephrem Abathun Ayalew** **Contact details: 10342435@mylife.unisa.ac.za**
Supervisor(s):	**Name: Prof D.D Mphuthi** **Contact: mphutdd@unisa.ac.za** **Name: Dr K.L. Matlhaba** **Contact details: matlhkl@unisa.ac.za**

Title: ***Development of culturally sensitive guidelines for breaking bad news in palliative care: Ethiopia.***

Degree Purpose: PhD

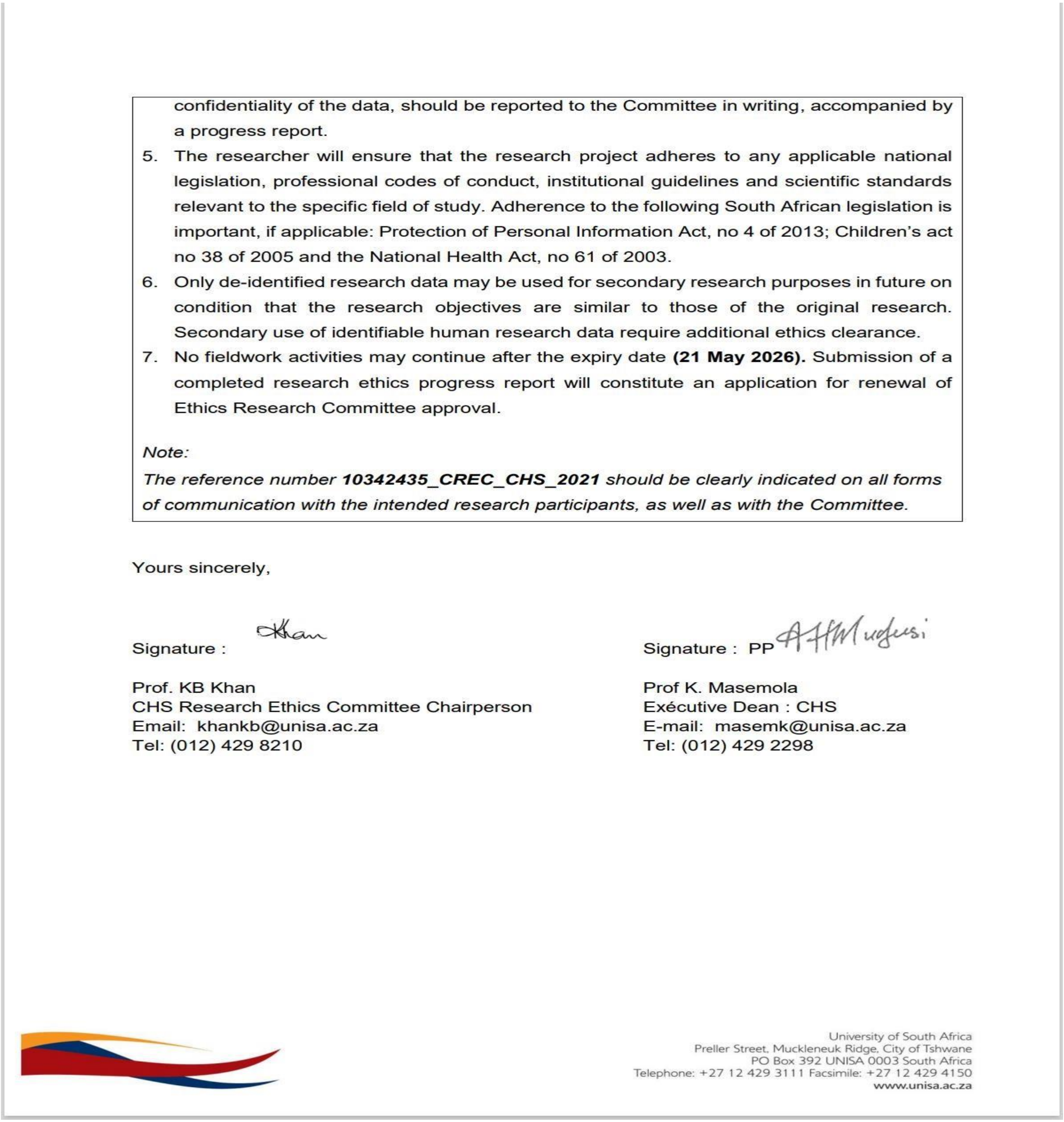
Thank you for the application for research ethics clearance by the Unisa College of Human Science Ethics Committee. Ethics approval is granted for five year.

The ***low risk application*** *was reviewed by* College of Human Sciences Research Ethics Committee, in compliance with the Unisa Policy on Research Ethics and the Standard Operating Procedure on Research Ethics Risk Assessment.

The proposed research may now commence with the provisions that:

1. The researcher(s) will ensure that the research project adheres to the values and principles expressed in the UNISA Policy on Research Ethics.
2. Any adverse circumstance arising in the undertaking of the research project that is relevant to the ethicality of the study should be communicated in writing to the College Ethics Review Committee.
3. The researcher(s) will conduct the study according to the methods and procedures set out in the approved application.
4. Any changes that can affect the study-related risks for the research participants, particularly in terms of assurances made with regards to the protection of participants' privacy and the

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za



confidentiality of the data, should be reported to the Committee in writing, accompanied by a progress report.

5. The researcher will ensure that the research project adheres to any applicable national legislation, professional codes of conduct, institutional guidelines and scientific standards relevant to the specific field of study. Adherence to the following South African legislation is important, if applicable: Protection of Personal Information Act, no 4 of 2013; Children's act no 38 of 2005 and the National Health Act, no 61 of 2003.
6. Only de-identified research data may be used for secondary research purposes in future on condition that the research objectives are similar to those of the original research. Secondary use of identifiable human research data require additional ethics clearance.
7. No fieldwork activities may continue after the expiry date **(21 May 2026).** Submission of a completed research ethics progress report will constitute an application for renewal of Ethics Research Committee approval.

Note:

*The reference number **10342435_CREC_CHS_2021** should be clearly indicated on all forms of communication with the intended research participants, as well as with the Committee.*

Yours sincerely,

Signature : Khan

Prof. KB Khan
CHS Research Ethics Committee Chairperson
Email: khankb@unisa.ac.za
Tel: (012) 429 8210

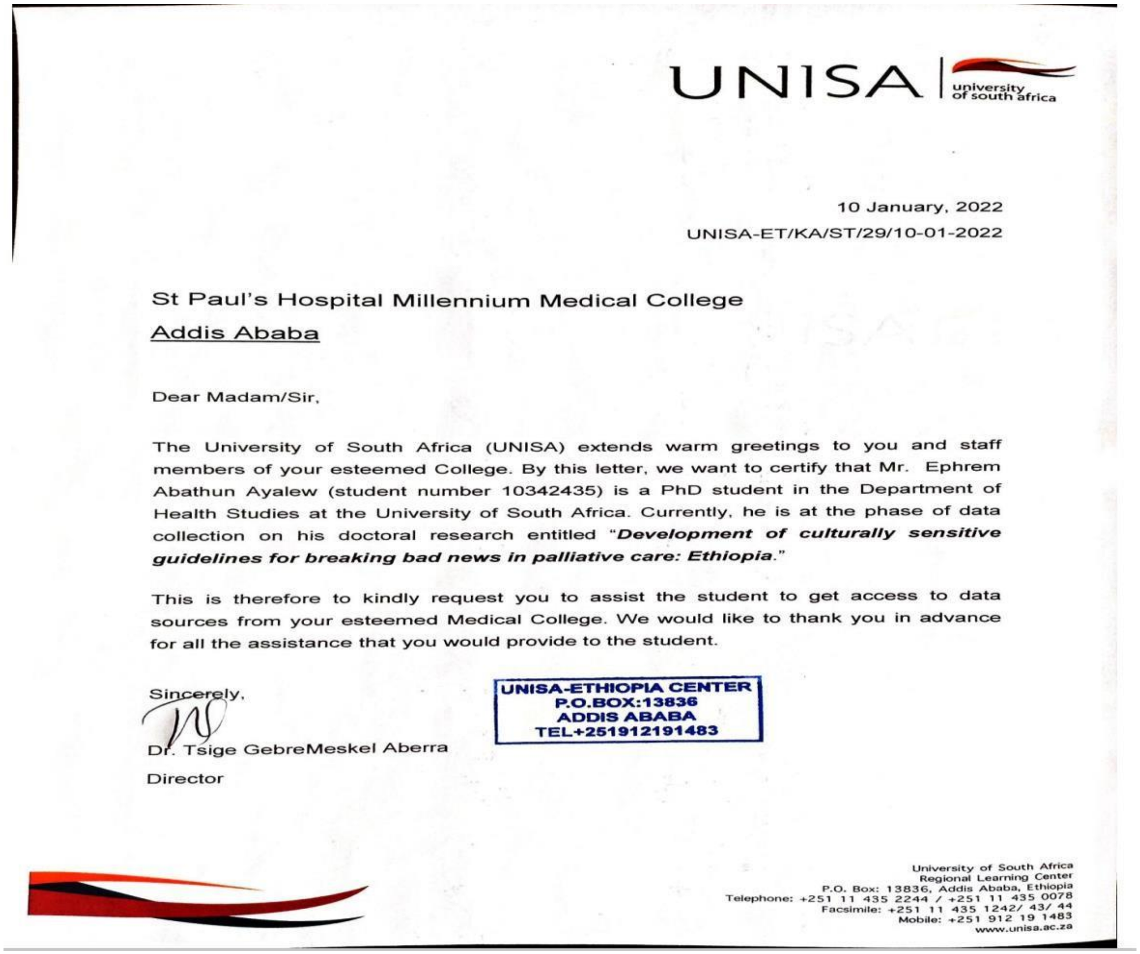
Signature : PP

Prof K. Masemola
Exécutive Dean : CHS
E-mail: masemk@unisa.ac.za
Tel: (012) 429 2298

University of South Africa
Preller Street, Muckleneuk Ridge, City of Tshwane
PO Box 392 UNISA 0003 South Africa
Telephone: +27 12 429 3111 Facsimile: +27 12 429 4150
www.unisa.ac.za

Annexure two:

Letter of support from the University of South Africa, Addis Ababa branch



UNISA university of south africa

10 January, 2022
UNISA-ET/KA/ST/29/10-01-2022

St Paul's Hospital Millennium Medical College
Addis Ababa

Dear Madam/Sir,

The University of South Africa (UNISA) extends warm greetings to you and staff members of your esteemed College. By this letter, we want to certify that Mr. Ephrem Abathun Ayalew (student number 10342435) is a PhD student in the Department of Health Studies at the University of South Africa. Currently, he is at the phase of data collection on his doctoral research entitled "***Development of culturally sensitive guidelines for breaking bad news in palliative care: Ethiopia***."

This is therefore to kindly request you to assist the student to get access to data sources from your esteemed Medical College. We would like to thank you in advance for all the assistance that you would provide to the student.

Sincerely,

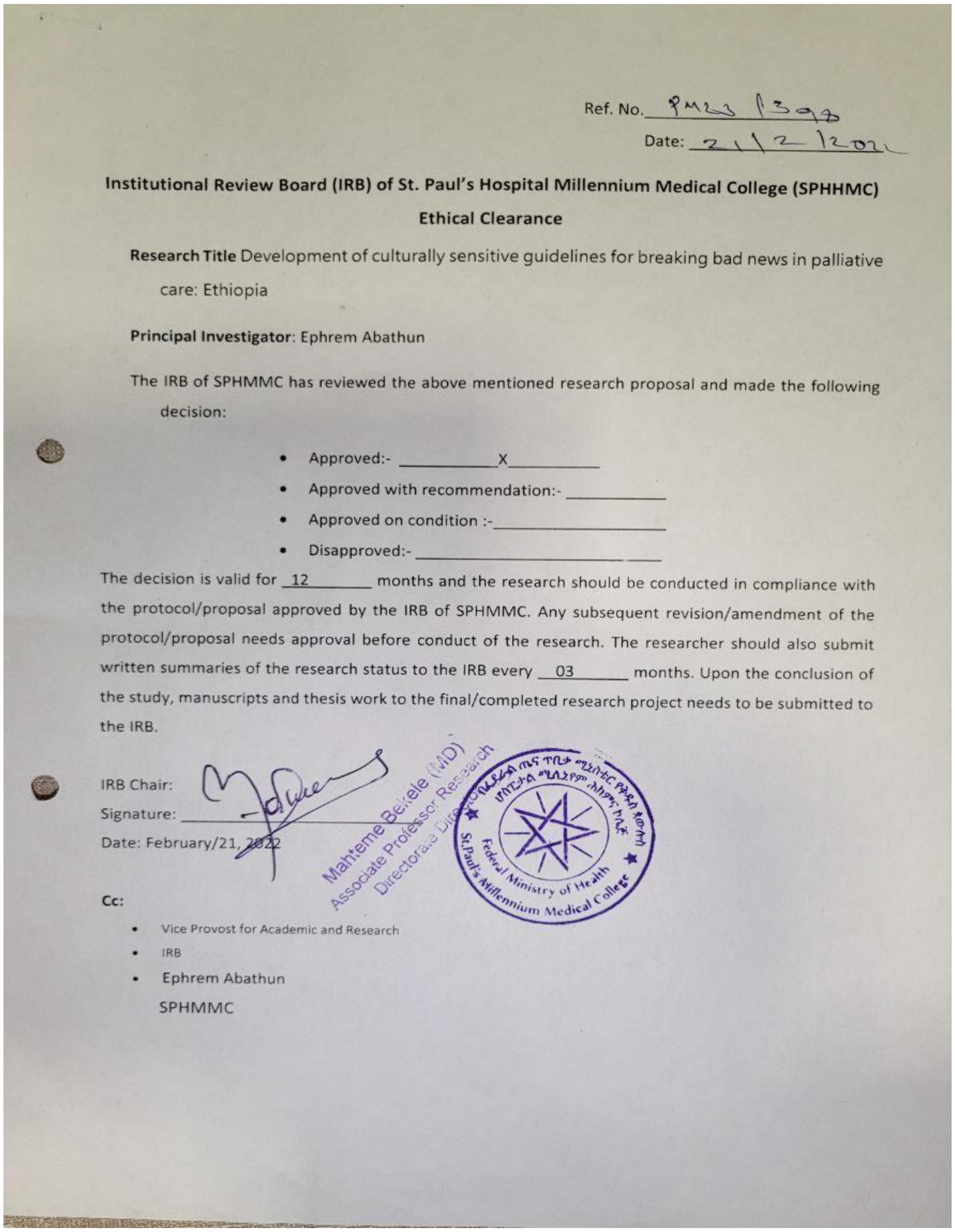
Dr. Tsige GebreMeskel Aberra
Director

UNISA-ETHIOPIA CENTER
P.O.BOX:13836
ADDIS ABABA
TEL+251912191483

University of South Africa
Regional Learning Center
P.O. Box: 13836, Addis Ababa, Ethiopia
Telephone: +251 11 435 2244 / +251 11 435 0078
Facsimile: +251 11 435 1242/ 43/ 44
Mobile: +251 912 19 1483
www.unisa.ac.za

Annexure three:

Letter of permission from St Paul's Hospital Millennium Medical College



Ref. No. የM23 /1398

Date: 21/2/2022

Institutional Review Board (IRB) of St. Paul's Hospital Millennium Medical College (SPHHMC)

Ethical Clearance

Research Title Development of culturally sensitive guidelines for breaking bad news in palliative care: Ethiopia

Principal Investigator: Ephrem Abathun

The IRB of SPHHMC has reviewed the above mentioned research proposal and made the following decision:

- Approved:- X
- Approved with recommendation:- ____
- Approved on condition :- ____
- Disapproved:- ____

The decision is valid for 12 months and the research should be conducted in compliance with the protocol/proposal approved by the IRB of SPHHMC. Any subsequent revision/amendment of the protocol/proposal needs approval before conduct of the research. The researcher should also submit written summaries of the research status to the IRB every 03 months. Upon the conclusion of the study, manuscripts and thesis work to the final/completed research project needs to be submitted to the IRB.

IRB Chair:

Signature:

Date: February/21, 2022

Mahteme Bekele (MD)
Associate Professor Research
Directorate Di

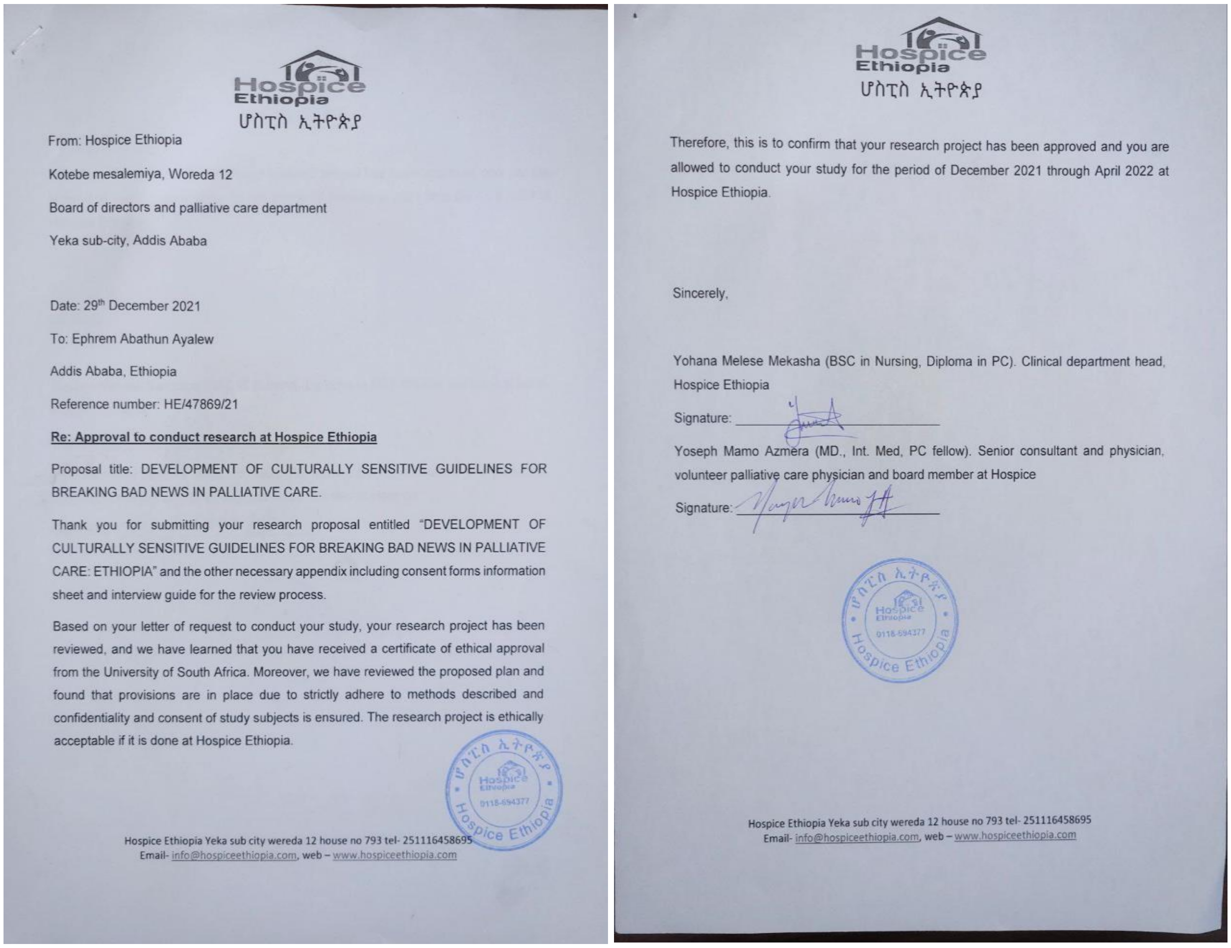
Cc:

- Vice Provost for Academic and Research
- IRB
- Ephrem Abathun

  SPHMMC

Annexure four:

Letter of permission from Hospice Ethiopia



Hospice Ethiopia
ሆስፒስ ኢትዮጵያ

From: Hospice Ethiopia

Kotebe mesalemiya, Woreda 12

Board of directors and palliative care department

Yeka sub-city, Addis Ababa

Date: 29th December 2021

To: Ephrem Abathun Ayalew

Addis Ababa, Ethiopia

Reference number: HE/47869/21

Re: Approval to conduct research at Hospice Ethiopia

Proposal title: DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE.

Thank you for submitting your research proposal entitled "DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA" and the other necessary appendix including consent forms information sheet and interview guide for the review process.

Based on your letter of request to conduct your study, your research project has been reviewed, and we have learned that you have received a certificate of ethical approval from the University of South Africa. Moreover, we have reviewed the proposed plan and found that provisions are in place due to strictly adhere to methods described and confidentiality and consent of study subjects is ensured. The research project is ethically acceptable if it is done at Hospice Ethiopia.

0118-694377

Hospice Ethiopia Yeka sub city wereda 12 house no 793 tel- 251116458695
Email- info@hospiceethiopia.com, web – www.hospiceethiopia.com

---

Hospice Ethiopia
ሆስፒስ ኢትዮጵያ

Therefore, this is to confirm that your research project has been approved and you are allowed to conduct your study for the period of December 2021 through April 2022 at Hospice Ethiopia.

Sincerely,

Yohana Melese Mekasha (BSC in Nursing, Diploma in PC). Clinical department head, Hospice Ethiopia

Signature: ______________________

Yoseph Mamo Azmera (MD., Int. Med, PC fellow). Senior consultant and physician, volunteer palliative care physician and board member at Hospice

Signature: ______________________

0118-694377

Hospice Ethiopia Yeka sub city wereda 12 house no 793 tel- 251116458695
Email- info@hospiceethiopia.com, web – www.hospiceethiopia.com

Annexure five: PATIENTS

Information sheet

REQUEST TO PARTICIPATE IN THE STUDY

1st February 2022

Title: DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA

Dear Prospective Participant

My name is Ephrem Abathun and I am doing research with David D. Mphuthi, a Professor in the Department of Human Science towards a PhD at the University of South Africa. We have not received funding from anybody for this study. We are inviting you to participate in a study entitled DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA.

WHAT IS THE PURPOSE OF THE STUDY?

I am conducting this research to find out the Ethiopian community cultural preferences for receiving bad news. This information will be used to develop a culturally competent breaking bad news guideline in Ethiopian context. This can benefit people diagnosed with life threatening illness, physicians, and nurses by promoting good way of bad news communication, and enhance patient satisfaction.

WHY AM I BEING INVITED TO PARTICIPATE?

I have obtained your contact detail from your friend or colleague. You have been chosen to participate in this research because you are diagnosed with life-threatening illness and the knowledge, we gain from you will help me to understand issues about breaking bad news, I assumed that you have the knowledge in cultural components about breaking bad news. The number of study participants will be small in this study as I would like to understand the phenomenon in detail.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

Your role in this study entails providing your perspective, experience, and values in related to breaking bad news. The study involves audio taping, one-by-one interview using semi-structured interview with your permission. The interview will last around 30 - 45 minutes. The questions will be open-ended and the following questions will be asked:

What are the cultural things relating to perceptions, values, beliefs, and preferences of people diagnosis and prognosis of life-threatening illness in Ethiopia? What would you think regarding culturally sensitive way of receiving bad news? What would you think about cultural preferences, values and beliefs related to diagnosis and prognosis of life threatening illness? How much details would you want to know about your diagnosis and prognosis of life-threatening illness? How would you think breaking bad news should be done? What would be your preferred ways of bad news communication?

Observation is the second method of data collection in this study. the researcher will observe when you discuss with your doctor about your medical conditions. The researcher merely observe, and will not intervein in your conversations or discussions.

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participating in this study is voluntary and you are under no obligation to consent to participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without losing any of your rights or benefits and giving a reason.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

There are no direct personal benefits from participating, nonetheless the findings will be used to develop culturally sensitive breaking bad news. This will facilitate better communication between physicians and patients so as to people with life threatening illness get better information and receive the truth and patient can make informed choice of treatment.

ARE THEIR ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

There are no substantial harm that may be caused by participating in this study. The interview will take your time. There may be mild emotional distress and the researcher should allow you to take a break or get relax if it occurred. Moreover, you will not be alone and the researcher will stay to help you, and you will get help from professional counsellor if you need or feel distressed.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Explain the extent, if necessary, to which confidentiality of information will be maintained.

You have the right to insist that your name will not be recorder anywhere and that no one, apart from the researcher and identified members of the research team, will know about your involvement in this research OR your name will not be recorded anywhere and no one will be able to connect you to the answers you give. Your answers will be given a code number or a pseudonym and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings.

Your answers may be reviewed by people responsible for making sure that research is done properly, including the transcriber, external coder, and members of the Research Ethics Review Committee. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

The information that will be collected from this research project will be kept confidential and secured against unauthorized access. Information about the study participants will be kept confidential by assigning codes to the data to maintain anonymity when the data is used for research report, journal articles, and or conference proceedings.

Your direct identifiers such as name will be removed and indirect identifiers such as age, occupation and religion will be aggregated so that your personal information will not be identified in reports or publications and your identity will not be linked to your response.

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard/filing cabinet at the principal researcher house for future research or academic purposes; electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable. Hard copies will be shredded and/or electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme, if necessary.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

You will not be provided with any financial incentives to take part in this research. The investigator will provide you a bottle of water and snack.

HAS THE STUDY RECEIVED ETHICS APPROVAL

This study has received written approval from the Research Ethics Review Committee of the *College of Human Science,* Unisa. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Ephrem Abathun on +251911637271 or abathunephrem@yahoo.com. The findings are accessible for 10 years.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact +251911637271 or abathunephrem@yahoo.com.

Should you have concerns about the way in which the research has been conducted, you may contact Professor David D. Mphuthi on mphutdd@unisa.ac.za Tell: 012 429 2058. Contact the research ethics chairperson of the CREC, Dr KJ Malesa, maleskj@unisa.ac.za, 012 429 6054 if you have any ethical concerns.

Thank you for taking time to read this information sheet. If you are willing to participate in this study, kindly complete the consent form below.

Kind regards

____

Researcher

Annexure six: HEALTHCARE PROFESSIONALS

Information sheet

REQUEST TO PARTICIPATE IN THE STUDY

1st February 2022

Title: DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA

Dear Prospective Participant

My name is Ephrem Abathun and I am doing research with David D. Mphuthi, a Professor in the Department of Human Science towards a PhD at the University of South Africa. We have not received funding from anybody for this study. We are inviting you to participate in a study entitled DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA.

WHAT IS THE PURPOSE OF THE STUDY?

I am conducting this research to find out the Ethiopian community cultural preferences for receiving bad news. This information will be used to develop a culturally competent breaking bad news guideline in Ethiopian context. This can benefit people diagnosed with life threatening illness, physicians, and nurses by promoting good way of bad news communication, and enhance patient satisfaction.

WHY AM I BEING INVITED TO PARTICIPATE?

I have obtained your contact detail from your friend or colleague. You have been chosen to participate in this research because you are a physician or a nurse working with patients diagnosed with life-threatening illness and the knowledge, we gain from you will help me to understand issues about breaking bad news, I assumed that you have the knowledge in cultural components about breaking bad news. The number of study participants will be small in this study as I would like to understand the phenomenon in detail.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

Your role in this study entails providing your perspective, experience, and values in related to breaking bad news. The study involves audio taping, one-by-one interview using semi-structured interview with your permission. The interview will last around 30 - 45 minutes. The questions will be open-ended and the following questions will be asked:

What are the cultural things relating to perceptions, values, beliefs, and preferences of people diagnosis and prognosis of life-threatening illness in Ethiopia? What would you think regarding culturally sensitive way of receiving bad news? What would you think about cultural preferences, values and beliefs related to diagnosis and prognosis of life threatening illness? How much details would you want to know about your diagnosis and prognosis of life-threatening illness? How would you think breaking bad news should be done? What would be your preferred ways of bad news communication?

Observation is the second method of data collection in this study. The researcher will present and observe how you convey and discuss with patients about serious medical news. The researcher merely observe, and will not intervein in your conversations or discussions.

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participating in this study is voluntary and you are under no obligation to consent to participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without losing any of your rights or benefits and giving a reason.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

There are no direct personal benefits from participating, nonetheless the findings will be used to develop culturally sensitive breaking bad news. This will facilitate better communication between physicians and patients so as to people with life threatening illness get better information and receive the truth and patient can make informed choice of treatment.

ARE THEIR ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

There are no substantial harm that may be caused by participating in this study. The interview will take your time. There may be mild emotional distress and the researcher should allow you to take a break or get relax if it occurred. Moreover, you will not be alone and the researcher will stay to help you, and you will get help from professional counsellor if you need or feel distressed.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

You have the right to insist that your name will not be recorder anywhere and that no one, apart from the researcher and identified members of the research team, will know about your involvement in this research OR your name will not be recorded anywhere and no one will be able to connect you to the answers you give. Your answers will be given a code number or a pseudonym and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings.

Your answers may be reviewed by people responsible for making sure that research is done properly, including the transcriber, external coder, and members of the Research Ethics Review Committee. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

The information that will be collected from this research project will be kept confidential and secured against unauthorized access. Information about the study participants will be kept confidential by assigning codes to the data to maintain anonymity when the data is used for research report, journal articles, and or conference proceedings.

Your direct identifiers such as name will be removed and indirect identifiers such as age, occupation and religion will be aggregated so that your personal information will not be identified in reports or publications and your identity will not be linked to your response..

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard/filing cabinet at the principal researcher house for future research or academic purposes; electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable. Hard copies will be shredded and/or electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme, if necessary.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

You will not be provided with any financial incentives to take part in this research. The investigator will provide you a bottle of water and snack.

HAS THE STUDY RECEIVED ETHICS APPROVAL

This study has received written approval from the Research Ethics Review Committee of the *College of Human Science,* Unisa. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Ephrem Abathun on +251911637271 or abathunephrem@yahoo.com. The findings are accessible for 10 years.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact +251911637271 or abathunephrem@yahoo.com.

Should you have concerns about the way in which the research has been conducted, you may contact Professor David D. Mphuthi on mphutdd@unisa.ac.za Tell: 012 429 2058. Contact the research ethics chairperson of the CREC, Dr KJ Malesa, maleskj@unisa.ac.za, 012 429 6054 if you have any ethical concerns.

Thank you for taking time to read this information sheet. If you are willing to participate in this study, kindly complete the consent form below.

Kind regards

____

Researcher

Annexure seven: COMMUNITY MEMBERS

Information sheet

REQUEST TO PARTICIPATE IN THE STUDY

1st February 2022

Title: DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA

Dear Prospective Participant

My name is Ephrem Abathun and I am doing research with David D. Mphuthi, a Professor in the Department of Human Science towards a PhD at the University of South Africa. We have not received funding from anybody for this study. We are inviting you to participate in a study entitled DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA.

WHAT IS THE PURPOSE OF THE STUDY?

I am conducting this research to find out the Ethiopian community cultural preferences for receiving bad news. This information will be used to develop a culturally competent breaking bad news guideline in Ethiopian context. This can benefit people diagnosed with life threatening illness, physicians, and nurses by promoting good way of bad news communication, and enhance patient satisfaction.

WHY AM I BEING INVITED TO PARTICIPATE?

I have obtained your contact detail from your friend or colleague. You have been chosen to participate in this research because you are the member of Ethiopian community and the knowledge, we gain from you will help me to understand issues about breaking bad news, I assumed that you have the knowledge in cultural components about breaking bad news. The number of study participants will be small in this study as I would like to understand the phenomenon in detail.

WHAT IS THE NATURE OF MY PARTICIPATION IN THIS STUDY?

Your role in this study entails providing your perspective, experience, and values in related to breaking bad news. The study involves audio taping, one-by-one interview using semi-structured interview with your permission. The interview will last around 30 - 45 minutes. The questions will be open-ended and the following questions will be asked:

What are the cultural things relating to perceptions, values, beliefs, and preferences of people diagnosis and prognosis of life-threatening illness in Ethiopia? What would you think regarding culturally sensitive way of receiving bad news? What would you think about cultural preferences, values and beliefs related to diagnosis and prognosis of life threatening illness? How much details would you want to know about your diagnosis and prognosis of life-threatening illness? How would you think breaking bad news should be done? What would be your preferred ways of bad news communication?

CAN I WITHDRAW FROM THIS STUDY EVEN AFTER HAVING AGREED TO PARTICIPATE?

Participating in this study is voluntary and you are under no obligation to consent to participation. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a written consent form. You are free to withdraw at any time and without losing any of your rights or benefits and giving a reason.

WHAT ARE THE POTENTIAL BENEFITS OF TAKING PART IN THIS STUDY?

There are no direct personal benefits from participating, nonetheless the findings will be used to develop culturally sensitive breaking bad news. This will facilitate better communication between physicians and patients so as to people with life threatening illness get better information and receive the truth and patient can make informed choice of treatment.

ARE THEIR ANY NEGATIVE CONSEQUENCES FOR ME IF I PARTICIPATE IN THE RESEARCH PROJECT?

There are no substantial harm that may be caused by participating in this study. The interview will take your time. There may be mild emotional distress and the researcher should allow you to take a break or get relax if it occurred. Moreover, you will not be alone and the researcher will stay to help you, and you will get help from professional counsellor if you need or feel distressed.

WILL THE INFORMATION THAT I CONVEY TO THE RESEARCHER AND MY IDENTITY BE KEPT CONFIDENTIAL?

Explain the extent, if necessary, to which confidentiality of information will be maintained.

You have the right to decide on with whom to share your response or information. Your private information will not be share and will be kept confidential. You have the right to insist that your name will not be recorder anywhere and that no one, apart from the researcher and identified members of the research team, will know about your involvement in this research OR your name will not be recorded anywhere and no one will be able to connect you to the answers you give. Your answers will be given a code number or a pseudonym and you will be referred to in this way in the data, any publications, or other research reporting methods such as conference proceedings.

Your answers may be reviewed by people responsible for making sure that research is done properly, including the transcriber, external coder, and members of the Research Ethics Review Committee. Otherwise, records that identify you will be available only to people working on the study, unless you give permission for other people to see the records.

The information that will be collected from this research project will be kept confidential and secured against unauthorized access. Information about the study participants will be kept confidential by assigning codes to the data to maintain anonymity when the data is used for research report, journal articles, and or conference proceedings.

Your direct identifiers such as name will be removed and indirect identifiers such as age, occupation and religion will be aggregated so that your personal information will not be identified in reports or publications and your identity will not be linked to your response..

HOW WILL THE RESEARCHER(S) PROTECT THE SECURITY OF DATA?

Hard copies of your answers will be stored by the researcher for a minimum period of five years in a locked cupboard/filing cabinet at the principal researcher house for future research or academic purposes; electronic information will be stored on a password protected computer. Future use of the stored data will be subject to further Research Ethics Review and approval if applicable. Hard copies will be shredded and/or electronic copies will be permanently deleted from the hard drive of the computer through the use of a relevant software programme, if necessary.

WILL I RECEIVE PAYMENT OR ANY INCENTIVES FOR PARTICIPATING IN THIS STUDY?

You will not be provided with any financial incentives to take part in this research. The investigator will provide you a bottle of water and snack.

HAS THE STUDY RECEIVED ETHICS APPROVAL

This study has received written approval from the Research Ethics Review Committee of the *College of Human Science,* Unisa. A copy of the approval letter can be obtained from the researcher if you so wish.

HOW WILL I BE INFORMED OF THE FINDINGS/RESULTS OF THE RESEARCH?

If you would like to be informed of the final research findings, please contact Ephrem Abathun on +251911637271 or abathunephrem@yahoo.com. The findings are accessible for 10 years.

Should you require any further information or want to contact the researcher about any aspect of this study, please contact +251911637271 or abathunephrem@yahoo.com.

Should you have concerns about the way in which the research has been conducted, you may contact Professor David D. Mphuthi on mphutdd@unisa.ac.za Tell: 012 429 2058. Contact the research ethics chairperson of the CREC, Dr KJ Malesa, maleskj@unisa.ac.za, 012 429 6054 if you have any ethical concerns.

Thank you for taking time to read this information sheet. If you are willing to participate in this study, kindly complete the consent form below.

Kind regards

____

Researcher

Annexure eight:

Informed consent

CONSENT TO PARTICIPATE IN THE STUDY

Observationa; for healthcare professional

I, ________________________________ (participant name), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read (or had explained to me) and understood the study as explained in the information sheet.

I have had sufficient opportunity to ask questions and am prepared to participate in the study.

I understand that my participation is voluntary and that I am free to withdraw at any time without penalty.

I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.

I agree the researcher to observe when I convey bad news to patient or next of kin my and to the recording of my conversation with the patient or next of kin.

I have received a signed copy of the informed consent agreement.

Participant Name & Surname………………………………………….. (Please print)

Participant Signature…………………………………………..Date…………………

Researcher's Name & Surname: Ephrem Abathun Ayalew

Researcher's signature:

Date…………………

CONSENT TO PARTICIPATE IN THE STUDY

Observation; for Patient

I, __________________________________ (participant name), confirm that the person asking my consent to take part in this research has told me about the nature, procedure, potential benefits and anticipated inconvenience of participation.

I have read (or had explained to me) and understood the study as explained in the information sheet.

I have had sufficient opportunity to ask questions and am prepared to participate in the study.

I understand that my participation is voluntary and that I am free to withdraw at any time without penalty.

I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but that my participation will be kept confidential unless otherwise specified.

I agree the researcher to observe when my doctor/ nurse/ health officer communicate by medical condition and to the recording of my conversation with my doctor/nurse/health officer.

I have received a signed copy of the informed consent agreement.

Participant Name & Surname………………………………………….. (Please print)

Participant Signature…………………………………………..Date…………………

Researcher's Name & Surname: Ephrem Abathun Ayalew

Researcher's signature: ___ ___________Date…………………

Annexure nine:

Data collection tool; Interview guide

INTERVIEW GUIDE

Interview guide: Patients diagnosed with life-threatening illness

Dear participant, my name is Ephrem Abathun and I am a clinical/health officer working with Hospice Ethiopia. I am the principal researcher for the research titled with DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA at the University of South Africa.

Thank you for taking the time to participate in this study. Let us discuss about your cultural views, needs of information and preferred ways of bad news communication.

1. Would you tell me about your biographic details please?
2. I understand that you have a diagnosis of life-threatening illness, would you tell me how you would like to be told the bad news?

   Prompt:

   How much details would you like to know about your medical condition?

   Who do you think should be told the bad news?

   Who would you think should make a decision on treatment?

3. Would you tell me your experience with your doctor or nurse in disclosure of your medical diagnosis/prognosis and what helps you to cope with your situation?

   Prompt:

   How would you think the cultural perspectives that your doctor or nurse should see during disclosure of bad news?

   What would you prefer to be taken in to account when you receive the bad news?

4. Would you have any other opinion?

Interview guide: Healthcare professionals

Dear participant, my name is Ephrem Abathun and I am a clinical/health officer working with Hospice Ethiopia. I am the principal researcher for the research titled with DEVELOPMENT OF CULTURALLY SENSITIVE GUIDELINES FOR BREAKING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA at the University of South Africa.

Thank you for taking the time to participate in this study. I would like to ask you some questions about your experience about breaking bad news.

1. Would you tell me about your biographic details and work experience?
2. Would you tell me your experiences with a patient or next of kin in disclosure of bad news?

   Prompt:

   How would you like the bad news to be conveyed?

   Who do you think should receive the bad news?

   How do you disclose bad news in your practice?

   Who would you prefer to communicate bad news?
3. How would maintaining the cultural matters when your break bad news?

   Prompt:

   What are the cultural matters you think should be maintained when bad news is conveyed?
4. What are issues you have experienced when you convey bad news? What was helping to handle them?
5. Would you have any other opinion?

Annexure ten:

Research assistant confidentialtty agreement

Research Assistant Confidentiality Agreement

A. INSTRUCTIONS

Please read through the entirety of this form carefully before signing.

> **Electronic signatures are not valid for this form.** After completing the required fields, please print and sign this form in blue or black ink. After this form has been signed by the research assistant, it should be given to the principal investigator of the research study for submission. After receiving the *Research Assistant Confidentiality Agreement*, the principal investigator should scan and upload the signed form to their IRBNet project package.

The research assistant should keep a copy of the *Research Assistant Confidentiality Agreement* for their records.

B. CONFIDENTIALITY OF A RESEARCH STUDY:

Confidentiality is the treatment and maintenance of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure (the consent form) without permission. Confidential information relating to human subjects in a research study may include, but is not limited to:

- Name, date of birth, age, sex, address, and contact information;
- Current contact details of family, guardian etc.;
- Medical or educational history and/or records;
- Sexual lifestyle;
- Personal care issues;
- Service records and progress notes;
- Assessments or reports;
- Ethnic or racial origin;
- Political opinions, religious or philosophical beliefs.

As a research assistant you will have access to confidential information pertaining to the research study. Many participants have only revealed information to investigators because principal investigators have assured participants that every effort will be made to maintain confidentiality. That is why it is of the upmost importance to maintain full confidentiality when conducting a research study. *Below is a list of expectations you will be required to adhere to as a research assistant. Please carefully review these expectations before signing this form.*

C EXPECTATIONS FOR A RESEARCH ASSISTANT

Title of the study: development of culturally sensitive guidelines for breaking bad news in palliative care: Ethiopia

In order to maintain confidentiality, I agree to:

1. Keep all research information that is shared with me (e.g. flash drives, notes, transcripts, data, etc.) confidential by not discussing or sharing this information verbally or in any format with anyone other than the principal investigator of this study;

2. Ensure the security of research information while it is in my possession. This may include:
   - Keeping all documents and/or data related to the research study on a password protected computer with password protected files;
   - Closing any programs, documents, or data files related to the research study when away from the computer;
   - Keeping any printed documents and/or data related to the research study in a secure location such as a locked filing cabinet;
   - Permanently deleting any digital communication containing documents and/or data related to the research study.

3. Not make copies of documents and/or data related to the research study unless specifically instructed to do so by the principal investigator;

4. Give all research information/data and research participant information/data back to the principal investigator upon completion of my duties as a research assistant;

5. After discussing it with the principal investigator, erase or destroy all research information that cannot be returned to the principal investigator upon completion of my duties as a research assistant.

Name of Research Assistant:

IRBNet Tracking Number:

Title of Research Study: development of culturally sensitive guidelines for breaking bad news in palliative care: Ethiopia

Name of Principal Investigator: Mr Ephrem Abathun

By signing this form, I acknowledge that I have reviewed, understand and agree to adhere to the expectations for a research assistant described above. I agree to maintain confidentiality while performing my duties as a research assistant and recognize that failure to comply with these expectations may result in disciplinary action.

____ ____________

Signature of Research Assistant Date

____

Print Name

SAMPLE OF INTERVIEWS

INTERVIEW 9 I9P9 HCH DR

Investigator: OK thank you in advance, Thank you for your time, for your willingness to participate in the study. So can you tell me about yourself, your education, your age, your general family situation?

I9P9: My name is ---------. In my profession, I am a doctor. I have a degree in medical doctor. Then I specialized in internal medicine. Then I had a year of training in palliative care fellowship. I am 57 years old. My gender is male. I am a father of two children. And my wife is a nurse, a health professional, and I work in medicine as well as non-communicable disease care and palliative care.

Investigator: How many years of experience do you have?

I9P9: About 30 years; I have a total of 30 years of work experience. I started working in 1991, so the number is from 91 to 4 and a half years in GP, 3 years residency internal medicine training; 7 years as a lecturer at Jimma University, another 7 years in the HIV program, and another 7 years of non-communicable disease, maybe 14 years of palliative care, but I haven't done much.

Investigator: So now about bad news

I9P9: I'm wrong, 30 years sorry; No, I'm right, Ehh. It's been 30 years, isn't it? We started working together.

Investigator: So share your experience with bad news communication and how to break it?

I9P9: When it comes to bad news, here it is the most difficult job of a doctor in Ethiopia. Well, there is always a heavy burden for a doctor to tell bad news; In fact, doctors often avoid this practice. It is a very difficult time. Because, we are trying to leave it to Junior or the nurses; First of all: To share my personal experience, then, what is the question, in my experience, then, my experience from my youth, If illness is a lifethreatening condition, it is very difficult to say, but we do not usually tell the patient directly. We often tell family. And the family situation is very serious, especially acute disease and it is life threatening; but we would do our best. But that is how you should prepare. Often we do not tell this directly to the patient. Because, first, we do not tell the patient directly, so that we would not be accused the patient of dying because he was shocked by this news, or because he was shocked by this news. But we often know in our conscience that the patient should know this, but we do not dare to speak. To give some examples, I, for example, I had a patient with Lymphoma and HIV and the condition of this patient is HIV, for example I did not tell him. It is too much to say, because of his critical condition, he had Lymphoma and while we were treating him for that Lymphoma, the patient died before we could tell him. At this point, the situation was critical; we are not saying this now; we did not tell him or his family. A few days later, after a long time, his wife said, "Nothing, we don't know where the property is, the bank account, where the book is, and I have trouble raising my children." I was very sad. Because he did not know that this man was going to die, he did not know how serious his illness was; only the doctor could tell that, but we did not tell him, he seemed to be cured so he died with his secret. So we had offended his family. Another example is that learning from this, if we speak, it will benefit people, and on another occasion, for example, I met a woman with cancer, who worked hard for many years, but who had cancer with pleural infusion, and she was a businessman, and she was rich. So I thought if I tell her, she would benefit; Going abroad, there is a procedure called pleurodesis, for the palliative care measure so it does not bother to refill her with regular fluids, and when she has pleurodesis, that fluid does not come, so she has at least quality of life. We told the patient that we would not usually do this news directly. When I went there the next morning, it was all shaken. The evil doctor told her straight away, and she spent the night crying. How could he say such a thing? There was a commotion, so I went and apologized again, "I did not say you will not be cured, this is not an incurable disease, you can be cured, it will be cured," I denied again; Because there was chaos, so wrong thing with wrong. So this level has a problem. The third person I remember was a pilot by profession who came with HIV, but we did not dare to tell him that he had HIV. But the problem is that one of his legs is paralyzed and hemiplegia is starting, he is unable to tread on weakness and brakes. And we said you have a neurologic problem, and the urologic problem is irreversible, so we said we can't do anything for you, but we didn't tell him he had HIV. This is when early HIV came. How do we tell? That is to say, later this patient went abroad. He went abroad and was told that he was HIV-positive and could not be treated, and then he came back and said, "Let me tell my doctors," and he came to us and said, "I have HIV." HIV is an infectious disease, he said the nerves grow in the tumor here, and that's why. Our leading physician, said, "We know that." Later the patient became angry, how come you did not tell me? "I sold my house, I sold my property, you kept me from going for an incurable disease," he said, leaving us very sad. So, as you can see, bad news communication is something I learned from this, because we don't have the skills, some of them want to know, but they get crazy when we tell them. We don't tell others not to go crazy, but they do get crazy. Whether we speak or not, the sick are harmed; so what I understand that we do not have the ability and the courage, and that we need the most skill, I understand and I apologize for talking too much.

Investigator: So how should it be delivered? How can a health professional tell bad news from your experience, taking into account our culture, beliefs, traditions, and the community? What about the delivery process?

I9P9: So, as I told you, first of all, we have to believe, it is important to know the patients, to know their condition, it is very, very important. What is the problem? So, the first thing according to my practice and our culture first it should be discussed with the family. Because in our culture it is a next of kin who takes care of the patient even in the hospital even a nursing care; not a nurse. As a result, 99% of nursing care is on the shoulders of next of kin. Therefore, it is not possible for us to expel the patients and talk to them directly, as in the western countries. It's my belief, or so the first thing to do is sit down and talk with his close relatives, so it is important to know who the closest relatives are. If there is no wife, no children, then there is a brother, a sister, and so on; therefore, extensive discussion is needed first. Extensive discussion is needed on the benefits and drawbacks. In this discussion, whether it took a longer time or shorter time the patient should know, so we have to agree on this. (we may be discussed) on When? In what process? How do we do it?, (but we should agree) that the patient needs to know. Because if the patient does not know, many problems will arise. The decisions, there are many decisions that need to be made by him; there are things that family does not know, but which the patient keeps secret, that he does not want his relatives to know, so we have to agree (with the family during the discussion). Hiding is hurting him, but when, in what way, at what time to tell him? I believe we need to plan with the family. I would recommend to deliver based on this process.

Investigator: very nice; Based on your experience, how do you think it should be delivered?

I9P9: So, if you ask me about my experience, I have been trained as a doctor. I use the methods and methods I have trained. I also believe it is necessary to modify some of the techniques by comparing that technique with our culture. For example, the first thing is how the technique simply works in English; No, in English, there is something called "going around the bush"; the first thing is to walk around, first, what do you know about this serious illness? And evaluate their knowledge, how much do they know about this problem? How much do you know about the risk to this patient? And what have they done so far? What was examined? What did doctors say? What are the results they are told? And they may already know that there is a serious problem in this process: If they know it will be easier to move on to the next one: But if they do not know that there is a serious problem, if there is indication then there is a need to delay. If they do not know if the person has cervical cancer, for example, and if she does not know how dangerous the cervical cancer itself is, then they have no knowledge. So, instead of simply saying that this disease is fatal and you will not survive, how often do you get sick? it would be better to go through like how often did he suffer? Why do you think he is not getting better? But if they already know about cancer and these kinds of things, he should proceed with what is the stage of the disease, approximately how much longer can he live; this is definitely controversial; When people hear prognosis, they are said to have three months left, and if they do not die after three months, they will be lost. In Ethiopia's context prognosis should be told carefully. But some kind of thing is given to them but it has to be grounded so because it is important for the medical profession. and there are issues that needs decision such as what kind of treatment should they take? Sell a house, do not sell it; should they be sent abroad or should they not, does he have enough time? Does he have enough money? What is the result of the treatment? Because everything they say has issues, they have to make these decisions, so they need to be explained clearly. And what is the benefit of being told? To make decisions. Why should bad news be told? For me first, to see what intervention can be done. After all, if money is spent, what will be the result? For example, if a seventy-year-old teacher has terminal illness and, for example, the person needs treatment for hepatitis; He must be able to think critically. I am seventy years old, I have Hepatitis, I have chronic liver Hepatitis; So should I get treatment for Hepatitis, or should I not? How much does it cost in the first place? Could it be a hundred thousand? Could it be two hundred thousand? Does a seventy-year-old teacher have a hundred thousand birr? Maybe he has children. He may have married late, given birth, and had children. What if he was asked if he had any? What he has is his house, should he sell his house, or should he not? What is the benefit? Liver disease to prevent chronic disease after 15 years of treatment. And 15 years later, how old is he to prevent cancer? Then 90. So, instead of deciding these things, we need to talk about what needs to be done to help them decide. And it is important specifically to tell the patient clearly. There would be reactions. So, gradually, seeing the reaction of the relatives, and then the patient; Doing it one day, seeing different situations by appointing different dates, how much do they accept? Invite them again, saying, Do you want to hear more serious, or do we have to do it another day? Looking at the signs, what is the main problem, is it cancer, is it HIV, can it be cured? What is needed is to go slowly, in different ways. The challenges are time, willingness, space. These are the challenges that need to be addressed. Sometimes they may not have time so they might say, just tell us. "Why are you going around the corner, just say the word?" There is another person who does not understand, so you have to be patient. And in terms of patient load, because of the large number of patients who come, it takes a long time to pay attention and it is difficult at our health facility to say so. In terms of load, however, special counseling service is required. For example, the experience of HIV is that one person sees 10 patients a day. Like that, like HIV counseling, bad news communication cannot be alongside with the regular practice. It has to be done on its own. Because time is of the essence.

Investigator: So what other cultural values should we keep in mind?

I9P9: When it comes to cultural values, it is good to see that some of the features of “Merdo” approach, even older ones, have been practiced. Some values I see, for example, bad news are reported in the morning, not at night. When I think about it, that person is going to cry all night, no one else is going to sleep all night, he is not going to rest and the other person is not going to rest, if told at night. So the reason why it is delivered in the morning is that he got rest at night and has a good mind, he receives the bad news in the morning. So he can wait until the funeral or for a while.

Because he is in a good position, he is calm, someone else will help you during the day, keeping in mind these things, for example this is a good cultural value. There are other things that are not good in the culture. For example, he condemns to tell bad news directly to the person with the problem. There is a belief that he says "how" and "it hurts". This is one of the challenges. I believe there are challenges to not talking about death, not talking about serious illness.

Investigator: Are there other issues to consider regarding religion, traditions, and customs?

I9P9: So, when it comes to faith, I do not see anything that prevents a person from knowing the problem. But sometimes rejection. When you say, "You have a serious illness," there are beliefs that encourage him not to accept so; don’t accept it, if you accept this news, it will happen to you. There is a religious impression that "if you do not accept it, it will not happen to you." So there are things that encourage denial. Other than that, we need to know that denial is sometimes a copying mechanism. So we have to be patient; that process takes some time, people struggle, fight, and that is a good thing. He prays for healing, takes holy water for healing, and tries different things. So it is energy for that. So denial is part of the process in the early stages. So, we can accept this and delay the cultural impact here. And copying mechanism protracted, from a religious point of view, denial can last, and I think that is a barrier to bed news communication.

Investigator: In terms of telling this bad news, in a traditional way, bad news, is there anything else we haven't talked about? Do you share your experience, your general preparation with the past?

I9P9: In terms of culture and religion, what was the word bad news communication simply? There is a word divination. It is said, "Do not speak bad divination." Bad divination means bad news, bad speech if they accept it; it will happen. If you do not accept it, deny it, and also happened. I think this has an effect. In our culture, it is called divination, speaking evil. Like divination, evil comes from speech rather than from reality; There is nothing else I can remember, I will tell you when I remember.

Investigator: Ok! You have already told me that patients have different reactions: And how did you manage those reactions? How should it be managed?

I9P9: Yes, in my case, some managements are wrong. For example, when he is upset and crying for example, to deny again is no… to say "OK! OK" This must be a mistake; to comfort that reaction, Not just denial or saying, "just leave it, the disease will be cured, what I was saying was" All you have to do is accept that emotion quietly for example, when he is crying, the other person bows his head in silence and starts talking after a while. But to give them time, if they are angry, to express their anger without panic, for example, when we tell the pilot that we know, he speaks angrily, believing that he should be angry. So we should say "yes" it is very sad, not it has no problem, according to our culture we should not say it does not matter, there is no problem. We do not have to say that but we often say that. And when the person is angry, instead of saying no, what makes you angry? Yes, you have good reason to be angry; by saying that there is a mistake in our side, we need to deal with the emotions of others.

Investigator: I am finished my question, if you have any ideas on this.

I9P9: So, in general, what is bad news in Amharic? Delivering bad news is a duty and responsibility of healthcare professionals. It is a right of patients and families to know, but, it is not their obligation. So I think, the patient should be asked such as do you want to know more about this issue? Would you like to know more about the extent of the damage? Do you want to?. If they say no, then it is their right to do so. We cannot force them. They do not have to know the truth; They have the right to know the truth and a healthcare professional has a responsibility to tell the truth. But we cannot force them to tell them. So this is basic. But we must have the skill, the skill. Such conditions can benefit patients in many ways. Their benefits outweigh their disadvantages. Bad news communication, the benefits outweigh the harms. But we must not force or tell because the benefits outweigh the costs or because we have the obligation to tell or because we have the right to tell. We must deliver it carefully, with consultation, with wisdom. So, what I want to say here is that it is our responsibility. But it is our responsibility and the skills we need to carry it out properly. So we have to try to get that skill as health professionals; "They don't want to know" and if we ignore that, we are doing harm. Therefore, we must not act as if we were careless, as if we were escaping. We have a responsibility but we cannot force it. In order for people to receive the bad news, we must develop good skills. If we neglect to let go, we are doing harm. Again, we are not acting in the best interest of the patient. We violate all ethical values. Therefore, I believe we need to train properly and deliver it properly.

Investigator: Thank you so much for our time.

I9P9: I thank you too.

INTERVIEW 7 I7P COMMUNITY MEMBER

Investigator: OK, thank you for your willingness to take part in this study and for the time you have given me. Introduce yourself first, including your age, family status,

T7P7: My name is________.My place of birth is Ilibabor. I am 57 years old;

Investigator: What about the family situation?

T7P7: I am married. I have 5 children. That’s all.

Investigator: What is your level of education?

T7P7: I am in the 12 grade.

Investigator: all right, thanks a lot. Now, as I told you earlier, the purpose of this study is to focus on the bad news. How do you think such bad news should be told if you or your family is sick?

T7P7: If one of my family is sick, it is best to let one of the family members be informed and know the degree to which the illness is mild or severe. If the patient is told too soon about the type of illness, he or she may develop other problems, such as lose of hope. So, it is good to tell his family that something is wrong. If it is on his own, for example, if the family feels the same way as I told you, then I think it is good for the family simply say that this disease is not bad and that there is nothing wrong with it.

Investigator: Explain it to me very well. You are speaking well now. How can it be said in a simple way?

T7P7: Take courage, for example! I do not know how to explain it, And be confident, you will be cured of the disease; Well, at least he didn't go down without explaining himself first I think so. Unless otherwise stated, in a discouraging manner; But the same process is only for deception, not really.

Investigator: Yes, it should be said as you said before: The family must be informed; You suggested that I tell my family if I was sick. As How do you think doctors or nurses should talk?

T7P7: Once you know the status, Consolation of hope, Let him not expect too much, to tell him not to expect that is for the family. Lest he be weary in waiting for his family; Not only discouraged but also discouraged and deserved: For example, by consulting a religious leader; I think it is better to take care of the person as long as he is there, to take care of him, and not to waste his resources.

Investigator: So which ones, we have different values regarding our culture.

There are different types of cultural activities. How can such a bad news be told in terms of our culture?

T7:P7: Culture? For example, is culture a religion or?

Investigator: It could be religious traditions like them, there are other values we have as a community, we Ethiopians say this culture does not allow; When we say bad news, we start with the words; Starting presentation, etc.?

T7P7: Well. . . (Silence)

Investigator: OK, how religiously, when doctors say such bad news, what should they consider?

T7P7: If he is a religious father, He may be called and teach many things. That man may be comforted by the word of God; they can teach. Then he would be comforted and would be able to go there even if he did not give up. I think it would be good if he used it that way.

Investigator: If you have ever had the experience of sharing bad news with your family, please share it with me.

T7:P7: Nothing happened to me, except at work, even in my family.

Investigator: what else? In particular, as I mentioned earlier, The main purpose of this study is to report the bad news in a culture-centered and patient-centered way, which I want to talk about more and that a disease such as cancer may not be cured in medicine at times; Treated, treated can be impossible. So to speak is that the medicine just doesn't work, your disease is incurable; What do you think about that?

T7P7: So, that obligation must speak; if he is in the final stages, he will be able to take care of his family and take care of him for the rest of his life; or he may be able to relax and have a good time. Organizations For example, there are different organizations that do a lot of things

Let those who teach him,

Investigator: In the case of such a serious health problem, in the case of a serious health problem, in terms of treatment, in terms of decision making; The current state of health, for example, is difficult to treat, such as cancer, so what should be the decision? Who do you think should make the decision in the treatment process?

T7P7: It is a family. It is up to the family to decide. I think the family should know that because he can not do anything on its own, the family asks for many things, and the care is on the family.

Investigator: all right. The other idea I mentioned earlier is that I still have to go back, and how much information do you think the patient should be told? How much information should be given? For example, when the doctor speaks, should he explain it well? Or is it something small? What do you think?

T7P7: No! I do not think it is necessary to explain it well. I think it is important to think only of certain good things. It is important to say it in a way that does not affect the person.

Investigator: all right! Should the patient know about such bad health news? Or should the family know? Or should it be told to both? In what way and who should know?

T7P7: First, the family needs to know. But at the end of the day, it is important for the patient to know that he or she has to prepare for many things.

Investigator: do you think the patient needs to be told at the last minute?

T7:P7: Yes!

Investigator: Why do you think it should be like that?

T7P7: He should not spend the rest of his time worrying, not giving up, not giving up, and not spending the rest of his time worrying.

Investigator: Well, in our culture, what do you think about talking about the rest of (the time left for) one's life?

T7P7: To begin with, who knows age? But to stay the rest of the time is the same, to ask God; It is asking God in prayer.
To the patient, take courage! By saying that God is the Savior.

Investigator: Sometimes in the health of some health professionals, in our country occasionally, then your disease has reached this stage. This is how long he will live, they say. What do you think about this?

T7P7: So; God knows. It should not be discouraging. Do not despair of God! However, a doctor can say that according to his profession. but, that person also should not give up and just wait for the day.

Investigator: How do you feel about it in terms of our culture?

T7:P7 it is also a duty and a duty of the professional, however it is certainly not appropriate to tell prognostications.
Investigator: So you have another idea, which I might not mention; In terms of telling this bad news. tell me if you think it would be good for health professionals to consider it?

T7P7: I really do not think there is anything wrong with the health professional. It is necessary; because they have to tell; They have to tell. But if it is possible, I do not think it is possible, but because a sick person will go on his own. So by not making him panic; I think it would be good if he spent the rest of the time talking to the doctors about what to do, how to say it. However, there is nothing wrong with saying that what a health professional says. Because it is necessary, it is a matter of profession, but that person must prepare himself.

Investigator: What kind of support is best for him? When such bad news is reported to a patient, family, what kind of support do you think is good?

T7P7: Support should be provided spiritually, psychologically.

Investigator: Thank you so much for the time you gave me, for the interview.

T7P7: Thank you too.

INTERVIEW 1 I1P1 PATIENT

Data collection procedures: I have obtained the letter of permission from Hospice Ethiopia. Then, the palliative care department linked me with the home care leader, Nurse Filagot Tadele at Hospice Ethiopia. I spoke with Filagot and briefly shared about the purpose of the study, inclusion criteria and requested to find the right prospective participant over the phone. Three days later, she told me that she has talked with the prospective participant and informed me to do the interview at the participant's home. I and Filagot met in person and explained more about the study two hour before the making the interview. Then Filagot has connected me with the participant, we went to the participant's home together, and she stayed with me during the interview. The study participant (Muna Kebede) welcomed us with a warmest smile. She invited us to get into her home, and we took a seat. Nurse Filagot and Muna have exchanged greetings for some time.

I introduced about myself; my name, professional background, work place, what I am studying/doing and the reason I come to her home. I had explained about the purpose of the study, benefits and risk of harm to participate in the study, confidentiality, and why she is selected. I also have explained that her participation is entirely voluntary based, the right of refuse or withdraw from the interview, and either of her decision will not affect the care she is receiving through Hospice Ethiopia. I also have offered a chance to ask any question or clarification prior to consent, but she did not have questions. She mentioned

she is pleased to take part and participate in the study. A written informed consent was taken, and the participant signed on informed consent prior to the interview.
The investigator provided a bottle of water for the participant.

COVID protocol followed during fieldwork to conduct face-to-face in-depth interview: I made sure that I and the nurse had no signs of COVID-19 infection first of all. In addition, the principal data collector (I) and nurse Filagot have used surgical face mask to adhere to COVID-19 prevention and control measures. Moreover, We have used alcohol based hand sanitizer before the interview, during using and sharing pen and after the interview. We have maintained a 1.5 meter distance as well as kept the door open during the interview.

Face-to-face in-depth interview:

The participant's Socio-demography: She is a 36-years old, female living with her 11years of daughter in Addis Ababa. She follows evangelism Christianity. She has elementary level, grade 3 education.

Investigator (Ephrem):- Ok Muna, I am sincerely thank you, first, I thank you very much for your willingness to participate and dedicating your time to participate in the study. I think that I will learn a lot from you. It is to learn from you. Thank you. As I have explained earlier the focus of my interview is that I want to know about your general health condition and to learn and understand your view on your illness. First of all, and prior to the next interview, please introduce me about yourself; tell me about yourself.

I1P1- My name is Muna Kebede. I was born and raised here in Addis Ababa. Hmmm… I am the mother of a child. I have had done prostitution; I have spent a lot of time in street life; Hmmm…that is my first life on the street and as a prostitute. I have gone through different journey in life. I have come here today with God. I have a daughter, her name is Rachel Abdu. My illness is that I have HIV, I am taking anti epilepsy (medications) and I have cervical cancer.

Investigator- Ahaaa….Ok, you know that you've been told that you now have the epilepsy, cancer, HIV. I guess that you've been told these diseases in different times by the doctor. Yes, the participants replied during the investigator talk. The investigator continued asking, look at the previous time and tell me in what way they told you? what was the situation like in general? Ammm… when an illness, such as life-threatening, and bad health news are communicated, how and in what way do you think it would be nice to be told; share me your journey based on your experience?

I1P1- When I first found out about HIV, I didn't have a child, I was shocked, I didn't say anything. At that time they tell (without care). It is said to be there a counselling. But, I did not have (receive care) as such. I was not cared for well, but I was shocked. First I was like (questioning) how could this happened? There was time I stopped taking my drugs. But when I stopped, I hurt no one, but myself. I want to teach this, stopping taking medicines hurts the patient. I had discontinued, and I started the medication when I was pregnant with my child. At present, I lost weight, because I had discontinued my medications. Discontinuing and taking medicines incorrectly hurts; I have had hurt myself, not the doctor. I made a mistakes, I made that things wrong. Because I did not hear (take it painlessly or follow). I even had tried to spoil (revenge) many people. I made many mistakes. I used to be doing openly. I do not care if anyone knows that I have (HIV) it, because I want to teach. Even I want to teach the person who have (HIV) it. Discontinuing taking medicine means very….

Investigator- why did you discontinue your medicines?

I1P1- I was desperate. At one time that discourages you, it's very disgusting when you think about the life I was in, like in the street; I discontinued so many times. I mean I have discontinued twice. I was admitted to mother Theresa home when I was sick. I come across many things….Hmmmm….Pause. For that reason, I want to teach: Especially, discontinuing taking anti-HIV medicine hurts the person. The doctors gives me advice; It was due to my own reasons. But, praise God I am alive today. Thanks to God. The doctors would advise me. There was a time I had been traced when I was discontinued and refuse to take my medicines. I began to take appropriately when my first child is died. I have lost my first baby. Who made that mistake? By my own fault? My own mistake. Pause…..

Investigator- When were you told you had HIV?

I1P1- At least it has been seven years. Is not this baby Ten/eleven years old? before that.

Investigator- you remember in general when they told you that you had HIV in your blood at that time, how was your communication with the doctor and they was he told you?

It was disgusting. It was disgusting. It was not like this time. The approach was disgusting. It is bad when it is like that. It is better this day when I knew about my cancer. I insult the doctors. When the human being (the person/patient) is told, he needs something, he needs a treatment (care), as you said earlier. Did you understand it? He may get upset, he could say something; he may ask why to me and do something to himself. I was shocked. When I was told that I had HIV, it was in a bad approach. There was a rumour that they (healthcare professionals) tell you in a good way and treat you well. But, it did not happen when I was told the first time. But nurses are better than doctors sometimes, they treat you and do something. Doctors tell you directly. That shall not happen. When it comes to a question like what if you have it; they say to you what would you feel if you have it or not. For me, I live like anybody whether I have it or not. The difference is just taking the pills. Otherwise, you can eat, can drink, and work if you can.

Investigator- When you say it was disgusting at that time, what went disgusting, explain for me more

I1P1- His discourse. What will happen to you (you feel) if you have it. This is disappointing. That means he told me (something is wrong) frankly (directly). It would have been nice if the question was like what if you do not have, first. The discourse, if you have it had some (adverse) influence when doctors communicate previously, I do not know currently. But, when I have been diagnosed with cervical cancer, they've called me and done many investigations of my pain, but they have found nothing. Then, they informed me and asked my permission to do the other investigations. I thank them, now a days. But, the past is disgusting.

Investigator- Tell me what the process was when they told you. What went well good for you? like you said now, explain it more

More Hmmm….What is better for me is that they treated me, but there was much improvement. Therefore, they asked me to get a cervical cancer investigations voluntarily, no one forced me to do it. Then, I said it is not a problem if I get cured. (They said to me), Muna, you should accept it, there is a chance to get cured; You may not have it or you may have it. They gave me this advice first at the health center. Then they advised me not to give up, and said you are good. So that I can't be discouraged. We have discussed it. They told me so many times. Let me get tested, no problem (I said). But, they told me (advised me) many times not to be desperate what if this thing (the cancer) is diagnosed. It has many hope for cure, if I take the treatment appropriately. They gave me that hope. Then, I have started my treatment. When they review the results of the treatment, it (the disease) remains the same. They immediately referred me then. If it was treatable at their level they would have done it there. But, they referred me (to hospital). They let me to seat down and advised me. They advised me that they are sending me for better treatment. It is not because they could not fix it there, but for better treatment. Hmmm…I want to thank Bole health center. They really have advised me. What they have for me is pleasing/ good.

Investigator- You told me the nurses were well looked after you, so how was their care? How did they care for you?

I1P1- their advice. They call you, and in all things. They give advice. Hmmm…their advices. Hmmm…They advise more than anyone else, I am pleased at at this health center.

Investigator- Aha…How much would you like to know about your health and illness? How much information would you want to know?

Participant- I would love to know. Knowing my problems will help me to live with hope.. You got it? You enjoy yourself with your child, and you play like anyone, and die if your day comes. That is inevitable. I am not the one who brought the day, it is God. It is in your day; you may die of a simple stone hit. Illness also belongs to Satan. It is not ours. Because it belongs to demons, it may be taken off in his day. In the time that God permits, it will be taken away. You will be saved. You may get sick, but, you will be saved and in

God, you will walk like anybody; that will happen. Hmmm…God, I took all that treatments, I would be pleased to know what it is.

Investigator- What do you meat what it is?

I1P1- I want to learn on the diseases. I would like to know (discuss) about my diseases like I discuss with you about it now, and live with it. It is possible to live. I would be glad because I will take lessons for my own; I will take first for my child, and my neighbor and other people. I would disclose my and be able to teach others. It is nice for me, if I know it.

Investigator-When you say if I know it about the situation? I1P1- Yes, if I understand more about it. Understand more about it

Investigator-Is that to know/determine the stage/status or…..

I1P1- I want to understand it. If they explain to me like this and that, if they describe it; you are more of a professional than I am, so if you teach me, I should understand it. God gives wisdom. God has given you wisdom. You are given for us under God. We can learn from you. Pause…..That is what I would say.

Investigator- Beautiful. The other thing, Muna how would you think such kinds of health related bad or serious new should be told for patient based on your experience?

I1P1- For me, it should be told with love and by someone like the nurse, especially if the patient has no family. What's the problem if we talk about it? First, if he is informed indirectly, as if it happened to someone else, and with appropriate reassurance (small at a time). If he is informed immediately, that person may commit suicide. Some people are good at it and can deal with it, but others may lose hope quickly or become desperate. When your hope is broken, and all of your other problems load on top of each other, you may become psychologically ill. I am pleased for sister (the nurse) because she treats me. She gets closer and the way she treats is nice. Hmmm….Pause. At hospital, if it has given something like half an hour and informed of his illness he (the patient) will be pleased. If he is told that he can live like with others, and if he knows that hmmm….God is helping him with his needs, I hope he will survive. Hmmm….He needs the doctors' help. The problem is that the doctors tell you directly, immediately. But, it would have been good if they treat (care) you, inform you that you can survive and live with others when they tell you. (Her phone was ringing in the middle of her talk and she rejected it). Pause….

Investigator-Hmmm…please explain more about what you mean by if they treat. You also told me that sister (the nurse) treats you and you sad that it would be good if the healthcare workers treat when they tell him. Hmmm…You raised a good idea, how would you think they need to treat, explain it more.

I1P1- If the doctor could not tell alone, it would be good to involve a nurse. (The phone call comes in again, and she rejected it). As to me, it would be good, if they connect her with a nurse and reassure that it is possible to live with. I really thank God for sister (nurse Filagot). Let God gives you (the nurse) the strength. I am pleased (for her).

Investigator- Hmmm…The patient will go for treatment after his illness is diagnosed right? Yes, Muna said. About the treatment, the types of treatments, a sort of differ things…..(The phone call comes in again, and the investigator said it is not a problem, answer and will continues. She answered the call). She is my friend let us continue, it has no a problem, Muna said. Hmmm…I was asking you about the type and amount of information, and when the illness is serious the treatment will also not be simple, and it may be related to various issue such as costs, its side effects.

I1P1- like I told you earlier, when I wanted to know the level of my white blood cell (CD4), I am telling you the truth, I have had no health insurance. I do not have health insurance. Even if you have the insurance you do not get (medicines and tests) it especially at the public hospitals. Leave alone four or seven thousand birr, I did not have one birr. It is in the help of God. The cost was five thousand birr for the injection used to test the stage of the cancer. The drug is tough by itself. Where could I get five thousand birr? I could not find it there (at public hospital); it is found outside (of the hospital pharmacy). I thank the Ethiopian people, I asked. I have taken the injection and found that it is stage four. The stage….Hmmm… I have heard that there are injectable medicines they are expensive when others bought them. What about those who have no capacity (to buy)? You see?

The hospitals say we give free service, but you don’t get them mostly. You will find them outside. What will happen to the person who does not have the (financial) capacity to buy? If God does not connect you with such organization….it is painful when you hear that people with cancer, and kidney disease seek for help. It would have been great if the treatment is available here in Ethiopia. Pause….

Investigator- So, who do you think should make the decision about treatment?

I1P1- the government.

Investigator- Hmmm….I mean, the type of treatment that you need to take after you have diagnosed with cancer, for example.

Participant- the doctor, when the doctor communicate and make the decision…..

Investigator- in what way, who do you think should be involved?

I1P1- first, the government should be involved. For example, you will not get them at black lion hospital. I have bought that medicine birr five thousand outside of the hospital with the help of others. Also, I began chemotherapy, but it is not available in that hospital. It is available outside of the public hospital and costs fifteen thousand birr. How could I afford that? I am telling you honestly, I would say let God gives me the healing. The treatment makes you worried. I still worry about the treatment. It is not the disease makes me worried, rather whether the medicine be accessible that makes me worried. If you take chemotherapy, you also need somebody who will say something (reassure/assist) you. You may encourage yourself. The medicine is tough.

Investigator- There are different types of chemotherapy; like you said it now, if it is needed to take (prescribe) chemotherapy. When the doctor decides the types of medicine to be taken and want to give to the patient, how would you think he needs to make the decision, alone? Or should he include individuals like the patient family? From this perspective, who do you think needs to be involved in the decision process when the treatment is prescribed?

I1P1- family should be involved, if they present or available. The doctor needs to involve family when he gives this things (treatments), not alone, because it may be serious. There are some types of foods to eat with the medicines, and type of illness. You got it? Family should do that. If family is not available, there are (charity) organizations. It should be informed to such institution/ organization, and say take this medicines and do this and that

Investigator- which kind of organization do mean, when you say such institution/organization?

I1P1- Like the sister's (the nurse Filagot; Hospice Ethiopia)

Investigator- You already have been told that you have HIV, cancer and Hmmm….you are taking medicines. I would like to know what helped / assisted you to cope with it after you have heard the bad news.

I1P1- For me it is God! It is not by my capacity/power. To be honest, it is God who has helped me in any ways. I am careless. I want to live relaxed and do not want to be worried. That is the reason I do not want to get married as it causes stress. If I get it (food) I will eat, if not I take sleep with my child. I do not want to be stressful. It is God who has encouraged me; it could not happen in my capacity. God gave me the strength. You also feel encouraged when you see other patients in worst situation. I am not in bed. I thank God. I can walk; when you thank God, he will add to you more blessings. Praising is above all. I am not admitted to hospital; thanks be to God. I do walk like anybody and I can do something; what if I was admitted to hospital? You see? You would need a person for positioning….pause….

Investigator- Hmmm….I am very glad about what you are telling me and it makes me eager to know more. How God did helped you? Like you said earlier, it is God who helped you to cope up with your problems. How and in what way helped you, explain it more.

I1P1- Praise; when you thank (God) it will be add to you. It will not be taken off from you. Whether it happens or not; whether it is successful or not. I thank Him very much. I used to eat leftover foods on street. I had said to Him, if really you are present, take me out of this life. Above all, that (street life) is the worst life for me and I hate it.

Investigator- which one?

I1P1-the first one, the one I used to lived. The reason was that I was raped by my uncle. Please say it is enough, you gave me this baby. It is more difficult to raise a female baby in this situation. If it was bot, he could have survive in any way. Honestly speaking, I do not want a female to pass through that life. I do not want her to live it as I did. It is very tough. Hmmm….I was raped by my uncle so that I left my parent's home. I used to smoke, drink and chew kchat. It is God who said that it is enough; who else? if you look at my own way and how much I was drinking and chew Kchat, I would have discontinued my medicines. I had discontinued twice. Pause……The one I take it twice a day

Investigator- which medicine?

I1P1- The ART. It is through God's encouragement, not by myself. Nothing will happen in my capacity when I live in this world. I had overcome Corona by the help of God. I prayed, Lord help me for the sake of my child, I would also say it now, please encourage me until she get mature; you (God) encourage me; I want your encouragement, not mine. You need to have God more than humans. You need humans next to God who will reassure you. When I was wondering the nurse visit and asking why the nurse did not call, she called me yesterday. I was surprised by the coincidence. I would have call to her today. I have stayed at home when you (the nurse) say I will come. She said we are like family. It gives a pleasure when you receive the word how are you doing. She may have a lot of work, I understand that and she may not (be able) come to visit me. But, when she says how are you, Muna, I feel as if I have somebody. That gives you a pleasure. You see. God has given me; there are many else. I feel upset when it is only me perusing and call them and say, why they (friends/family) do not call me. Would they think that I am perusing to call them just for my problem? You think like that, thus you decrease approaching them.

Investigator- Hmmm….when doctors, nurses tell bad news what kind of cultural rituals should be considered? According to Ethiopian culture, your life expectance and belief, what would you think that should be considered and would be good when bad news is delivered?

I1P1- For the patient, it would be good if they first ask him his religious faith in order to accommodate both means. It would be good, if they ask your religious faith and tell you to take your medicine in accordance with your beliefs and rituals; we lost many people who had stopped their medicines and use holy water only. Poor understanding. They stopped their medicines when they start to use holy water. Let me tell you from my experience; I have had received a message in the church and I had stopped taking medicines for a couple of days. But, I would have taken them both. I did not consult a doctor. But, I sat down and I asked myself, why did I do this? Then, I have consulted a security guy in the church and he said, “Do not discontinue your medicine”. You can take your medicine and pray. Then test and you may be free; you can stop at that time. I have started taking the medicines immediately.

Investigator-what was the message?

I1P1- You are cured from your situation.

Investigator- Which of your illness?

I1P1- HIV

Investigator-Did he tell you openly as if you are cured from HIV?

I1P1- yes, I had stopped that things as I was told that

Investigator- what you do mean by ‘that things’?

I1P1- I had stopped the anti-epilepsy drugs too. I had suffered due to that. I should not do that. Because, I could have test while I was taking the medicines, but I threw the medicines in the church. I have collected (the medicines) again (from health center). The nurses should have had to understand it, but they were upset at me. They had to understand it. I told her that ‘faith is personal, but nation (country) is mutual’. I may have my own faith like any one may have a belief. They asked me as, why you did not consult a doctor first? You are there under God, I said to her. God has given you under him. I had received the message and believe in it so that I had threw over it. Why do you come if you believe in it and helped?, (they asked me). To take both together. You see, there are such kind of weakness among the doctors and nurses. They should have to understand that. Of course, there are more nurses in the health center

Investigator- what was the reason she got upset at you?

I1P1- Because I stopped the medicines. She should have to advise me as I can do both together rather be angry at me.

Investigator- very good. Now, you told me that doctors or nurses should take the patient's belief/faith in to consideration when they tell such kind of bad news. From our culture perspective, what should they take in to account when they tell such kind of bad news for a patient? Our religion/faith is one of part of culture. As Ethiopian residence what cultural doctors or nurses should take in account when, for example they tell the patient bad news such as a cancer diagnosis or HIV or poor prognosis of cancer? You told me well that they need to consider the patient's belief/faith, what else do you think they should consider according to our culture?

I1P1- If it is according to our culture, it (the illness) can upset the patient. Illness (should be managed) with patience, and patience is needed, we may feel sadness, uncomfortable when we are in that position, or we may be upset and speak (bad words) to them there, and if they respond in the same way we will go to in problem together. I would be pleased if they have patience.

Investigator- What you're telling me is a good thing right now……in what way you wanted to be told, for example should such bad news be told for the patient or the family or both or…. in what condition should be told? What is your thought? tell me from your experience.

I1P1- it should be with the family if you have family. Some (people) with HIV hide a family. That person will be hurt, if it is disclosed in the future; will not that person be hurt? The patient will be hurt. He would live worried on whispered or confidentiality if heard tomorrow. You should not worry rather live freely. God is there more than any of you and other persons. God knows that (the situation). That person is a human being like you. He is perishable. It does not matter whether he knows or not, but is the family knows….I know a lady who hide from her husband. What if he has it? Wouldn't hurt? All the neighborhood right here know about me. Because if I am in problem they are the one who will help me. I should care for them. I understand that they will respect me by knowing it, they will not stigmatize me. I would be respected. But you may be insulted by a stupid guy; what would you do? You would contempt him and leave it. It will knock his door tomorrow. I will knock everyone's door tomorrow. If you are insulted by him, you leave it, it will be a message for him.

Investigator-Let us see in terms of cancer, who should be told an illness like cancer?

I1P1- If it is cancer the owner (patient) should know.

Investigator- When you say the owner, the patient?

I1P1- The patient. If there is family with family. If he has no family, if the doctor tells him that he can be cured and what it there, that will encourage him. If you give him smile face, that will strengthen him. That is it as to me.

Investigator- what do think has benefits of knowing him how to treat the illness, he will do them. There is a doctor here, she is called Beza. I told her (about me) and she said to me, do something that gives you a pleasure at home and listen to music. When you have happiness in you, and when you dance you would forget it. It needs a pleasure as I understood about it.

Investigator- What did you get benefited by knowing? What are the benefits you have got by knowing or being told that you have illness such as cancer, HIV?

I1P1- I am pleased. There is no (problem) so far. The benefit for me is that I can teach someone else, who is in distressed. I can teach. If cancer present, I know that it can be cured. I can teach the other. You can live freely. There would be nothing to makes you worried. I am glad I know (about) myself. What if I do not know? I would die at home before I go to hospital. I am taking my medicines as I know it. If I know the stage…..the white blood cell should be corrected. I have learned about white blood cell. This is a big deal for me. I am learning. Which means I am going to fix what I need to fix.

Investigator- Please tell me more what you mean by ‘what I need to fix’?

I1P1- Hmm…how I should fix the white blood cell. I am told that the white blood cell should be fixed to take chemotherapy, is it not? How to fix my white blood cell. Today, even my body speaks (that I have gained weight), even sister (the nurse) can witness. It is because I am taking my medicines appropriately, I know on my condition, and I have not worries. That helps to fix. I started the medicine and walk away like anybody. Knowing about self is above all. If you get sick tomorrow…(pause), you will die; it is inevitable. Unwittingly; but it is a pleasure to know. If you know, you take you medicines. Even if you do not have something, you may beg. You might beg and get treatment. It is a great pleasure to know. You can keep yourself and your child… pause.. Hmmm….from anything like obeying what doctors said do not. But, our weakness is that we do not follow the doctor’s advice because hmmm….There are perceptions that how the doctor knows about us as he does not know for himself. God is the giver of wisdom, I speak it again. God has these healthcare workers. Our weakness is that we underestimate their knowledge; would they be there if they did not know? He thought me as he has the knowledge. Disease belong to Satan. The doctor is there to diagnose the disease. That illness. Hmmm….The doctor will give you his medicines. You can keep your faith or belief and be cured. You will be saved either by the doctor of by God. You can be saved by both. Paused…..

Investigator- Let us say that by chance if the illness is incurable, as Hmmm….all illness cannot be cured. Hmmm….or the treatments may not bring the expected results and the illness may get worse. So Hmmm….if the disease gets progressed and become incurable, what benefits patients would get by knowing it? Now, you described me mainly the benefits of knowing bad news such as taking the prescribed medicines properly, as caring for himself and so on. Hmmmm Let us the illness is incurable what would be the benefits for the patient of knowing, describe it more.

I1P1- Muna- it cannot be. If it is not curable, the patient needs to persuade his mind with the doctor. He should treat it with the doctor, and family. If it is incurable and beyond the capacity, there is nothing the doctor can do. So that he would go to his creator without having a lot of suffering, but if God wants him to live longer he may take his own decision. I think so. Hmmmm It is your mind that you should work on and convince it. If there is no solution or cure, there is nothing you can do. Why do you struggle with yourself? You would fight with others, with yourself, and with your Creator, and finally you would get madness and die without the knowledge of your family and even your family may not be there for funeral. So, if you convince your mind either you survive or die. That is, it is about mind. You need to work on your mind first. This is how I think.

Investigator- I am done my questions. Finally, if you have anything else, any idea that you may add about breaking bad new let me give you the chance for you.

I1P1- I have said most of them, there is nothing I may add. There is a (limitation) in government hospital, so let the government hospital treat them.

Investigator- How should they treat them?

I1P1- Treat means to have a talk with that person closely. You may not have enough time, but if you have given them half an hour that people would be pleased. They make you angry at hospital; I fought with them at Tikur anbesa hospital. They do not treat fairly and they give priority unfairly. Everybody is your kinship in spite of the fact the you do not have blood relationship.

Investigator- I thank you very much for the time we had.

I1P1- I thank you very much too.

Investigator- May God bless you.

I1P1- You are welcome.

CULTURALLY SENSITIVE GUIDELINES FOR DELIVERING BAD NEWS IN PALLIATIVE CARE: ETHIOPIA

Experts Review Report

Introduction: This guideline for delivering bad news is developed and sent to experts comprising of healthcare professionals, community members. Experts were requested to review and evaluate the protocol and provide their response using open ended questions towards the feasibility, cultural sensitivity (if it embraces the cultural values, beliefs), clarity and applicability of the guideline. Moreover, they were requested to check for the accuracy of the cultural issues, relevance and to give any feedback or comments on the guideline. All participants were asked if they recommend the guideline be used in palliative care and all agreed to be used and emphasized its significant roles and it assists when breaking bad news. This report provides a brief summary of some of the comments delivered by the experts.

Reference (Participant)	**Feedback**
HCP-1	I found the guidelines interesting, appropriate and relevant in the field of palliative care. Warning statements before telling bad news should get enough attention. The patient should be well prepared before breaking bad news. When the patient's family is involved in delivering bad news, they should be prepared to avoid extreme emotional reactions that may hurt the patient. The task of breaking bad news should be a one-time event; it needs follow up and continued conversations in different time. "Who shall tell the bad news shall be elaborated well". "Otherwise, an excellent document" (HCP-1)
HCP-2	I suggest presenting the guideline in tabular or flow chart. Should the patient be accompanied by family or should only the family be told or patient alone. How does one decided which approach to take? The assessment step: you must come up with ideal questions or a collection of questions that help assess the areas you indicated (annexed or footnoted) without that your recommendation is incomplete. What if family members refuse or do not agree with telling bad news? What does one do? Proceed against their wish or negotiate with family? If the later how to negotiate?

	Knowing the patient's background is important to reassure using religious belief sounding terms. "What is not possible for human is possible to God" if patient is religious. This is a general statement that may help people of all religion. The guideline suggests to "fix an appointment for further discussion…." I think not only fixing an appointment but also need to take time and convince the patient that such follow-up visits and support are helpful to him/her. If patient finds traveling pointless, costly or a cause for discomfort, then arrange either telephone communications or home visits if resource allows. A flow chart or tabular presentation of the guideline could make the guideline easier to follow.
HCP-3	I read the draft guideline and found it wonderful with detailed explanation of its steps. But I have the following comments: My suggestion would be: make an introduction statement to the guideline. E.g. breaking bad news have 6 steps and use mnemonics PAPDAS and learning from the Ethiopian cultural concepts and values of breaking bad news (meredo). Consider the perceptions about life, disease, and death. All the truth should not be communicated at once. This should be suggested in the guideline. When I attempt to breaking bad news, I face the patient doesn't know about his/her disease and only need to relive his/her pain. So how would you address this in the protocol? If family members hear bad news first you bridge autonomy, if patient hear first, you bridge family trust and blames you about patient prognosis so how can you proceed is the biggest question
HCP-4	Assess: Introducing ourselves, the team and explaining their responsibility, before that greeting by standing from our sitting showing respect, allowing them to introduce themselves will open the floor for further communication. Accommodation of family needs: Family members may be informed first depending on the mental status of the patient's age, readiness of the patient, educational background closeness of the family. "This can be done by ensuring how much you care for the patient when you tell, by saying that mostly patients want to hear of their illness, and that you break bad news if the patient is willing to hear or be told. It is also useful to disclose the downsides of hiding from the patient including patient's right to know" this is perfectly explained. In our culture we fear of saying the truth in front of others so we should ask the patient privately who he/she really wants to be there during breaking bad news.
HCP-5	I trust that this guideline will aid the healthcare workers to convey bad news and help patients be aware of their conditions and improve the

	quality of our services in palliative care. When we provide care in an acceptable manner, the patient benefits emotionally, accepts the diagnosis, is motivated to pursue curative treatments, and is aware of the nature of the illness and its prognosis. This guideline meets the expectations and values of our community and culture established in all public and private healthcare facilities. My issue is that public health facilities have little time and must find it difficult to facilitate private rooms while still managing to do so at the bedside. The guideline is quite helpful for both our patients and our team.
HCP-6	One of the most crucial steps in this guideline is step one which is planning for breaking bad news in order to give providers time to get ready. This step is crucial for all subsequent steps as well. Knowing the patient's and family's background makes it easier for the provider to know how and in what way to convey the information in step two, which is crucial. Step three is necessary, however in our nation's government hospitals, there is a unique debate over time, place, and professions. How should this be implemented, in your opinion? In the fourth step: Regarding a religious perspective, it is excellent, especially in our culture. Step five is well done. In general, the steps are highly beneficial, applicable and the protocol helps for breaking bad news effectively, to demonstrate breaking bad news in a systematic, organized, and professional manner.
HCP-7	I think this is a nice protocol and relevant for our practice. I would suggest taking lesson from Merdo and make some English words clearer. Terms like Ash should be replaced with “Emnet”. Using religious rituals like Kibakidus, Tsebel should be stated as part of important cultural values. It would be better to use metaphor when appropriate.
Com-8	I have taken the time and seen the document. I would like to thank you for your great work. This is an area where there is a big gap when serious illness is diagnosed. I think the guidelines have adapted our cultural values and religious perspectives. A sympathetic approach is required when telling serious news in our culture. My recommendation would be reassuring with religious view and terms.
Com-9	It is well done guideline. I think it is acceptable to our culture if one could follow this protocol. It has embraced our values and scientifically sounding approaches for communication. I would suggest the doctors should break bad news sympathetically. I appreciated the gradual approach recommended by the protocol. I want to add that introduction before breaking bad news should be recommended. Otherwise, I am

	convinced the guideline depicted our cultural issues in breaking bad news and it will be very helpful in the field.