



# MONASH University

***Investigation of a Sustainable Public Health Approach to the Provision of  
Palliative Care: A Regional Case-Study in Ethiopia***

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A thesis submitted for the degree of *Doctor of Philosophy* at

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*Faculty of Medicine, Nursing and Health Sciences*

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## Abstract

Access to palliative care is an international human right. Of the estimated 40 million in need of palliative care annually, only 14% have accessed it. In low-and middle-income countries, 78% of adults need palliative care. Despite increased development in Africa, only 5% of those in need of palliative care have access. In Ethiopia, palliative care unmet need is increasing due to factors including improvement in the treatment of communicable disease, increased ageing, and non-communicable diseases. Despite palliative care being included in national health policies and guidelines, millions of people in Ethiopia have limited access to palliative care.

The aim of this study was to understand, investigate and make recommendations for a sustainable public health approach to the provision of palliative care in rural and regional Ethiopia. The research questions driving the study were: what is the current palliative care status in rural and regional Ethiopia and, how could a sustainable public health approach be implemented in rural and regional Ethiopia?

A multiple embedded mixed method case study design was used: a survey embedded with two cases was conducted. A self-administered questionnaire was used to collect the quantitative data, whilst the qualitative data included interviews and focus group discussions. A total of 173 participants completed the survey. In the qualitative data, 38 interviews and two focus groups with eight members each, were analysed. The World Health Organization Public Health Strategy was used as a theoretical framework for the data analysis and discussion of the findings.

Overall, greater than 40% of participants of the Context, Case 1 and Case 2 responded correctly to the modified version of Palliative Care Quiz for Nursing (PCQN). In all health care settings, the pain and symptom management category was most poorly answered; and the psychological care category of PCQN was the best answered. In total, more than 50% participants correctly responded to the modified version of Frommelt Attitudes Toward Care of the Dying Scale (FACTOD-B) with the lowest correctly responded to the communication part and highest correctly responded to the family as caring part of the FACTOD-B. Majority of participants from the Context (77 (87%), Case 1 (31, 88.6%), and Case 2 (32, 65%) scored lower than 75% for self-reported palliative care practice. The survey results indicates that despite that participants had positive attitudes to providing palliative care, they had insufficient knowledge and poorer self-reported practice in the three health care levels

(Context, Case 1 and 2), which was supported by the qualitative findings. The qualitative findings indicated that despite palliative care being included in national health policies and guidelines, only a few leaders were aware of them. The professionals at the bedside had no access to these documents and were unaware of their existence. In addition, palliative care was not integrated to the undergraduate health care curricula. For this reason, professionals lacked awareness of palliative care, and the consequence of this meant that the community had low palliative care awareness. Despite the doctors' attitudes towards morphine prescription were improved, there was inconsistent availability of morphine in the tertiary hospital and Case 2 general hospitals and none in the Case 1 general hospital or primary health care units. For this reason, professionals mostly prescribed tramadol as an alternative pain medication for morphine. Palliative care or pain management training was delivered to a few professional staff especially to the staff working in HIV clinic/ ART staff. In addition, palliative care was only implemented for patients with human immunodeficiency virus in health care settings as well as in patients' homes, the service was not delivered to other chronically ill patients. This may be due to NGO financial support for HIV projects in all levels of health care settings, lack of palliative care integration to the existing health care system and the national health care budgets. Therefore, the findings indicated that there was limited access to palliative care in rural and regional health care settings. However, potential strategies for sustainable palliative care were described: families provided care at home; Health Extension Workers promoted community health through education and home visits; psychosocial support was provided by several volunteer groups; the health care system is networked; and mobile phones are used for health care issues. It is recommended that palliative care training be facilitated within training organisations, policymakers consider including palliative care in Health Extension Workers components of care and the existing health systems. Further, strategies to enhance supply and accessibility of morphine should be considered for the development of palliative care in rural and regional Ethiopia.



## Publications during enrolment

1. Aregay, A., O'Connor, M., Stow, J., Ayers, N., & Lee, S. (2020). Strategies used to establish palliative care in rural low-and middle-income countries: an integrative review. *Health Policy and Planning*, 35(8), 1110-1129.

## Thesis including published works declaration

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes one original paper published in peer reviewed journals. The core theme of the thesis is strategies for sustainable rural and regional palliative care. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the student, working within the Monash University, Faculty of Medicine, Nursing and Health Sciences, school of Nursing and Midwifery under the supervision of Associate Professor Susan Lee, Emeritus Professor Margaret O'Connor, Dr Jill Stow, and Dr Nicola Ayers.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

In the case of chapter two, my contribution to the work involved the following:

Thesis Chapter	Publication Title	Status (published, in press, accepted or returned for revision, submitted)	Nature and % of student contribution	Co-author name(s) Nature and % of Co-author's contribution*	Co-author(s), Monash student Y/N*
2	Strategies used to establish palliative care in rural low- and middle-income countries: an integrative review	<i>Published</i>	<i>50%. Concept design, collecting data and data analysis, writing first draft</i>	1) Associate Professor Susan Lee, <i>concept, design, data analysis and input into manuscript</i> 25% 2) Emeritus Professor Margaret	<i>No</i>

				O'Connor, <i>input into manuscript 15%</i> 3) Dr Jill Stow, <i>input into manuscript 5%</i> 4) Dr Nicola Ayers, <i>input into manuscript 5%</i>	
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I hereby certify that the above declaration correctly reflects the nature and extent of the student's and co-authors' contributions to this work. In instances where I am not the responsible author, I have consulted with the responsible author to agree on the respective contributions of the authors.

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## Table of contents

Copyright Notice.....	ii
Abstract.....	iii
Publications during enrolment .....	v
Thesis including published works declaration .....	vi
Acknowledgments.....	viii
Table of contents.....	ix
List of tables.....	xiii
List of figures.....	xiv
List of Abbreviations .....	xv
Glossary of Terms.....	xvi
Chapter One: Introduction .....	1
Background to the study.....	2
Global overview in palliative care.....	2
Palliative care in low-and middle-income countries .....	3
Palliative care in Ethiopia.....	4
Research questions and aim .....	12
Scope of the study .....	13
Significance of the study .....	13
Thesis structure .....	14
Chapter Summary.....	14
Chapter Two: Literature Review .....	16
Introduction .....	16
Publication.....	16
Chapter Summary.....	37
Chapter Three: Research Methodology and Methods .....	38
Introduction .....	38
Philosophical assumptions .....	39
Post-positivism .....	39
Social constructivism.....	40
Pragmatism .....	40
History of case study research.....	41
Definition and description of case study research .....	43
A case study in palliative care research.....	44

Strength and limitations of case studies .....	45
Research methodology .....	46
Research design .....	46
Research methods.....	49
Study settings.....	49
Study participants .....	49
Case screening and recruitment of participants .....	50
Data collection tools and procedures.....	51
Data quality .....	54
Data management and analysis .....	56
Ethical considerations.....	59
Chapter Summary.....	61
Chapter Four: Context Results.....	62
Introduction .....	62
Survey results of the Context .....	62
Socio-demographic variables .....	63
Nurses' knowledge about palliative care.....	64
Nurse's attitudes towards palliative care .....	66
Self-reported palliative care practices .....	70
Examining relationships between outcome variables in the Context.....	71
The association between the demographic and outcome variables in the Context .....	71
Qualitative results of the Context.....	72
Palliative care policy and guidelines .....	73
Palliative care education.....	78
Palliative care implementation .....	88
Chapter summary .....	113
Chapter Five: Case 1 Results .....	116
Introduction .....	116
Survey results of Case 1 .....	116
Socio-demographic variables .....	116
Nurses' knowledge about palliative care.....	117
Nurse's attitudes towards palliative care .....	119
Self-reported palliative care practices .....	122
Correlation between outcome variables in Case 1.....	123
Qualitative results of Case 1.....	124
Palliative care policy and guidelines .....	125
Palliative care education and training.....	128

Palliative care implementation .....	132
Chapter Summary.....	146
Chapter Six: Case 2 Results.....	148
Introduction .....	148
Survey results of Case 2 .....	148
Socio-demographic variables .....	148
Nurses' knowledge about palliative care: Case 2 .....	149
Nurse's attitudes to palliative care.....	151
Self-reported palliative care practices .....	154
Correlation among outcome variables .....	155
The association between the demographic and outcome variables in Case 2 .....	156
Qualitative results of Case 2.....	158
Palliative care policy and guidelines .....	159
Palliative care education and training.....	163
Palliative care implementation .....	167
Chapter summary .....	184
Chapter Seven: Integrative Discussion .....	187
Introduction .....	187
Awareness of palliative care policy and guidelines .....	188
Policy status of palliative care .....	188
Palliative care budget.....	189
Palliative care education and training .....	189
Cultural attitudes to palliative care .....	190
Integrating palliative care into under-graduate and post graduate curricula .....	191
Inadequate palliative care knowledge.....	192
Using mass media to promote palliative care awareness .....	194
Availability and accessibility of opioid medications .....	194
Availability, Accessibility and Affordability of opioids .....	195
Training for physicians prescribing opioids such as Morphine.....	197
Palliative care implementation .....	198
Palliative care service in health care settings .....	199
Palliative care service in a patient's home.....	200
Mobile phone in palliative care service .....	202
Palliative care research .....	202
Chapter summary .....	203
Chapter Eight: Conclusion, Limitations and Recommendations .....	206
Study Overview .....	206

The key findings.....	207
The current status of palliative care .....	208
Strategies and challenges for a sustainable public health approach to the provision of palliative care .....	211
Strength and Limitations .....	212
Recommendations .....	213
Recommendations – Policy/Education/Clinical Practice .....	213
Recommendations for future research .....	215
Conclusion.....	216
Postscript.....	218
References.....	220
Appendix 1A: The explanatory statement for leaders .....	228
Appendix 1B: Interview questions framework for leaders .....	235
Appendix 1C: Consent form for leaders .....	238
Appendix 2A : Survey questionnaire .....	241
Appendix 2B: Explanatory statement survey .....	253
Appendix 2C : Poster .....	258
Appendix 3A: Focus Group questions framework .....	260
Appendix 3B: Focus Group Explanatory statement .....	262
Appendix 3C: Focus Group consent form .....	268
Appendix 4: Monash University Human Research Ethics Committee Approval Certificate	270



## List of tables

Table 4.1 Demographic variables of nurses working in the Context (n=88*).....	64
Table 4.2 Nurses' knowledge about palliative care in the Context (n=87) .....	65
Table 4.3 Nurse's Attitudes towards palliative care (n=89) .....	68
Table 4.4 Self-reported palliative care practices (n=89).....	70
Table 4.5 The correlation among the outcome variables. ....	71
Table 4.6 Context themes and sub-themes .....	73
Table 5.1 Demographic variables among nurses working in Case 1 (n=35).....	117
Table 5.2 Nurses' knowledge about palliative care in Case 1 (n=35) .....	118
Table 5.3 Nurses attitudes towards palliative care (n=35).....	120
Table 5.4 Self-reported practice of palliative care nurses (n=35).....	122
Table 5.5 Correlation between the outcome variables in Case 1. ....	123
Table 5.6 Case 1 themes and sub-themes .....	125
Table 5.7 Available palliative care and related document in Case 1 .....	128
Table 6.11 Demographic variables for nurses working in Case 2 (n=49) .....	149
Table 6.2 Nurses' knowledge about palliative care .....	150
Table 6.3 Nurses' attitudes to palliative care.....	152
Table 6.4 Self-reported palliative care practices of nurses .....	155
Table 6.5 Correlation between the outcome variables in Case 2. ....	156
Table 6.6 Case 2 themes and sub-themes .....	159
Table 6.7 Available palliative care and related documents in Case 2 .....	162

## List of figures

Figure 1: Geographical map of administrative divisions of Ethiopia (TUBS, 2019) .....	5
Figure 2: Geographic map of Tigray region Tigray online (2018) .....	6
Figure 3: Ethiopian Health Sector Organisation adapted from Ethiopia Health Sector (2013).9	
Figure 4: Ethiopian Health Tier System adapted from FMOH (2015) .....	11
Figure 6: Case study methodology history and evaluation adapted from (Harrison et al., 2017, p. 5) .....	43
Figure 7. Types of case study design adapted from (Yin, 2018) .....	48
Figure 8: The study participants in the two Cases and the Context.....	50
Figure 9: Maintaining a chain of evidence adapted from Yin (2018).....	55

## List of Abbreviations

ART	Anti-Retroviral Therapy
BSc	Bachelor of Science
FATCOD	Frommelt Attitudes Toward Care of the Dying Scale
HEW/s	Health Extension Worker/s
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
HSTP	Health Sector Transformation Plan
LMIC/s	Low- and middle-income countrie/s
Md	Median
MUREC	Monash University Research Ethics Committee
NCCP	National Cancer Control Plan
NCD/s	Non-communicable disease/s
NGO/s	Non-Governmental Organisation/s
PCQN	Palliative Care Quiz for Nursing
PFHI	Pain-Free Hospital Initiative
PFSA	Pharmaceutical Fund and Supply Agency
SD	Standard Deviation
SPSS	Statistical Software Package
WHA	World Health Assembly
WHO	World Health Organization

## Glossary of Terms

**Analytical generalisation:** refers to “corroborating, modifying, rejecting or otherwise advancing theoretical concepts that the researcher referenced in designing the case study” (Yin, 2018, p. 38).

**Case:** is “the concrete manifestation of any abstraction” (Yin, 2018, p. 31). In this study the case under examination is regional palliative care.

**Comprehensive Specialised Hospital:** it is a regional tertiary referral hospital.

**Cross-case synthesis:** the intent of this cross-case synthesis is a ‘case-based’ rather than ‘variable -based’ approach; in a case-based approach, the goal is to retain the integrity of the entire case and then to compare or synthesise any within- case patterns across the cases (Yin, 2018, p. 196).

**Embedded case study design:** a unit of analysis that includes sub-units. For example, in this case study, participants of health care settings are the embedded sub-units under investigation (Yin, 2018).

**General Hospital:** it is the secondary level of health care setting within a ‘Zone’.

**Health Centre:** in rural areas, the Health Centre is the primary health care setting.

**Health Post:** in the rural area, the health post provides health prevention and promotion service directly to the local community.

**Iddir:** are local, voluntary widespread associations found in urban settings of Ethiopia, the number of participants may differ from place to place. The role of the ‘Iddir’ is to provide financial, resource, social and spiritual support to members in need. In rural areas, similar organisations are known as ‘Mahber’.

**Kebele:** it is the lowest administrative district of the region.

**Literal replication:** “selecting two or more cases in a multiple- case study because the cases are predicted to produce similar findings” (Yin, 2018, p. 287).

**Multiple case study:** “a case study organised around two or more case studies” (Yin, 2018, p. 287).

**Mixed-method case study:** “a single study using both qualitative and quantitative methods, with a case study potentially being one of the methods” (Yin, 2018, p. 287)

**National health policies and guidelines:** this refers to the inclusion of palliative care in the following documents: national Health Sector Transformation Plan (HSTP); the National Cancer Control Plan (NCCP); Ethiopian Primary Health Care Clinical Guidelines; the Ethiopia Hospital Transformation Guidelines (EHSTG); the National Strategic Action Plan for Prevention & Control of Non-Communicable Diseases; and the National Palliative Care Guideline.

**Participant:** a person who is involved in the data collection through interview, focus group, or survey.

**Primary Hospital:** it is the primary health care level within a ‘Woreda’ which is the closest hospital-based service to the rural patients, capabilities include medical services and emergency surgery.

**Region:** is an administrative state of the country. For example, Ethiopia has nine-administrative regions. Administrative responsibility devoted to the region

**Replication logic:** “the logic for selecting the two or more cases in a multiple-case study” (Yin, 2018, p. 288)

**Theoretical replication:** “selecting two or more cases in a multiple- case study because the cases are predicted to have contrasting findings, but for anticipatable reasons.” (Yin, 2018, p. 288)

**Woreda:** it is an administrative district; the ‘Woreda’ is reports to the ‘Zone’.

**Zone:** within the region, administrative responsibility is dedicated to the Zones of the region. For example, Tigray has seven administrative ‘Zones’.

## Chapter One: Introduction

Care for people with life-limiting illness is a major concern worldwide. In 2014, the World Health Assembly (WHA) urged member states “to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems” (World Health Assembly 67, 2014). This WHA resolution also recommends the integration of “evidence-based, cost-effective, and equitable palliative care services in the continuum of care, across all levels of health service, emphasising primary care, community and home-based care, and universal coverage schemes” (p. 3).

The World Health Organization (WHO) defines palliative care as: “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (Connor & Sepulveda Bermedo, 2014, p. 5).

The WHO “pioneered a Public Health Strategy to integrate palliative care into existing health care systems” (Stjernswärd, Foley, & Ferris, 2007, p. 487). The Public Health Strategy is considered the best approach for translating new knowledge and skill into evidence-based practice and an affordable intervention for all individuals in need (Stjernswärd et al., 2007). This strategy is applied when the government integrates palliative care into all levels of the health care system, and it is owned by the community. The WHO Public Health Strategy includes four components: appropriate policies; adequate drug availability, particularly opioids; education of health care professionals, policymakers and the public. Additionally, implementation of services needs to reflect the culture and context of the specific country (Callaway, Connor, & Foley, 2018).

Access to palliative care in low- and middle-income countries (LMICs) has been affected by several challenges such as lack of palliative care integration within existing health care services (Grant et al., 2017); lack of access to opioids (Hannon et al., 2016); and dependence of the palliative care program on Non-Governmental Organisations (NGOs) (Herce et al., 2014; Logie & Harding, 2012). Recommendations from previous studies include those related to the WHO Public Health Strategy (Blinderman, 2009), and palliative care in rural Ethiopia (Ayers, 2015).

This case study investigated the status of palliative care and recommended a sustainable public health approach for the provision of palliative care in rural and regional Ethiopia. This

chapter includes the background to the study; research question and aim; scope of the study; and thesis structure. Finally, the summary of this chapter is described. The thesis is presented using APA 6<sup>th</sup> edition as a style guide in accordance with Monash University (American Psychological Association, 2012).

## Background to the study

The palliation of pain and other symptoms has always been part of medical care although it has received very limited attention in modern medicine (De Lima & Pastrana, 2016).

Palliative care was developed in the second half of the twentieth century, when doctors (mostly anaesthesiologists) working in the alleviation of severe pain were confronted with patients who had incurable diseases (De Lima & Pastrana, 2016). “Cicely Saunders, an English social worker, nurse and physician, founded St. Christopher Hospice in South London, considered the first modern hospice” (De Lima & Pastrana, 2016, p. 359) that provided the standard on how to care for people who were dying (Abel & Kellehear, 2016).

The standard includes professional development in palliative medicine and nursing, developing multi-disciplinary teams by adding social, spiritual, and allied health workers, and providing networks with community volunteers. The term ‘palliative care’ originated after the opening of a palliative care unit in Royal Victoria Hospital in Montreal, Canada (De Lima & Pastrana, 2016); it was considered that the word hospice, originally French, did not readily translate into English. In most places in the world, palliative care and hospice are used interchangeably. The global overview of palliative care, palliative care in LMICs, and particularly palliative care in Ethiopia are described next.

## Global overview in palliative care

Palliative care is argued to be “an ethical responsibility of health systems, and it is the ethical duty of health care professionals to alleviate pain and suffering” (World Health Assembly 67, 2014, p. 2). Suffering includes physical, psychosocial, or spiritual problems, regardless of the disease or condition, and end-of-life care for individuals is among the critical components of palliative care.

Access to palliative care is acknowledged as an international human right (Gwyther, Brennan, & Harding, 2009). Key obligations were stated in relation to this right irrespective of a country’s resources and include access to health care facilities, goods and services on a non-discriminatory basis; the provision of essential medications as defined by WHO; and the adaption and implementation of a WHO Public Health Strategy (Gwyther et al., 2009). In the

context of palliative care, a patient with life-limiting illness has the right to access a palliative care service and basic medication for symptom control, as well as inclusion of palliative care in the national health policies (Connor & Sepulveda Bermedo, 2014). However, access to palliative care for millions of people in the world is still limited or absent (Gómez-Batiste & Connor, 2017).

The WHO estimates that 40 million people need palliative care annually (Gómez-Batiste & Connor, 2017). Worldwide, only about 14% of people who need palliative care currently have access (Connor & Sepulveda Bermedo, 2014), which is mostly limited to high income countries (Poudel, Bhuvan, Shrestha, & Nissen, 2019). This need is rapidly increasing as the global population ages and the incidence of chronic disease and life-limiting illnesses is growing.

#### [Palliative care in low-and middle-income countries](#)

In LMICs, nearly 80% of adults are in need of palliative care (Connor & Sepulveda Bermedo, 2014; Poudel et al., 2019). Palliative care is “integral to the management of all patients with incurable non-communicable diseases (NCDs) and communicable diseases, and it has been most closely linked to cancer care” (Hannon et al., 2016, p. 62). The prevalence of NCDs is high in LMICs (Poudel et al., 2019). It is estimated that more than eight million people die from cancer annually; this number is expected to double over the next two decades, in part from population ageing, with 50% of these expected to occur in LMICs (Hannon et al., 2016). The study conducted by Sleeman et al. (2019) indicated that the global burden of serious health related-suffering will increase by 2060, compared with 2016 with the largest proportional rise in low-and middle-income countries. By 2060, an estimated 48 million people experiencing serious health related-suffering will die which represents an 87% increase from 26 million people in 2016, 83% of these deaths will occur in low-and middle-income countries. This indicates that the global people in need of palliative care will double over the next four decades.

In Sub-Saharan Africa, 44 million people are aged 60 and older and this number is expected to increase fourfold to 160 million by the year 2050 (Hoffman & Pype, 2016). Despite this, most care for older people in Sub-Saharan Africa is provided by families who live in poverty and with infrastructural constraints. Although palliative care services are increasing in Africa, only 5% of those in need are currently receiving it (Downing, Grant, Leng, & Namukwaya, 2015).



One study focusing on mapping levels of palliative care development indicated that only 30 (15%) of 198 countries globally have achieved advanced levels of palliative care integration into mainstream health service provision, and only two of these countries are in Africa (Clark et al., 2020). A range of factors has been found to affect the integration of palliative care into the health systems in Sub-Saharan Africa. Some of these are poverty, the increasing incidence of chronic diseases, fragile health systems, poor transport networks, cultural beliefs, conflicts, and lack of access to essential medications (Grant et al., 2017). In addition, a study conducted in rural Malawi showed that palliative care was dependent on NGO financial support, and this affected ongoing sustainability (Herce et al., 2014).

### *Palliative care in Ethiopia*

In Ethiopia, the palliative care movement commenced in response to the health system's inadequacy in responding to the human immunodeficiency virus/ acquired immunodeficiency syndrome (HIV/AIDs) epidemic, rather than a desire to provide an alternative care setting (Mamo et al., 2020). Home-based care was the only alternative in the absence of Anti-Retroviral Therapy (ART) but was not part of the recognised national health care system. Hospice Ethiopia was established in 2003 to advocate for home-based care services and palliative care delivery has significantly progressed over the past two decades (Mamo et al., 2020).

### *The context of Ethiopia*

Ethiopia is second largest and one of the most populated countries in Africa, with the population estimated as 114,963,588 at mid year 2020 according to United Nations data: of these, 21.3% (24, 463,423) live in urban settings (worldometer, 2020). Ethiopia is landlocked on the horn of Africa bounded by Sudan, South Sudan, Kenya, Somaliland (Somalia), Djibouti and Eritrea. It has more than 80 ethnic groups, cultures, and religious differences (FMOH, 2015) and a federal system of government, divided into nine administrative regional states and two city administrations (Muluneh, Animut, & Ayele, 2020) (see. Figure 1).

Figure 1: Geographical map of administrative divisions of Ethiopia (TUBS, 2019)



Tigray is one of nine administrative national regional states of Ethiopia, and is found at the northern tip of the country (Zeru, Berihu, et al., 2020). It is bordered by Eritrea in the north, Amhara region in the south, Afar region in the east and by Sudan in the west (Tigray Regional Health Bureau, 2015). According to a projection plan by the Central Statistical Agency of Ethiopia, the Tigray population was estimated as 5.4 million in 2019 (Central Statistics Agency, 2019). The regional state is divided into ‘Zones’, which in turn are sub-categorised into ‘Woreda’ (an administrative district unit consisting of a population of an average of 100,000 people), and ‘Woreda’ are divided into ‘Kebele’ which is the lowest administrative division of Ethiopia. The Tigray region has seven administrative ‘Zones’ including one special ‘Zone’ (large city), 52 ‘Woredas’ (34 rural and 18 urban) and 814 ‘Kebeles’ (753 rural and 61 urban) (Tigray Regional Health Bureau, 2015) (Figure 2).

Figure 2: Geographic map of Tigray region Tigray online (2018)



### *Palliative care initiatives in Ethiopia*

As one of the oldest nations in the world, Ethiopia is with a rich history of traditional medicine practice (Habte & Mehari, 2012). For instance, Ethiopians reduce pain and suffering by managing psycho-social dimensions; and they are inclined to be stoic in the face of suffering. The majority of Ethiopians (about 80%), receive their health-care from traditional healers who may use herbs, and/or religious beliefs like ‘Tebel’ (holy water) and communal prayers, traditional and spiritual healers (Habte & Mehari, 2012). Traditional healers have a significant role, particularly when modern medicines have been unsuccessful in meeting the patient’s need (WHO, 2004). Ethiopians use traditional medicine not only to cure disease, but also to prevent suffering through the protection and promotion of physical, psycho-social and spiritual well-being. This is consistent with the palliative care philosophy where holistic care by a multidisciplinary team is emphasised.

Ethiopia was involved with four other African countries in a WHO palliative project titled: *A Community Health Approach to Palliative care for HIV/AIDs and Cancer patients in Sub-Saharan Africa Project* (WHO, 2004), which aimed to improve quality of life of patients and

their families. The project found significant unmet palliative care and a need to improve quality of life for HIV/AIDs, cancer and other chronically ill patients and their families (WHO, 2004). According to this project, the preferred site of care in Ethiopia was reported as being in a health facility; however, the needs assessment of the project was undertaken exclusively among urban patients attending radiotherapy in the capital city and thus does not reflect the views of patients from wider or more rural communities (WHO, 2004).

Another project conducted in Ethiopia: *Building a palliative care program in Ethiopia: The Impact on HIV and AIDS patients and their families*, revealed that Home-and Community-Based Care had a positive outcome when the care was integrated with the support of ‘Iddir’, a community support group (Wube, Horne, & Stuer, 2010). Home-and Community-Based Care is one of the models of palliative care which plays a significant role in improving quality of life of HIV/AIDs patients and their families. This program reduced self-stigmatisation, provided awareness and open discussion with the patients and their neighbours, with the help of this community support group (‘Iddir’). These groups assisted patients and engaged in distribution of resources such as food, clothes and financial support for patients’ needs and for vulnerable children (Wube et al., 2010).

Currently, Ethiopia is one of the few countries in the world that includes palliative care as a fifth pillar of the five-year national Health Sector Transformation Plan (HSTP), adding it to the current four: promotion, prevention, curative and rehabilitation (FMOH, 2015). In addition, palliative care is integrated into the National Cancer Control Plan (NCCP) (Federal Ministry Of Health, 2015); Ethiopian Primary Health Care Clinical Guidelines (Federal Ministry of Health, 2017); and integrated into the Ethiopia Hospital Transformation Guidelines (EHSTG) (MOH, 2016) as well as the National Strategic Action Plan For Prevention & Control of Non-Communicable Diseases (MOH, 2014-2016). The National Palliative Care Guideline has also been developed in the country (Federal Ministry of Health, 2016). Since 2016, the role and responsibility of policy makers and health professionals, in each level of health care system of the country, have been clearly stated in the National Palliative Care Guideline and the NCCP. The NCCP outlines interventions to reduce the burden of cancer through life-style improvement, primary prevention, screening and early diagnosis, appropriate follow-up, treatment, and provision of palliative care. In the NCCP, the government planned to ensure at least 50% of health facilities provided palliative care services by 2020 (Federal Ministry Of Health, 2015). Despite all these initiatives, palliative

care is poorly practiced in regional Ethiopia (Zeru, Gerensea, Beriheru, Zeru, & Wubayehu, 2020).

### *Factors that indicate unmet palliative care need in Ethiopia*

In Ethiopia, palliative care unmet need is increasing due to factors that include the need to improve treatment of communicable diseases, longer life expectancy and expansion of urbanisation (Fantahun, Berhane, Högberg, Wall, & Byass, 2009; Reid, Gudina, Ayers, Tigineh, & Azmera, 2018). “Ethiopians have begun to live longer as evidenced by improvement in the estimated average life expectancy at birth, to 64 years from 45 in 1990” (FMOH, 2015, p. 23).

Ethiopia has made significant efforts to prevent major health problems such as communicable diseases and nutritional disorders (Ministry of Health, 2010). Death due to communicable diseases - neonatal, maternal and nutritional diseases were the leading causes of premature death in 2015 (Misganaw et al., 2017). As the prevalence of communicable diseases has decreased, the population diagnosed with NCDs is increasing (Jembere, Cho, & Jung, 2018). In 2015, six of the 10 leading causes of death were NCDs; however, only two of the NCDs were in the top five leading cause of death (Misganaw et al., 2017). These top five are ischemic heart disease; lower respiratory infection; diarrhoeal disease, tuberculosis; and haemorrhagic stroke.

In Ethiopia, it is reported that “cancer accounts for about 5.8% of the total national mortality” (Federal Ministry Of Health, 2015, p. 7). Although a population-based cancer register does not exist in the country except in the capital Addis Ababa, it is estimated that 21,563 males and 42,722 females were diagnosed with cancer in 2015 (Memirie et al., 2018). The most common cancer for women was breast and cervical cancer. Colorectal cancer and non-Hodgkin’s lymphoma were the most common malignancies in men. However, there is only one functional oncology centre with four qualified oncologists and two palliative care institutes in the country (Reid et al., 2018).

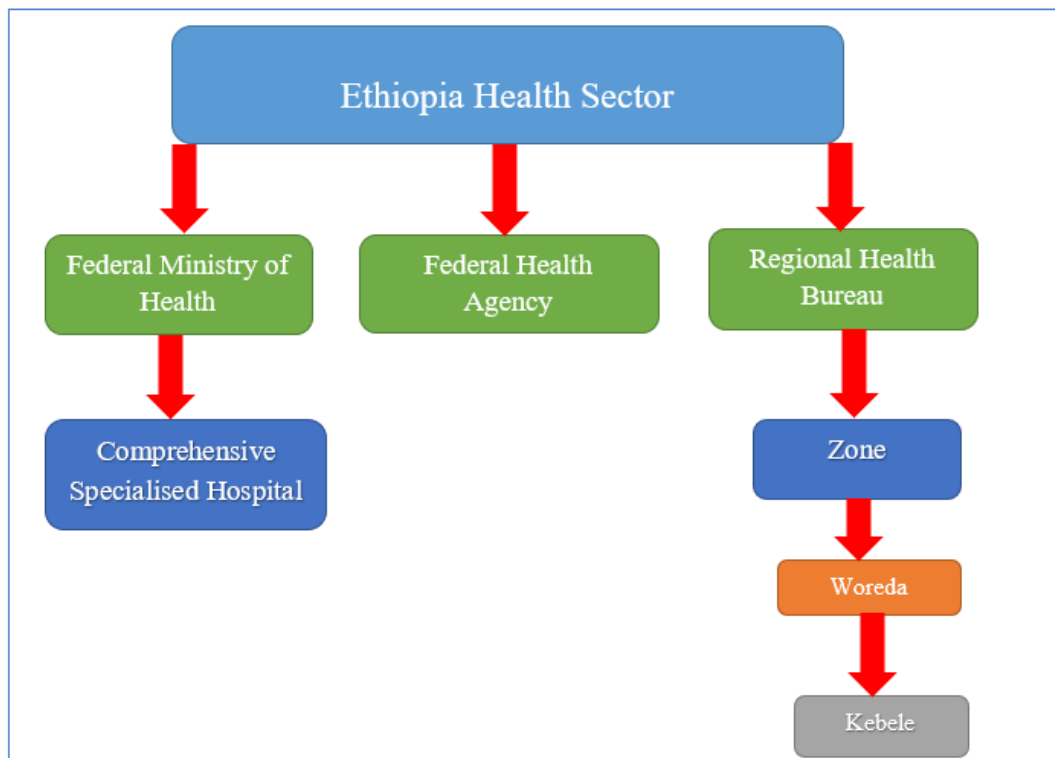
### *Ethiopia health care policy systems*

The transitional government produced a health policy in 1991 for the first time, to address health care problems (Ministry of Health, 2010). This policy is one of a series of political and socio-economic transformation policies. The translation of this policy was followed by four consecutive phases of a comprehensive Health Sector Development Plan. The key concepts of community ownership programs have been emphasised in all Health Sector Development

Plans (FMOH, 2015). For instance, the country leadership program, called the Health Extension Program, “delivers cost-effective basic health services to all Ethiopians, mainly to women and children” (FMOH, 2015, p. 22). The core principle of the Health Extension Program is “community ownership that empowers communities to manage their specific health problems” (FMOH, 2015, p. 22). In addition, the Ministry of Health used the Health Development Army to organise community and health care workers which “mobilises families, mainly women, to scale-up best practice gained from the Health Extension Program and ensure wider community participation, facilitating community ownership” (FMOH, 2015, p. 22). The Health Development Army commenced in line with the Health Sector Development Plan IV and formed one to five networks in the Ethiopian Fiscal Year 2006 (2013/2014).

In Ethiopia, the Health Sector is “a country-level government bureau composed of the Federal Ministry of Health, Federal Health Directorates and Agencies, and Regional Health Bureaus” (Ethiopia Health Sector, 2013, p. 2). The Regional Health Bureau administers the health facilities in the ‘Zone’, ‘Woreda’ and ‘Kebele’. The Federal Ministry of Health administers the Comprehensive Specialised Hospital located in the region (see Figure 3).

Figure 3: Ethiopian Health Sector Organisation adapted from Ethiopia Health Sector (2013)



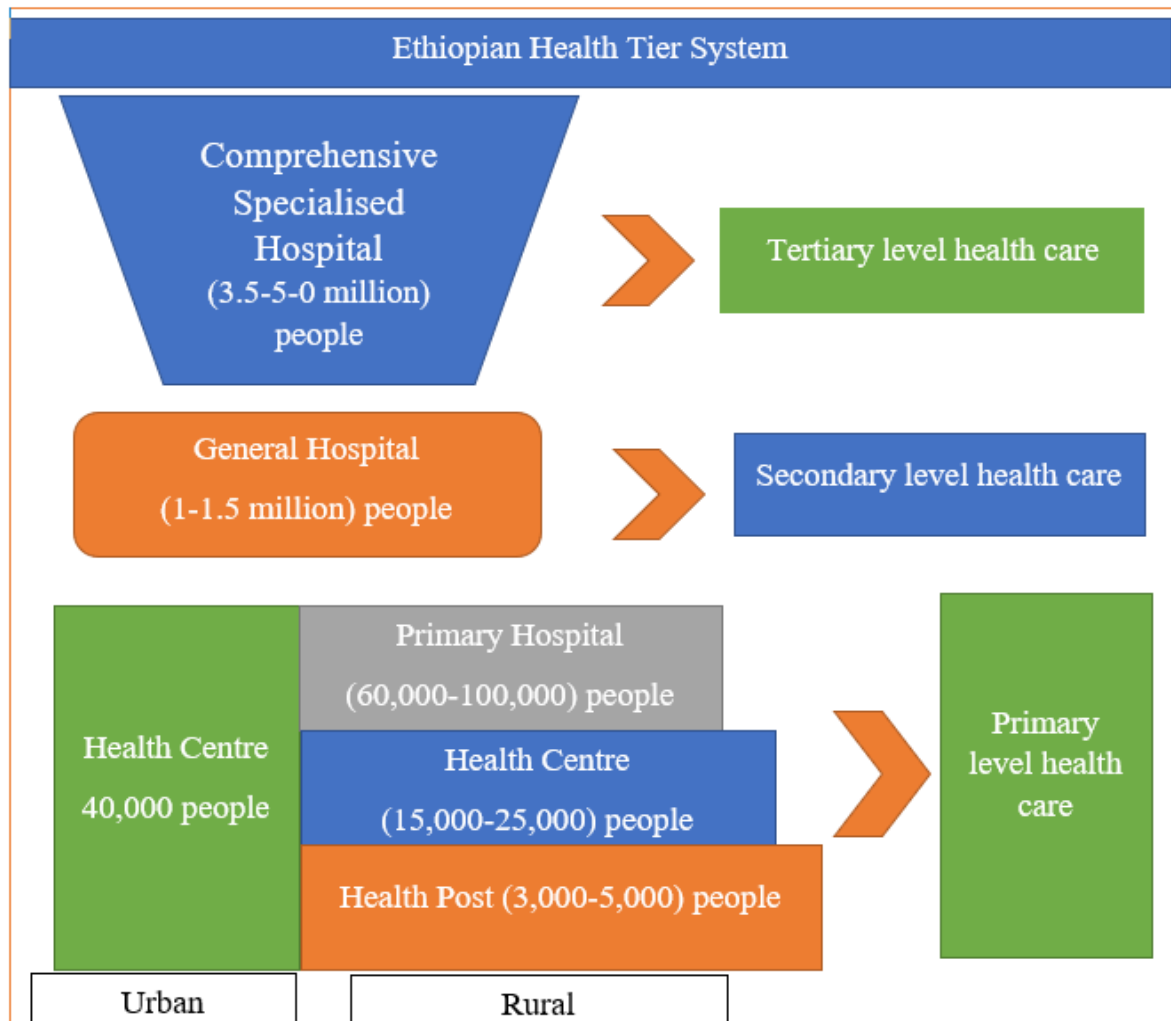


Ethiopia has a three-tier health care delivery system; primary, secondary and tertiary levels (FMOH, 2015), (Fig 5). The primary health care level in rural areas includes Health Posts, Health Centres, and Primary Hospitals; whereas the primary care level in urban areas includes only Health Centres (Abraham, Linnander, Mohammed, Fetene, & Bradley, 2015; FMOH, 2010). The first level of the tier is ‘Woreda’/ District health system, that administers a Primary Hospital; Health Centres and the satellite Health Posts that are networked to each other by a referral system (MOH, 2010). ‘Kebele’ is the smallest administrative district where the Health Post located. Each Health Centre has five satellite Health Posts which provide services to a population of approximately 25,000. The Health Extension Worker’s (HEWs) program is a pioneering community-centred strategy, where two HEWs spend less than 20% of their time in the actual Health Post, and more than 80% of their time on community outreach program visitation to households (MOH, 2010). It serves as a referral bridge for the community, as well as a practical training institution for HEWs and in-patient capacity of 11 beds (MOH, 2010).

Supporting the Health Posts, a Primary Hospital provides inpatient, ambulatory and emergency surgery services to an average population of 100,000 (MOH, 2010). It also serves as a clinical placement and training centre for health care professionals and as a referral point for the Health Centres under its catchment area. A Primary Hospital has “an inpatient capacity of 25-50 beds and is staffed by an average number of 53 persons” (FMOH, 2015, p. 142).

At the secondary level of the regional health system, the General Hospital caters for a population coverage of about 1-1.5 million people, providing “inpatient and ambulatory services to an average of 1,000,000 people. It is staffed by an average of 234 professionals and serves as a referral centre for Primary Hospitals” (MOH, 2010, pp. 82-83). It has an inpatient capacity of 50 beds and serves as a practical area and training centre for health care professionals. The Comprehensive Specialised Hospital in the tertiary-level or third tier covers a population of about 3.5-5 million and serves as a referral centre for General Hospitals; and is staffed by an average of 440 professionals (FMOH, 2015). It has an inpatient capacity of more than 110 beds (MOH, 2010) (Figure 4).

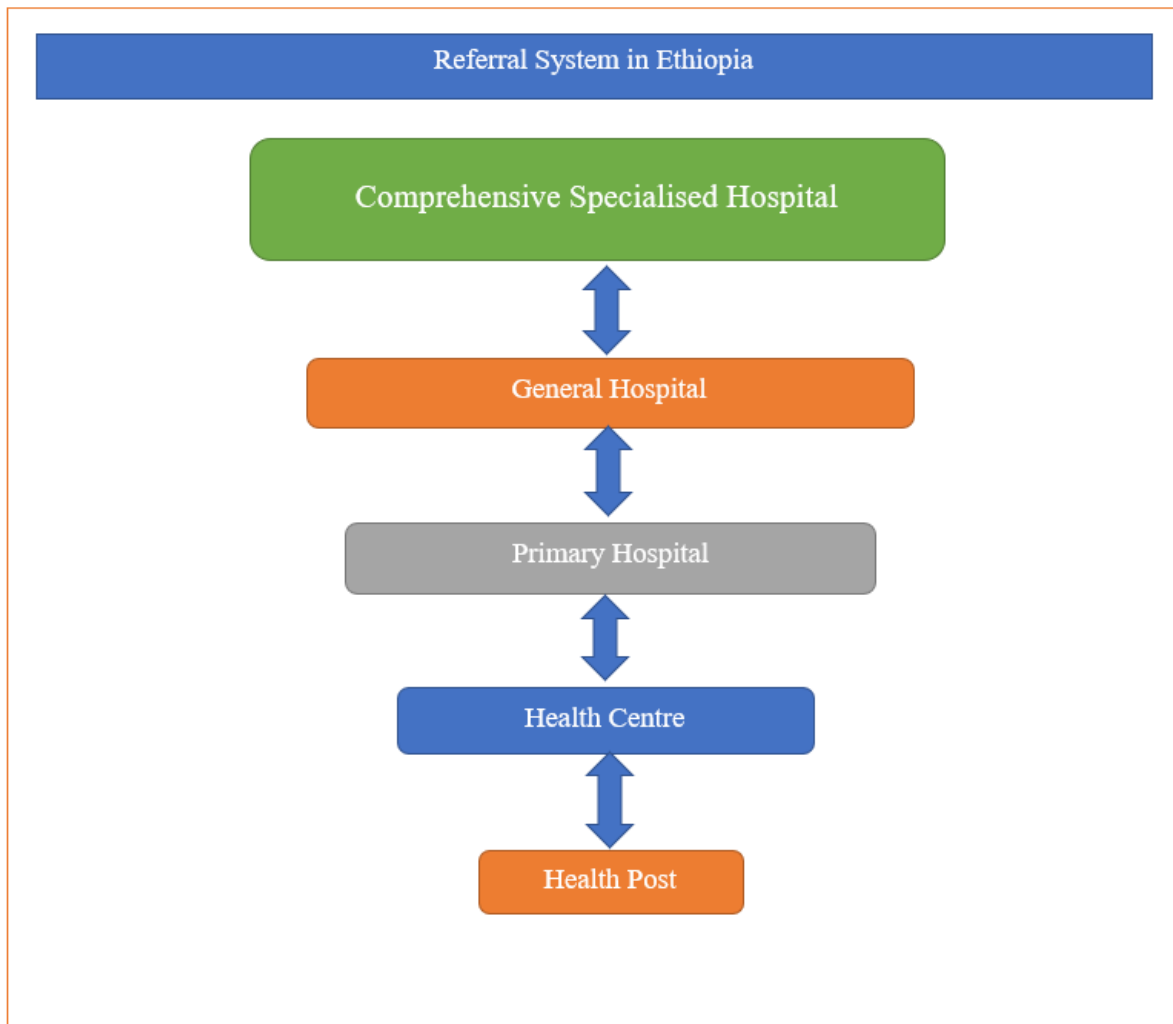
Figure 4: Ethiopian Health Tier System adapted from FMOH (2015)



Referrals may come from the bottom tier of the health system up; or from the top of the health system down, especially for follow-up and continuity of treatment such as TB medication, HIV treatment and child vaccination. The current study was conducted in all three levels of the health care system, based around the community members (Figure 5).



Figure 5: Referral system in Ethiopia (MOH, 2010)



### Research questions and aim

This research aims to understand, investigate, and make recommendations for a sustainable public health approach to the provision of palliative care in rural and regional Ethiopia. This research used a case study method which is appropriate for ‘how’ or ‘why’ study questions (Yin, 2018). In this study, descriptive case study research was used with the research questions as follows:

1. What is the current palliative care status in rural and regional Ethiopia?
2. How could a sustainable public health palliative care approach be implemented in rural and regional Ethiopia?

## Scope of the study

The scope of this study was to investigate the level of palliative care knowledge, attitudes and self-reported practice among the nurses working in the three-tier health care system of the region. A second group in this study were those education leaders working in the university and college, to identify the status of palliative care integration in undergraduate and postgraduate health care curricula. Leaders in the Regional Health Bureau and NGOs representatives comprised the third group, because of their knowledge and perception of national government or NGO's policy decisions associated with the development of the health care policy and funding for palliative care. A fourth group within the scope of this study were the nurses, pharmacists and medical leaders working in Comprehensive Specialised Hospital, General Hospitals and Primary Hospitals, Health Centres, and HEWs in the Health Posts of the region. These participants described their perceptions about the status of palliative care and the challenges and opportunities in their health care settings. The last group in this study were rural community members who described the care given to chronically ill patients, and the challenges and opportunities in their area. The concept of interest in this study was how each participant viewed the status of palliative care in their region, and the challenges and opportunities in provision of palliative care in their settings. Public health care organisations and rural community members were identified as important for the scope. Private sector professional perceptions were not included, because public health services are the main health care providers, being more accessible and affordable in Ethiopia.

## Significance of the study

As noted, the incidence of chronic and incurable diseases, as well as ageing populations are increasing. Despite palliative care initiatives, such as developing a National Palliative Care Guideline, and including palliative care in the national HSTP and NCCP, there is still unmet palliative care needs in Ethiopia. The studies conducted in Ethiopia have indicated that there was limited access to palliative care, lack of palliative care medication and a lack of palliative care trained professionals to deliver the service. Further studies conducted in rural Africa have indicated that palliative care was dependent on external funding and donors, so financial constraints were the major barrier to providing care. This study describes the current status of palliative care in order to identify the challenges and strategies for a sustainable public health approach to the provision of palliative care in rural and regional Ethiopia.

## Thesis structure

This thesis consists of eight chapters. The first chapter provides an introduction and background to the study, followed by an overview of palliative care as it relates to LMICs and Ethiopia. Palliative care in resource poor settings in Ethiopia; the significance of the study; research questions and aims; and concluding comments are also included in Chapter 1. In Chapter 2, a published integrative literature review is presented, with the strategies used to establish palliative care in rural LMICs discussed using the four components of WHO Public Health Strategy as a theoretical framework. In Chapter 3, the method and methodology are described. The philosophical assumptions of case study methods are first discussed, followed by a history of case study research design. A description of the study settings and study participants are described, followed by case screening. An outline of tools used and data collection procedures are presented, data quality and data analysis are summarised followed by the ethical considerations. In Chapter 4, 5 and 6, the findings are reported. In Chapter 4, the details of the Context survey and qualitative results are described. The survey results include socio-demographic variables; knowledge, attitudes, self-reported practice of nurses regarding palliative care; and the correlation among the outcome variables and association factors in palliative care. In the qualitative results, three major themes and several sub-themes were identified. Similarly, in Chapter 5, the Case 1 survey and qualitative results are presented using three major themes and different subthemes, which emerged from the data. In the survey results, the socio-demographic variables; the nurses' level of palliative care knowledge, attitudes and self-reported practice; and the correlation between these variables are presented. Chapter 6 mirrors Chapter 5, reporting on the survey and qualitative results of Case 2. The integrative discussion of the key findings is presented in Chapter 7. Lastly, in Chapter 8, the limitations of the study, the conclusion and recommendations for further research are reported.

## Chapter Summary

This chapter has provided the reader with key points of the study. While access to palliative care is recognised as an international human right, there has been limited development of palliative care in Ethiopia, which commenced in response to the HIV epidemic.

This study was designed to understand, investigate, and make recommendations for a sustainable public health approach to the provision of palliative care in rural and regional

Ethiopia. The Chapter outlined the current palliative care status and considers how a sustainable public health approach can be implemented in rural and regional Ethiopia.

The scope of this study extends across the three-tier health care system and includes all health care disciplines and their education systems in a regional and community context.

The next chapter provides a detailed description of the existing literature on the strategies used for developing palliative care in rural LMICs. An integrative review in a published paper: *Strategies used to establish palliative care in rural low-and middle-income countries: an integrative review* is included here and published in the journal *Health Policy and Planning*. The paper describes the strategies which were used to develop palliative care in developing countries and its challenges, focussing on the sustainability of palliative care programs in rural areas, considering the dependency on external donors or NGOs.

## Chapter Two: Literature Review

### Introduction

As outlined in Chapter 1, the purpose of this Chapter is to provide an integrative review of the literature relevant to the development of a palliative care strategy in rural areas. An integrative review is a methodological approach that incorporates diverse methods including experimental and non-experimental studies; it also combines data from theoretical and empirical literature (Souza, Silva, & Carvalho, 2010). An integrative review was chosen because there was insufficient homogeneity in the studies in relation to four components of public health model and there were too few studies to undertake systematic review. The review was undertaken early in the study period, to provide direction to the design of the study. This review describes the strategies and challenges used to establish palliative care in rural Low-and middle-income countries (LMICs) using the four pillars of WHO Public Health Strategy of policy, available medication, education, and palliative care implementation to frame the findings. The methodology utilised four electronic databases (Ovid MEDLINE, Ovid Emcare, Embase classic+Embase and CINAHL) and search terms were: palliative care, hospice care, end-of-life care, home-based care, volunteer, rural, regional, remote, and developing countries, Africa, Sub-Saharan Africa, low-income and middle-income countries. This review does not seek to critique the literature; rather it provides a more general analysis to identify the strategies used to establish palliative care in rural LMICs, and gaps in these strategies, to inform the design of the study.

### Publication

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# Strategies used to establish palliative care in rural low- and middle-income countries: an integrative review

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## Abstract

Globally, 40 million people need palliative care; about 69% are people over 60 years of age. The highest proportion (78%) of adults are from low- and middle-income countries (LMICs), where palliative care still developing and is primarily limited to urban areas. This integrative review describes strategies used by LMICs to establish palliative care in rural areas. A rigorous integrative review methodology was utilized using four electronic databases (Ovid MEDLINE, Ovid Emcare, Embase classic+Embase and CINAHL). The search terms were: 'palliative care', 'hospice care', 'end of life care', 'home-based care', 'volunteer', 'rural', 'regional', 'remote' and 'developing countries' identified by the United Nations (UN) as 'Africa', 'Sub-Saharan Africa', 'low-income' and 'middle-income countries'. Thirty papers published in English from 1990 to 2019 were included. Papers were appraised for quality and extracted data subjected to analysis using a public health model (policy, drug availability, education and implementation) as a framework to describe strategies for establishing palliative care in rural areas. The methodological quality of the reviewed papers was low, with 7 of the 30 being simple programme descriptions. Despite the inclusion of palliative care in national health policy in some countries, implementation in the community was often reliant on advocacy and financial support from non-government organizations. Networking to coordinate care and medication availability near-patient homes were essential features of implementation. Training, role play, education and mentorship were strategies used to support health providers and volunteers. Home- and community-based palliative care services for rural LMICs communities may best be delivered using a networked service among health professionals, community volunteers, religious leaders and technology.

**Keywords:** Palliative care, rural, low- and middle-income countries, integrative review, public health

## Introduction

Palliative care is increasingly recognized as a human right and an essential component of comprehensive care at the end of life (Gwyther *et al.*, 2009; Gómez-Batiste and Connor, 2017). Rural areas are distinct and need to have special consideration in order to provide palliative care (Rainsford *et al.*, 2017). However, people living in rural or remote areas have less access to palliative care

services (Spice *et al.*, 2012; Herce *et al.*, 2014; Hannon *et al.*, 2016).

Globally, 40 million people need palliative care (Gómez-Batiste and Connor, 2017), with the majority (69%) being older people over 60 years of age (Connor, 2014). The highest proportion of adults (78%) in need of palliative care are from low- and middle-income countries (LMICs) (Connor, 2014), but despite this, the majority have limited access (Lynch *et al.*, 2013).

### KEY MESSAGES

- Palliative care is recognized as an international human right. The World Health Organization recommends a Public Health Strategy as a cost-effective intervention for integrating palliative care in health systems. However, there is limited access to palliative care in rural low- and middle-income countries (LMICs).
- There is little evidence to support models of palliative care in rural areas of LMICs and no guidance in the WHO strategy regarding what sort of outcomes should be assessed as part of the development.
- LMICs rely on partnerships with non-government organizations in order to fund the provision of palliative care. This may be a risk to sustainability of programmes.
- Key processes that may support palliative care in rural and remote areas, including networked services to ensure medicines and care are accessible in communities. Training needs to include community members in addition to health professionals.

Different strategies to establish palliative care at all levels of the healthcare system have been described (Gómez-Batiste and Connor, 2017). Principally, the World Health Organization (WHO) recommends a public health model to integrate palliative care into existing healthcare systems. This strategy describes cost-effective and evidence-based practices that can reach everyone in need of palliative care (Stjernswärd, 2007). However, in order for a public health model to be effective, palliative care must be integrated by the government into all levels of health care and owned by the community (Stjernswärd, 2007; Callaway *et al.*, 2018). In addition, to effectively integrate into the community, the four components of the WHO public health model need to be addressed: policies; availability of palliative medicine; education; and implementation (Callaway *et al.*, 2018).

In all countries, palliative care strategies need to be defined according to the demographic scenario of their setting (Gómez-Batiste and Connor, 2017). For instance, in rural or remote areas with small populations and thus insufficient demand for specific palliative care beds, the palliative care team should develop appropriate intervention strategies involving the community (Gómez-Batiste and Connor, 2017).

A range of factors have been found to affect rural palliative care service delivery in previous reviews. Some of these are: limited access to specialized health facilities (Evans *et al.*, 2003; Hannon *et al.*, 2016), geographic isolation; lack of transportation (healthcare provider travelling long distances); time-consuming nature of palliative care; difficulty recruiting healthcare providers and lack of funds (Grant *et al.*, 2011; Spice *et al.*, 2012). Despite these challenges and limitations, those people living in rural environments who require palliative care have a strong desire to remain in their home until the end of their lives (Spice *et al.*, 2012). There is a lack of research studies about palliative care in LMICs and 1.3% of all the publications appear in journals with low or no impact factor (Hannon *et al.*, 2016). Most available publications in LMICs were observational studies, describing programme development, needs assessments and funding and policy issues; only 2% were randomized control trials (Hannon *et al.*, 2016). Further research has been suggested to describe palliative care strategies for diverse rural populations. The lack of homogeneous research describing and evaluating strategies meant a systematic review and meta-analysis was not feasible. Therefore, this review describes the strategies used to establish palliative care in rural LMICs countries.

## Methods

Whittemore and Knafl's (2005) integrative review guidelines were used to develop the methodology. Five stages are recommended: formulation of the problem (articulated in the background of this

review); literature search; data evaluation; data analysis; and presentation of results to combine qualitative and quantitative research and synthesize available literature related to the topic (Whittemore and Knafl, 2005). The four pillars of the described above were used to identify the different palliative care strategies utilized in the papers reviewed (Callaway *et al.*, 2018).

### Literature search strategy

A comprehensive literature search was conducted using four electronic databases (Ovid MEDLINE, Ovid Emcare, Embase classic+Embase and CINAHL). There were insufficient relevant MeSH headings to create an appropriate strategy, and so with assistance from a specialist librarian, search terms were collected from keywords of the articles initially retrieved and included: 'palliative care', 'hospice care', 'end of life care', 'home-based care', 'volunteer'; 'rural', 'regional', 'remote'; and a 'developing countries' identified by the United Nations (UN) as 'Africa', 'Sub-Saharan Africa', 'low-income' and 'middle-income countries' (United Nations, 2016). These terms were combined with Boolean operators 'OR' or 'AND'. One additional paper was found through manual searching of reference lists. Each search was downloaded to a database and duplications removed.

In total, 3371 papers were initially identified. Following removal of duplications, two authors checked titles and abstracts for eligibility, as noted above and at this stage 2072 papers were excluded. The remaining papers were retrieved in full text and evaluated to identify those which met the inclusion criteria.

Inclusion criteria were published in English; published between 1990 and 2019; and focused on palliative care of adults in rural communities. The search excluded editorials, commentaries, published abstracts and discussion papers that did not focus on specific strategies for the provision of palliative care for adults in rural communities.

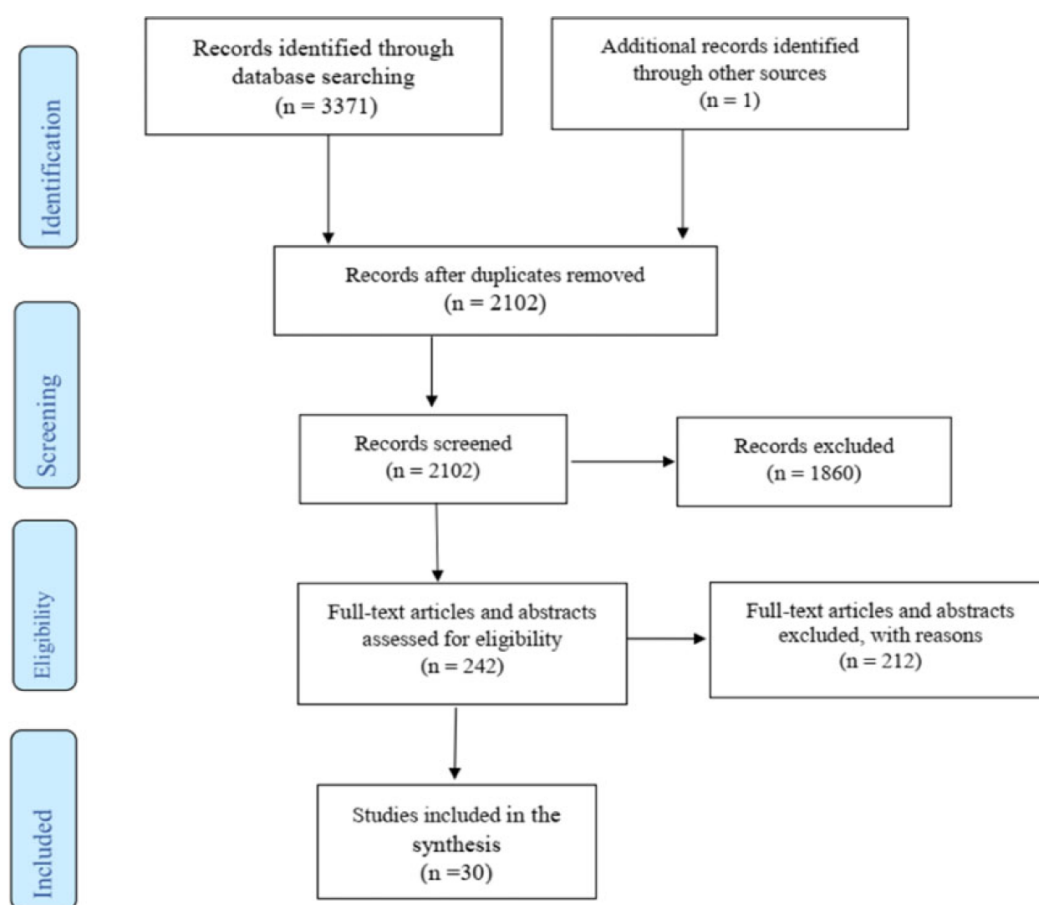
### Data evaluation

The quality of each paper was evaluated using the Critical Appraisal Skill Programme (CASP) Guidelines (Lobiondo-Wood and Haber, 2014) for quantitative, qualitative research and descriptions of models. Seven of the reviewed papers were not research papers, but descriptions of local models. A total of 30 papers were reviewed (Figure 1). The results of this evaluation are noted in Table 1.

### Data analysis and interpretation

The data were extracted from individual papers and described in tabulated form according to author name, year of publication, setting, research focus, design and methods, population focus, key findings, comments and challenges of the papers. The data extraction





**Figure 1** Prisma (Liberati *et al.*, 2009) screening process for paper selection.

was checked by a second reviewer with discrepancies resolved by discussion. The findings were analysed using content analysis (Lobiondo-Wood and Haber, 2014). Content analysis is ‘a systematic coding and categorizing approach use for a large amount of textual information to determine trend and patterns of words used’ (Vaismoradi *et al.*, 2013). In this review, the data were extracted from each paper, then coded and categorized based on their relevance to the four pillars of the WHO public health model for palliative care, as previously described (Figure 2).

### Presentation of results

Thirty papers met the inclusion criteria and were included in the synthesis. Tables 1 and 2 present the characteristics and findings of the included papers: three quasi-experimental (Dongre *et al.*, 2012; Chandra *et al.*, 2016; Namisango *et al.*, 2016); seven qualitative papers (Campbell, 2011; Jack *et al.*, 2011; Campbell and Amin, 2014; Campbell and Baernholdt, 2016; Jayalakshmi and Suhita, 2017; Jabbari *et al.*, 2019; Potts *et al.*, 2019); and seven service descriptions (Defilippi and Cameron, 2007; Kumar, 2007; Lemonica and Barros, 2007; Devi *et al.*, 2008; Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Boit *et al.*, 2014). Four papers used case study (Downing, 2008; Downing and Kawuma, 2008; Bond and Knopp, 2018; Freire De Castro Silva *et al.*, 2018); one used case series (Hennemann-Krause *et al.*, 2015); five used mixed-method (Dekker *et al.*, 2012; Logie and Harding, 2012; Hartwig *et al.*, 2014;

Munday *et al.*, 2018; Shabnam *et al.*, 2018); two used rapid evaluation methodology (REM) (Grant *et al.*, 2011; Herce *et al.*, 2014) and one paper was a quantitative paper (Sedillo *et al.*, 2015).

The research was mainly conducted in Africa: five papers South Africa (Defilippi and Cameron, 2007; Campbell, 2011; Dekker *et al.*, 2012; Campbell and Amin, 2014; Campbell and Baernholdt, 2016); four papers in Uganda (Downing, 2008; Downing and Kawuma, 2008; Jack *et al.*, 2011; Namisango *et al.*, 2016); two papers in Kenya (Boit *et al.*, 2014; Sedillo *et al.*, 2015); three papers in Tanzania (Nanney *et al.*, 2010; Hartwig *et al.*, 2014; Bond and Knopp, 2018); one in Zimbabwe (Di Sorbo *et al.*, 2010); one in Malawi (Herce *et al.*, 2014); one in Zambia (Logie and Harding, 2012); and one multisite paper in Uganda, Kenya and Malawi (Grant *et al.*, 2011). A further six papers originated from India (Kumar, 2007; Dongre *et al.*, 2012; Chandra *et al.*, 2016; Jayalakshmi and Suhita, 2017; Munday *et al.*, 2018; Potts *et al.*, 2019); three from Brazil (Lemonica and Barros, 2007; Hennemann-Krause *et al.*, 2015; Freire De Castro Silva *et al.*, 2018) and one each from Malaysia (Devi *et al.*, 2008); Iran (Jabbari *et al.*, 2019); and Bangladesh (Shabnam *et al.*, 2018).

Several models of palliative care were described including: seven home-based palliative care papers (Lemonica and Barros, 2007; Devi *et al.*, 2008; Di Sorbo *et al.*, 2010; Campbell, 2011; Logie and Harding, 2012; Boit *et al.*, 2014; Jayalakshmi and Suhita, 2017; Jabbari *et al.*, 2019); and four, community-based palliative care papers (Jack *et al.*, 2011; Dongre *et al.*, 2012; Hennemann-Krause



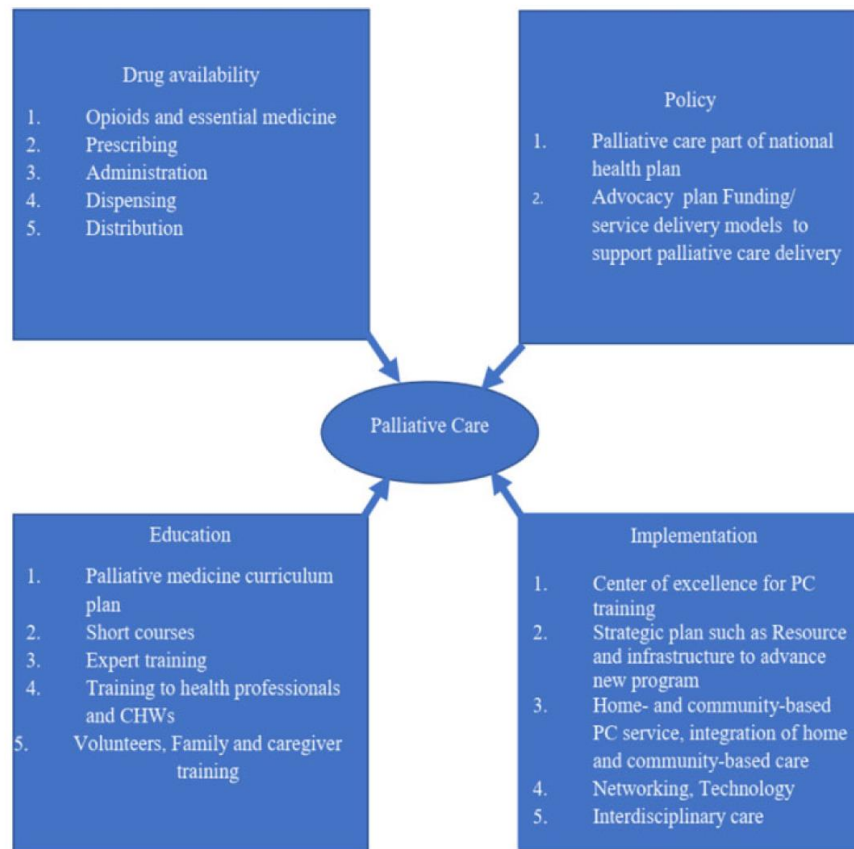
Table 1 Included papers (N = 30), 1990–2019

No.	Authors, year of publication, country	Research focus	Design	Population focus and number of participants	Study quality evaluation
1	Boit <i>et al.</i> (2014) Western Kenya	Description of Kimbilio—a model hospice.	Description of service	Chronic illness	None
2	Bond and Knopp (2018) North Tanzania	Description of community-based palliative care programme.	Case study	Twenty-six home-based palliative care programmes for chronically ill patients and those diagnosed with incurable diseases.	5/10
3	Campbell and Baerholdt (2016) South Africa	Evaluation of palliative care training session.	Qualitative	A total of 29 community health workers	7/10
4	Campbell (2011) South Africa	Experiences of nurses practising home-based palliative care (HBPC).	Qualitative	Four nurses' experiences	6/10
5	Campbell and Amin (2014) South Africa	Palliative care team experiences related to traditional healers.	Qualitative	Four nurses and 17 home-based workers	8/10
6	Chandra <i>et al.</i> (2016) Tamil Nadu, India	Improvement of community participation in palliative care.	Quasi-experiment	145 households with 601 residents	5/9
7	Defilippi and Cameron (2007) South Africa	Description of the ICHC model.	Service description	Hospice Palliative Care Association members	Not applicable
8	Dekker <i>et al.</i> (2012) South Africa.	Attitudes towards chronic pain and palliative care.	Mixed-method	A total of 45 patients receiving care and 26 healthcare workers	6/8
9	Devi <i>et al.</i> (2008) Malaysia	Improving palliative care through referral to home care and pain relief medication.	Service description	Pharmacists, doctors, nurses and patients	Not applicable
10	Di Sorbo <i>et al.</i> (2010) Zimbabwe	Integration of palliative care in rural communities.	Service description	Households receiving palliative care; Youth, home-based volunteer carers, Health professionals, Physicians, Pastors	Not applicable
11	Dongre <i>et al.</i> (2012) India	Evaluation of home-based service for village elders.	Quasi-Experiment	125 elderly members in Self-Help Groups (SHGs), project village and 80 elderly were members in SHGs, the control village	8/9
12	Downing (2008) Uganda	Effectiveness of an HIV/AIDS palliative care educational strategy.	A qualitative evaluation of a case study	Forty interviews and 20 focus group discussions of healthcare workers	7/10
13	Downing and Kawuma (2008) Uganda	Evaluation of a Mobile Training Team (MTT) HIV/AIDS palliative care education programme.	A qualitative evaluative case study approach	Forty interviews and 20 focus group discussions of healthcare workers	7/10
14	Freire <i>et al.</i> (2018) The Brazilian National Cancer Institute (INCA) in Latin America	Information and Communication Technology (ICT) environment of mobile phone to support the palliative cancer care programme.	A case study, description of the module of pain and symptom management	Patient in their home settings. Appointment with nurses and physicians	5/10
15	Grant <i>et al.</i> (2011) Uganda, Kenya and Malawi	Impact of three community-based palliative care interventions.	Ethnographic method for rapid evaluation	A total of 150 participants 33 patients, 27 family caregivers, 36 staff 25 volunteers, 29 community leaders, 12 observations of clinical care	9/10
16	Hartwig <i>et al.</i> (2014). Tanzania	Effectiveness of palliative care teams in reducing pain and increasing quality of life in the absence of Morphine.	A mixed-method study	145 records of cancer patients across the 13 rural hospitals and 6 nurses in the hospitals	7/10
17	Hennemann-Krause <i>et al.</i> (2015) Brazil			12 advanced cancer patients	10/10

(continued)

Table 1 (continued)

No.	Authors, year of publication, country	Research focus	Design	Population focus and number of participants	Study quality evaluation
Telemedicine as a form of additional support for traditional outpatient care.					
18	<a href="#">Heree et al. (2014)</a> Malawi	To evaluate and understand integrated inpatient and home-based care.	A prospective, longitudinal, qualitative, descriptive case series A situational analysis employing REM	Chart review of all adult patients, interviews with 11 caregivers; 7 key stakeholders	8/10
19	<a href="#">Jabbari (2019)</a> Iran	Experience of family physicians and key leaders about feasibility of palliative or end-of-life care.	Qualitative	Two focus groups with 23 physicians	7/10
20	<a href="#">Jack et al. (2011)</a> Uganda	Impact of a Community Volunteer Programme.	Qualitative	Twenty-one patients, 32 volunteers and 11 hospices clinical staff	7/10
21	<a href="#">Jayalakshmi et al. (2017)</a> India	Understanding the structure, organization, and delivery of palliative care and conformity to state policy.	Qualitative	139 patients in Poovar and 239 patients in Azhur taking palliative care services Interview for healthcare workers (doctors, palliative care nurses)	3/10
22	<a href="#">Kumar (2007)</a> India	Sustainable community-owned service offering comprehensive long-term care and palliative care.	Service description	Community-based palliative care in Northern and mid-Kerala covering the population of more than 12 million	Not applicable
23	<a href="#">Lemonica and Barros (2007)</a> Brazil	Educational opportunities to enable home-based palliative care service.	Service description	Integrated education for medical, nursing students and anaesthetic residents. Home care service to patients	Not applicable
24	<a href="#">Logie and Harding (2012)</a> Zambia	Evaluation of a strategic advocacy programme to enhance the provision of palliative care.	A mixed-method evaluation including rapid evaluation	Eight palliative care organizations (three urban and five rural)	4/10
25	<a href="#">Munday et al. (2018)</a> North India	Evaluation of mobile community teams (home visit) with the support of hospital services.	Rapid evaluation method using mixed-method realist approach	Five-hospitals, key informant interviews with two Emmanuel Hospitals Association (EHA) project leaders. 32 interviews with EHA palliative care staff and other staff, hospital management at each site. Twelve interviews with patients and carers	6/10
26	<a href="#">Namisango et al. (2016)</a> Rural and urban, Uganda	Exploring an electronic database to replace hard-copy documentation of medicines.	Quasi-Experiment	150 patients with palliative care needs in a rural setting	7/9
27	<a href="#">Nanney et al. (2010)</a> Tanzania	Providing a community involved home-based palliative care.	Description of service	Health (nurses, social workers, clinical officers, chaplains) training; support to home-based community volunteers;	Not applicable
28	<a href="#">Potts et al. (2019)</a> India	Feasibility and acceptance of a piloted home-based palliative care programme.	Qualitative descriptive study	Seven palliative care clinical team (nurses, physicians, behavioural counsellor, a study coordinator) and three CHWs	7/10
29	<a href="#">Sedillo et al. (2015)</a> Kenya	Palliative care provider self-competence and priorities for future education.	A descriptive cross-sectional pilot study survey	Five clinical staff, 11 caregivers and 8 support staff	6/8
30	<a href="#">Shabnam et al. (2018)</a> Bangladesh	Development, service use and challenges of 24/7 palliative care Telephone Consultation Service (TCS).	Mixed-method study	4195 calls from 1164 patients and their caregivers. Six participants (head department, clinical pharmacist, palliative care physicians)	5/10



**Figure 2** Strategies used by LMICs to establish palliative care, grouped according to the WHO public health model (Stjernsward *et al.*, 2007; Callaway *et al.*, 2018).

*et al.*, 2015; Bond and Knopp, 2018). In five papers, integrated models of community- and home-based care was described (Defilippi and Cameron, 2007; Kumar, 2007; Downing and Kawuma, 2008; Nanney *et al.*, 2010; Jack *et al.*, 2011; Herce *et al.*, 2014; Munday *et al.*, 2018).

## Results

The integrative review results are described using the four pillars of the WHO public health model (Figure 2). Although in some countries palliative care has been included as a part of government policy, translation of health policy and implementation in the community was often reliant on advocacy and the financial support from non-government organizations (NGOs).

### Policies

Policy strategies in the reviewed papers described the availability of palliative care in national health policy or non-government agency advocacy plans for incorporating palliative care in national health plans. Strategies varied widely between countries and included funding to support palliative care delivery both at the community and at healthcare organizational levels.

In this review, palliative care policy was described in 10 papers (Kumar, 2007; Lemonica and Barros, 2007; Devi *et al.*, 2008; Downing, 2008; Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Logie and Harding, 2012; Boit *et al.*, 2014; Herce *et al.*, 2014; Bond and Knopp, 2018). Although some governments provided policies about

the way palliative care will be provided (Bond and Knopp, 2018), the provision of palliative care was largely implemented by NGOs (Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Herce *et al.*, 2014). Five papers described government initiatives to develop palliative care in rural settings (Lemonica and Barros, 2007; Devi *et al.*, 2008; Logie and Harding, 2012; Herce *et al.*, 2014; Bond and Knopp, 2018). For instance, in Sarawak, Malaysia, Davi *et al.* (2008) found that palliative care to be part of the national healthcare policy and health professional practice. In response to the national policy, the Malaysian Ministry of Health (MoH) increased the allocated budget to establish palliative care units throughout the country. This budget was supplemented by a fundraising strategy to ensure families donated to a fund, and significant donations were used to set-up an NGO, the 'Sarawak Hospice Society' (Devi *et al.*, 2008).

Furthermore, in Botucatu (Brazil), the government allowed free essential medications such as Morphine for patients in need (Lemonica and Barros, 2007). While, in Zambia, MoH and the Palliative Care Association of Zambia provided a fund to enhance palliative care (Logie and Harding, 2012). However, in the Royal District of Marta, North Tanzania a national palliative care policy was developed but with no government budget allocation (Bond and Knopp, 2018).

Two papers, the Nankya Model in Uganda and Kimbilio a model hospice in Kenya, had an advocacy plan to establish palliative care at the district and national levels (Downing, 2008; Boit *et al.*, 2014). In the other three papers, NGOs undertook initiatives to establish palliative care. For instance, the Foundation for Hospice in sub-

**Table 2** Findings, implications and challenges of the included papers

Authors, year of publication, country	Findings	Comments and implications	Challenges
Boit <i>et al.</i> (2014)	<ul style="list-style-type: none"> <li><i>Policy:</i> Kenyan Hospice and Palliative Care Association (KEHPCA) has an advocacy plan and worked closely with the MoH.</li> <li><i>Drug availability:</i> Morphine included in the essential medicine list and its usage and accessibility is not restricted by law.</li> <li><i>Education:</i> the staff members trained on how to use Morphine and prevent pain and suffering.</li> <li><i>Implementation:</i> providing home palliative care service for those who live in a rural area. In 2013, 200 home visits were made.</li> </ul>	<ul style="list-style-type: none"> <li>No precise data collection, sampling or ethical review.</li> <li>The strength of interdisciplinary team; showing compassion; spending time with the community; listen to their concerns, and grieving with them.</li> </ul>	<ul style="list-style-type: none"> <li>The patients have an economic problem.</li> <li>Inadequate drug supplies, poor access to care in rural areas, health inequalities, and lack of awareness on basic palliative care among health-care providers and the community.</li> </ul>
Bond and Knopp (2018)	<ul style="list-style-type: none"> <li><i>Policy:</i> availability of national palliative care policy with no funding allocated for palliative care services by the government.</li> <li><i>Drug availability:</i> palliative care team provided paracetamol for mild and diclofenac for moderate and Morphine for severing pains.</li> <li><i>Education:</i> palliative care incorporated into medical and nursing curricula, and nurses are applying and disseminating their knowledge to other healthcare providers.</li> <li><i>Implementation:</i> palliative care team provides comprehensive care (physical, psychosocial and spiritual support) with no cost to the clients. Palliative care delivered to those clients diagnosed with a chronically ill and incurable disease who were suffering from pain. Referrals to palliative care centre made by community volunteers or by clients themselves.</li> </ul>	<ul style="list-style-type: none"> <li>No precise data collection, sampling or ethical review.</li> <li>Integrate palliative care into the existing healthcare system and to develop a cost-effective, cultural appropriate sustainable palliative care programme.</li> </ul>	<ul style="list-style-type: none"> <li>Poverty, lack of funding and limited human resource, fear of opioid usage among healthcare providers and the public.</li> <li>Obtaining a licence to administer Morphine and even having a license, getting access to the medication is challenging.</li> <li>Lack of vehicles and not all palliative care team can operate a motorcycle.</li> </ul> <p>The palliative care programme is free of cost and dependant on fund donated organizations.</p>
Campbell and Baernholdt (2016)	<ul style="list-style-type: none"> <li><i>Policy:</i> not applicable</li> <li><i>Drug availability:</i> not applicable</li> <li><i>Education:</i> The training sessions composed of six topics: general palliative care, HIV/AIDs, physical care at the end of life, grieving and mourning, and debriefing for CHWs. The evaluation indicated that majority of them (mean score 4.83) learned a new thing, and they should use in their daily work.</li> <li><i>Implementation:</i> not applicable</li> </ul>	<ul style="list-style-type: none"> <li>The evaluation questionnaire source is not clearly stated.</li> <li>Provide training for CHWs and evaluate the palliative care quality delivered by the CHWs.</li> </ul>	The CHWs and caregivers experienced multiple losses of patients and moral distress. Limited resources.
Campbell (2011)	<ul style="list-style-type: none"> <li><i>Policy:</i> not applicable</li> <li><i>Drug availability:</i> not applicable</li> <li><i>Education:</i> not applicable</li> <li><i>Implementation:</i> the nurses indicated that HBPC has many benefits such as the community supports, pain relief, understanding of deep-seated personal issues. HBPC also enables patients to practice their traditional customs and may allow access to traditional medicines, in Zulu, such as the traditional herbs that heal patient wounds.</li> </ul>	<ul style="list-style-type: none"> <li>Small-group of nurses participated in the study.</li> <li>Consider the safety issue of nurses who work in home-based palliative care though HBPC have lots of benefits in increasing access to care.</li> </ul>	<ul style="list-style-type: none"> <li>The patient and families in rural African homes expect and familiar with the concept of curative care but not palliative care from the HBPC nurses.</li> <li>The safety of nurses is also another challenge.</li> <li>Homes of the Kwa-Zulu poorly ventilated and masks may not be available.</li> </ul>
Campbell and Amin (2014)	<ul style="list-style-type: none"> <li><i>Policy:</i> not applicable</li> <li><i>Drug availability:</i> not applicable</li> <li><i>Education:</i> not applicable</li> </ul>	<ul style="list-style-type: none"> <li>The findings did not represent the nurses and home-based care workers experience.</li> </ul>	Traditional healers focused on beliefs/faith of

(continued)



**Table 2** (continued)

Authors, year of publication, country	Findings	Comments and implications	Challenges
Chandra <i>et al.</i> (2016)	<ul style="list-style-type: none"> <li><i>Implementation</i>: benefits and challenges when using traditional healers. They play a significant role in relieving pain and providing psychological care from a cultural perspective, so involving the patients in palliative care training. They were also sharing the work of nurses and CVWs.</li> <li><i>Policy</i>: not applicable</li> <li><i>Drug availability</i>: not applicable</li> <li><i>Education</i>: palliative care awareness increased using education campaign and community volunteers to provide home-based palliative care.</li> </ul>	<ul style="list-style-type: none"> <li>Nurses and home-based workers discussed the benefits and challenges when using traditional healers. Recommended palliative care training for traditional healers.</li> <li>Sampling technique—sample size calculation not clearly stated.</li> <li>Community-based care by volunteers is new to the community. Awareness and attitudinal change in palliative care increase through the education campaign.</li> </ul>	<p>individuals and not based on scientific evidence.</p> <p>The community expected to get palliative care from experts in hospitals not home-based care from volunteers.</p>
Defilippi and Cameron (2007)	<ul style="list-style-type: none"> <li><i>Implementation</i>: not applicable</li> <li><i>Policy</i>: not applicable</li> <li><i>Drug availability</i>: not applicable</li> <li><i>Education</i>: palliative care training course conducted for community caregivers, nurses and social workers. Bedside training provided for doctors in palliative medicine.</li> <li><i>Implementation</i>: mentorship a significant role in providing networked service through the integration of palliative home-based care with community caregivers, government hospitals, clinics and NGOs.</li> </ul>	<ul style="list-style-type: none"> <li>Description of the palliative care model (no precise data collection, sampling or ethical review)</li> <li>Mentorship helps in strengthening networked service.</li> </ul>	<p>Dependence on external funding organization which impacts the sustainability of the programme.</p>
Dekker <i>et al.</i> (2012)	<ul style="list-style-type: none"> <li><i>Policy</i>: not applicable</li> <li><i>Drug availability</i>: pain medication in clinics is limited to Paracetamol, Ibuprofen, Aspirin and diclofenac. Hospital dispensed ~8.12 g of Morphine per month in the form of 5% tablet, 68% syrup and 27% injection.</li> <li><i>Education</i>: fifty-eight per cent of health-care providers had taken palliative care training, including either formal training in school or informal training in the working area. Five of the six physiotherapists, occupational therapists and 9 of the 11 nurses had never trained.</li> </ul>	<ul style="list-style-type: none"> <li>Perceived dichotomy between palliative and curative care, and small sample size.</li> <li>Policymakers and healthcare providers to improve pain treatment and access to palliative care.</li> </ul>	<ul style="list-style-type: none"> <li>Limited prescription of palliative care medicine.</li> <li>Outside the hospital, access to pain medications was limited.</li> <li>Lack of awareness and unfavourable attitude to palliative care.</li> </ul>
Devi <i>et al.</i> (2008)	<ul style="list-style-type: none"> <li><i>Implementation</i>: not applicable</li> <li><i>Policy</i>: funding for training from hospitals and the government and palliative care unit's development throughout the country.</li> <li><i>Drug availability</i>: Morphine prescription policy changed from 2 weeks to 1 month and 3 months for patients in remote areas.</li> <li><i>Education</i>: health professionals trained, including doctors.</li> <li><i>Implementation</i>: experience sharing with the palliative care team. Palliative care access in rural areas increased with the active involvement of stakeholders. Palliative care service is networked from hospital to home care. Ninety per cent of the patients indicated that the programme and the service help to relieve their symptoms and the home visit was</li> </ul>	<ul style="list-style-type: none"> <li>Description of palliative care model (no precise data collection, sampling or ethical review)</li> <li>Educating and training health professionals, Cost-effective, sustainable home-based palliative care with strong family support and poor health infrastructure.</li> </ul>	<p>Family fears of Morphine addiction.</p>

(continued)

**Table 2** (continued)

Authors, year of publication, country	Findings	Comments and implications	Challenges
Di Sorbo <i>et al.</i> (2010)	<p>also helpful. Patients also got the service for free.</p> <ul style="list-style-type: none"> <li>• <i>Policy</i>: funding agency supported new palliative care programmes.</li> <li>• <i>Drug availability</i>: inadequate supply of Morphine in rural areas and limited availability in cities. NGOs compiled essential medicine list.</li> <li>• <i>Education</i>: palliative care training, mentorship to physicians, health professionals, programme officers, volunteers, pastors and youth. Efforts underway with the university to develop a palliative medicine curriculum.</li> <li>• <i>Implementation</i>: NGOs support resources to demonstrate home-based palliative care practices. Service for vulnerable youth described, also, assists with the integration of home-based palliative care with local clinics and hospitals.</li> </ul>	<ul style="list-style-type: none"> <li>• Description of palliative care model (no precise data collection, sampling or ethical review).</li> <li>• Recommended for more funding to scale up this model nationally strengthening a network among the community and all funding organizations.</li> </ul>	<ul style="list-style-type: none"> <li>• Morphine supply limited to cities and not distributed to rural areas.</li> <li>• More attention is given to long-term development and sustainability of the programme.</li> </ul>
Dongre <i>et al.</i> (2012)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: not applicable</li> <li>• <i>Education</i>: not applicable</li> <li>• <i>Implementation</i>: elderly patients received home care from a medical doctor and nurses, and a home visit from the community volunteers, and physiotherapy service in the rural area.</li> </ul>	The method section broadly described. A need to integrate the palliative care team activity to ensure a continuum of care from home to hospital.	<ul style="list-style-type: none"> <li>• Elderly problems are chronic in nature and this produce stress to the patients and families.</li> <li>• high prevalence of chronic diseases and risk factors</li> </ul>
Downing and Kawuma (2008)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: oral Morphine was available in the districts.</li> <li>• <i>Education</i>: health professionals develop new skills, attitudinal change, and confidence in providing care. Training assists the instructor to integrate palliative care into the nursing curriculum.</li> <li>• <i>Implementation</i>: health professionals motivated to implement community home-based care services. Endeavoured to integrate the existing healthcare system.</li> </ul>	<ul style="list-style-type: none"> <li>• Professional qualifications of participants not clearly stated.</li> <li>• Evaluating palliative care training and encouraging multidisciplinary teamwork.</li> </ul>	The participants' expectation of getting daily expenses of money from the training was not available.
Downing (2008)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: funding from the joint clinical research centre and MoH and Advocacy at the district or national level.</li> <li>• <i>Drug availability</i>: Mobile Training Teams (MTTs) develops drug availability, particularly oral Morphine.</li> <li>• <i>Education</i>: MMT 1-year modular training programme.</li> <li>• <i>Implementation</i>: MTT bringing about change in practice such as teamwork and attitudinal change of health professionals.</li> </ul>	<ul style="list-style-type: none"> <li>• Service evaluation broadly described. Specific methods and detailed results not clearly stated.</li> <li>• Developing culturally appropriate, affordable palliative care parallel to the four components of public health strategy.</li> </ul>	The issue of generalizability and validity of the model.
Freire <i>et al.</i> (2018)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: not applicable</li> <li>• <i>Education</i>: not applicable</li> <li>• <i>Implementation</i>: the information technology tools used in implementing palliative care and chronic pain management. The palliative care team used mobile devices for communicating with patients in remote areas.</li> </ul>	<ul style="list-style-type: none"> <li>• The data analysis technique and ethics part of the method is not stated.</li> <li>• Support of palliative care team in providing care and to inform pain scale using information system.</li> </ul>	Internet connection may be a challenge in remote areas.

(continued)

**Table 2** (continued)  
Authors, year of publication, country

	Findings	Comments and implications	Challenges
Grant <i>et al.</i> (2011)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: oral Morphine solution used.</li> <li>• <i>Education</i>: nurses and community volunteers developed awareness about the illness and changing families and community attitudes towards death and dying.</li> <li>• <i>Implementation</i>: volunteers significant in providing health education with links to religious and community leaders.</li> <li>• Mobile phone for rapid access in the clinical network.</li> <li>• Palliative care team provides home-based palliative care.</li> </ul>	<ul style="list-style-type: none"> <li>• Palliative care not reaching cancer patients compared to HIV patients.</li> <li>• Recommended to enhance awareness of cancer in the community.</li> </ul>	<ul style="list-style-type: none"> <li>• Volunteer and poverty challenges.</li> <li>• Distance and lack of skilled professionals.</li> </ul>
Hartwig <i>et al.</i> (2014).	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: in the absence of Morphine, pain score improved from an average of 3.8/5 (moderately severe pain) to 2.3/5 (moderate pain) and the non-pain symptoms such as psychological, spiritual and family issue improved through palliative care for cancer patients.</li> <li>• <i>Education</i>: four of the six nurses were trained to administer Morphine for severe and chronic pain. Three of the nurses have a diploma in palliative care, and the other three have at least 7 years of experience working in palliative hospice.</li> <li>• <i>Implementation</i>: the nurse provides holistic palliative care such as emotional, psychosocial support for patients and families; and improved pain management by keeping spiritual well-being. In rural Tanzania, palliative care is implemented, and pain managed in the absence of oral Morphine, but not to the degree that could be achieved if Morphine was available.</li> </ul>	The possibility of bias and error in translation because of only one interviewer and translator.	<ul style="list-style-type: none"> <li>• Lack of pain medications, such as oral Morphine.</li> <li>• Psychosocial and spiritual pain such as family conflicts, poverty, the child not going to school this thing add to the physical pain.</li> <li>• All the nurse tells the story of more than one patient who had suffered from untreatable pain before death.</li> </ul>
Hennemann <i>et al.</i> (2015)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: not applicable</li> <li>• <i>Education</i>: not applicable</li> <li>• <i>Implementation</i>: telemedicine is an essential technology in reducing symptoms, less time spent on transportation, and increased patient and family support. Also maintained quality of home-based palliative care for patients with advanced cancer.</li> </ul>	Patient and family members need home computer access and literacy.	Not applicable for patient and caregivers without computer access.
Herce <i>et al.</i> (2014)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: Neno Palliative Care Program (NPCP) a joint programme between the NGO and MoH, local and rural government, community and faith-based organizations. The Malawi MoH provides essential health service free of charge.</li> <li>• <i>Drug availability</i>: medications prescribed based on the level of pain, starting from mild analgesia to potent opioids.</li> </ul>	<ul style="list-style-type: none"> <li>• The key stakeholder's profession or responsibility not clearly stated.</li> <li>• Providing comprehensive palliative care integrated with disease-modifying treatment through public-private partnership and by establishing a network community-based and home-based care volunteers.</li> </ul>	<ul style="list-style-type: none"> <li>• Poverty, transportation, lack of food are the significant challenges of the patients'</li> <li>• Lack of consistent funding for palliative care activities,</li> <li>• competing for health priorities, as a threat to the sustainability palliative care services. A</li> </ul>

(continued)

**Table 2** (continued)  
Authors, year of publication, country

	Findings	Comments and implications	Challenges
	<ul style="list-style-type: none"> <li>• <i>Education</i>: all clinical providers were trained more than a week and these trained volunteer health workers.</li> <li>• <i>Implementation</i>: patient-related psychosocial needs linked with socio-economic needs, such as a need for income, receiving food, house repairs. Psychosocial support gained from family members, community churches, neighbours and friends. Most patients preferred home-based (46%) and community-based (30%), hospital-based (24%) palliative care.</li> </ul>		<p>knowledge gap exists in hospitalized patients. Most caregivers lack training and counselling skills in palliative care.</p>
Jabbari (2019) Rural Iran	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>drug availability</i>: not applicable</li> <li>• <i>Education</i>: not applicable</li> <li>• <i>Implementation</i>: there is a structure in the health system which indicates palliative care at each level, should integrate palliative care services with primary health care team including Family Physician (FP), nurses, psychologist, family member, social workers and religious person to provide palliative or end-of-life care. Services provided at no cost and with support from insurance companies. The team members can provide the service in home, charity, special centres and there is a referral system from and to community through the system.</li> </ul>	The strategy for palliative care should be based around the FP and the other levels of the health system receiving referrals (FP at first level, district hospital second and university hospital third level) using a computerized health information system.	<ul style="list-style-type: none"> <li>• Lack of education for health care providers and lack of responsibility among the providers.</li> <li>• Cultural and financial problems no sustainable funding.</li> </ul> <p>Lack of welcome by the private system and lack of health facilities.</p>
Jack <i>et al.</i> (2011)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: not applicable</li> <li>• <i>Education</i>: counselling and supporting patients and families in the right way of taking medication.</li> <li>• <i>Implementation</i>: CVWs identify the patient address and provide physical, psychological and family care. CVWs used to provide a linked patient with the hospice staff in the remote areas.</li> </ul>	<ul style="list-style-type: none"> <li>• Sample bias and risk of programme sustainability.</li> <li>• The community volunteer used as a bridge among the hospice team and the patients with their families.</li> </ul>	Lack of transportation and financial issues affect payment to CVWs.
Jayalakshmi <i>et al.</i> (2017) Two Local Self-government Institutions (LSGIs) of Kerala, India	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: palliative care medications were available in the palliative care unit, health centres and government hospitals.</li> <li>• <i>Education</i>: not applicable</li> <li>• <i>Implementation</i>: home visits in both places for those patients need urgent service the family members called the nurse. Some of the patients visited once a month, and some once in 2–3 months. The government, palliative care team, was nurse-led while the NGOs were more professional approach in terms of team composition.</li> </ul>	<ul style="list-style-type: none"> <li>• The description methods did not have a detail description of data analysis, ethical approval.</li> <li>• Public–private linkage used for the programme sustainability at community level.</li> </ul>	Lack of transportation and vehicles, availability of Morphine is also a challenge except in NGO, lack of adequate social welfare, absence of emergency referrals. Lack of institutional structure. No uniform team structure, infrastructure, training of healthcare workers.
Kumar (2007) Kerala, India	<ul style="list-style-type: none"> <li>• <i>Policy</i>: the NNPC has been engaged with the local governments to prioritize the local health needs. However, more than 90% of the resource of the project was local generated fund.</li> <li>• <i>Drug availability</i>: not applicable</li> </ul>	<ul style="list-style-type: none"> <li>• Description of NNPC (no clear methodology session).</li> <li>• Locally generated funds and the NNPC closely working with the local government for the programme sustainability.</li> </ul>	Poverty, lack of sanitation, primary health care, primary education and clean drinking water.

(continued)



**Table 2** (continued)

Authors, year of publication, country	Findings	Comments and implications	Challenges
Lemonica and Barros (2007) Botucatu, Brazil	<ul style="list-style-type: none"> <li>• <i>Education</i>: a structured training programme (16 h of an interactive theory session and 4 days of clinical practice under supervision) including evaluation at the end given to the volunteers. Creating skill and confidence of the local community.</li> <li>• <i>Implementation</i>: community volunteers provided a regular home visit and identified the non-medical issues such as financial problems, patients in need of care, and organizing awareness creation activities in the community. The NNPC focused on home care in our patients and closely working with the palliative care facilities in the inpatient units. The earlier structure doctor or nurse-led, replaced with the community, volunteer-led. The solution of the problem should be raised from the community by themselves.</li> <li>• <i>Policy</i>: the government provides essential medications free of charge.</li> <li>• <i>Drug availability</i>: the pain medications, including Morphine, were accessible with no cost.</li> <li>• <i>Education</i>: palliative care course-integrated to undergraduate and postgraduate curriculums of medical students, nursing education, Anaesthesia residents. It also provides continuing medical education programme speciality training for nurses leading to Masters and Doctoral degree.</li> <li>• <i>Implementation</i>: Pain Management and Palliative Care (PMPC) provides home care. Twice a week, the palliative care team visits an average of four patients each day. On-call medical service is available 24 h a day and 7 days a week.</li> </ul>	<ul style="list-style-type: none"> <li>• Description (data collection, analysis and ethics were not stated).</li> <li>• Improved experience of care for dying.</li> </ul>	Lack of hospital bed to provide inpatient care.
Logie and Harding (2012)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: advocacy with the MoH-led technical working party and funding organization.</li> <li>• <i>Drug availability</i>: multi-sectoral working group established and facilitating oral Morphine provision.</li> <li>• <i>Education</i>: expert palliative care training delivered for 1 week. Training for health professionals, diploma students and short courses delivered for all healthcare staff.</li> <li>• <i>Implementation</i>: attitudinal change of health professionals towards caring for dying patients; enhanced confidence and assisted with the delivery of home-based care.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of transparent methodology (research design, sampling or ethical consideration).</li> <li>• Recommends use of WHO public health strategy.</li> </ul>	Sustainability of the programme because of restricted funding and travel costs. Low consumption of Morphine.
Munday <i>et al.</i> (2018) Rural, North India	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: the team prescribed the appropriate medication. However, oncologist or anaesthetist was needed in the hospital to prescribe Morphine safely.</li> </ul>	<ul style="list-style-type: none"> <li>• In the methods section, sample size, number of participants in the quantitative part and ethical approval) were not stated.</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of funding</li> <li>• The number of daily visits varied because of travelled and has poor roads.</li> <li>• Time-consuming to get trust by the community.</li> </ul>

(continued)

**Table 2** (continued)  
Authors, year of publication, country

	Findings	Comments and implications	Challenges
	<ul style="list-style-type: none"> <li>• <i>Education</i>: palliative care team members trained for 10 days twice a year. The doctor took a diploma in palliative medicine and a 6 weeks course. Two nurses took more than a 1-month course—family members trained by the team members on how to care their relatives.</li> <li>• <i>Implementation</i>: home visits take place by the palliative care team 5 days a week. Family members have the team phone number to call if the problems severe. All the team have a skill of consultation and being a good listener. The team provides psychological, emotional and spiritual support for both patients and their families. The team is not telling the patient is dying because the community put them in the floor. The community and church leaders were supporting the team members in helping those in need.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide hospital inpatient palliative care and a home visit for home care service.</li> </ul>	<ul style="list-style-type: none"> <li>• Cultural and language difference is another challenge.</li> <li>• The patient and family were below the poverty line.</li> <li>• Lack of Morphine.</li> <li>• Lack of funding for the services.</li> </ul>
Namisango <i>et al.</i> (2016)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: not applicable</li> <li>• <i>Education</i>: not applicable</li> <li>• <i>Implementation</i>: compares the effectiveness of electronic application before and after implementation time. The m-health approach showed the need for pharmacies to improve medicine delivery. Also assists patient data security.</li> </ul>	<ul style="list-style-type: none"> <li>• Identified need for reliable power.</li> <li>• Enhance the operational process of pharmacy service in palliative care.</li> </ul>	Low reporting of patient contact details and lack of mobile phone use.
Nanney <i>et al.</i> (2010)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: NGO provide fund resources continuum of care for people living with HIV/AIDS.</li> <li>• <i>Drug availability</i>: palliative medicine available throughout the country.</li> <li>• <i>Education</i>: diploma training for health professionals and volunteers in home-based care by the government-certified trainer.</li> <li>• <i>Implementation</i>: palliative care for individuals used home-based palliative care volunteers' network; quality of palliative care service expansion to vulnerable children by providing a link with community and church leaders.</li> </ul>	<ul style="list-style-type: none"> <li>• Description of palliative care model (no precise data collection, sampling or ethical review).</li> <li>• A continuum of care to provide quality of palliative care.</li> </ul>	Home-based care volunteers and palliative care team face challenges to help families living in poverty.
Potts <i>et al.</i> (2019) Rural, Kolkata, India	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: not applicable</li> <li>• <i>Education</i>: CHWs were trained for 5 days. The CHWs was also trained in the family and caregivers.</li> <li>• <i>Implementation</i>: the CHWs provides primary care such as psychosocial and emotional support and providing comfort to the patients and their families with the guidance of the physicians. However, the CHWs need more training on how to handle patients during an emergency and what to expect during the dying process. CHWs have a good experience in record-keeping and documenting the service provided in each visit.</li> </ul>	<ul style="list-style-type: none"> <li>• The ethical approval session was not stated, small sample size.</li> <li>• CHWs integrated to the health system.</li> </ul>	Shortage of training days, lack of sufficient pay or incentives for CHWs.

(continued)

Table 2 (continued)

Authors, year of publication, country	Findings	Comments and implications	Challenges
Sedillo <i>et al.</i> (2015)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: not applicable</li> <li>• <i>Education</i>: self-competence scores differ according to palliative care provider type. findings direct choice of topics for future education.</li> <li>• <i>Implementation</i>: not applicable</li> </ul>	<ul style="list-style-type: none"> <li>• A pilot study with small numbers of self-confidence and education priorities among clinical care-givers and support staff.</li> <li>• Educational programme provided palliative care self-competencies in clinical care and patient and family communication.</li> </ul>	Scope of practice between participants differed.
Shabnam <i>et al.</i> (2018)	<ul style="list-style-type: none"> <li>• <i>Policy</i>: not applicable</li> <li>• <i>Drug availability</i>: not applicable</li> <li>• <i>Education</i>: not applicable</li> <li>• <i>Implementation</i>: The 24/7 TCS started in 2011 to address the needs of palliative care patients and caregivers, only for those who discharge to the rural areas of Bangladesh. The physicians starting from 2012 have reimbursement fee for the service. The service includes all types of everyday problems, from severe symptoms to invitations for funerals. The service is also a bridge that helps to connect the physician and the patients. Calling helps the patient to access information on the availability of bed on ward, to get advice, comfort and to get medicines.</li> </ul>	<ul style="list-style-type: none"> <li>• Risk of bias and a client may want to take an overdose.</li> <li>• The TCS provides a bridge for the patients, caregivers and physicians to reach for those who discharged from the hospital and live outside the capital.</li> </ul>	<ul style="list-style-type: none"> <li>• Physicians are not trained to consult and provide advice on the telephone.</li> <li>• Lack of patient record in the physician's hand. There is also a physical change, so the patients lack familiarity with alternative doctors.</li> </ul>

Saharan Africa (FHSSA), established palliative care sites in Zimbabwe (Di Sorbo *et al.*, 2010). The FSSHA (a non-profit U.S. National Hospice and Palliative Care Organization) with other international NGOs received funding to expand the palliative care programme by, e.g. the provision of resources for home-based care kits in different rural sites of Tanzania (Nanney *et al.*, 2010). Furthermore, in Kerala (India), 90% of the palliative care funding, was sourced by the neighbourhood network in palliative care (NNPC) sourced from local governments (Kumar, 2007). However, lack of funding (Logie and Harding, 2012; Boit *et al.*, 2014; Herce *et al.*, 2014; Bond and Knopp, 2018) and dependence on external donors or NGOs were associated with concern about sustainability when government policy was not associated with government funding (Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Logie and Harding, 2012).

### Medication availability

The availability of palliative medicines is an umbrella term that includes prescribing, distributing, dispensing and administering of medications, and usually includes a list of essential medicines suggested by WHO. Of importance is the availability of opioids for the management of pain.

The availability of medications varied widely and may be dependent upon relevant policy, culture and religious beliefs, and accessibility to medications. Sixteen papers described strategies and challenges in relation to palliative medicines (Lemonica and Barros, 2007; Devi *et al.*, 2008; Downing, 2008; Downing and Kawuma, 2008; Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Grant *et al.*, 2011; Jack *et al.*, 2011; Dekker *et al.*, 2012; Logie and Harding, 2012; Boit *et al.*, 2014; Hartwig *et al.*, 2014; Herce *et al.*, 2014; Jayalakshmi and Suhita, 2017; Bond and Knopp, 2018; Munday *et al.*, 2018). In rural Malawi and Brazil, Morphine was available free of charge (Lemonica and Barros, 2007; Herce *et al.*, 2014). In

rural Malawi, patients have used 53% of the Morphine prescribed (Herce *et al.*, 2014). Whereas, in rural Zimbabwe, the NGO provided a list of essential palliative medicines to the government supply-chain, where Morphine supply was limited and not available outside the main cities (Di Sorbo *et al.*, 2010). Additionally, in rural South Africa, palliative medicines are limited to supply from clinics (Dekker *et al.*, 2012). In rural areas in North Tanzania, a license is required to administer Morphine (Bond and Knopp, 2018). Besides Tanzania, Morphine supply is also a challenge in Uganda, Zambia and South Africa with the training of health professionals to administer oral Morphine found to increase the demand for the drug resulting in the medication being available in all districts (Nanney *et al.*, 2010; Logie and Harding, 2012). In the absence of Morphine in a rural hospital in Tanzania, a nurse provided advocacy for oral Morphine and pain scores improved through non-pharmacological management (Hartwig *et al.*, 2014).

In rural Western Kenya, North Tanzania and Kerala, palliative care medications were available without any legal restrictions (Boit *et al.*, 2014; Jayalakshmi and Suhita, 2017; Bond and Knopp, 2018). However, in rural North India, a hospital oncologist or anaesthetist was needed to prescribe Morphine (Munday *et al.*, 2018). In contrast, another paper described a networked system of medications from the large hospital to rural clinics (Devi *et al.*, 2008). Doctors in larger hospitals created a prescription which was faxed to the rural clinic nearest to a patient's home (Devi *et al.*, 2008). The medication was prescribed for 1 month in rural areas and 3 months in more remote areas. The Malaysian medication system was also capable of calculating the consumption level of opioids to enable appropriate supply distribution of essential medications (Devi *et al.*, 2008). In three rural African countries including Uganda, community volunteer workers (CVWs) played a significant role in ensuring the delivery of medication to patients' homes and advising them to take the right drug at the right time (Grant *et al.*, 2011; Jack *et al.*,

2011). To enhance medication availability, a software application was piloted to replace hard-copy documentation of palliative medication prescription in pharmacies (Namisango *et al.*, 2016). This software application reduced stock expiration, improved time-efficiency and medicine management.

However, the availability of Morphine in clinical care was mostly limited to hospitals in cities (Downing, 2008; Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Dekker *et al.*, 2012; Logie and Harding, 2012; Hartwig *et al.*, 2014; Munday *et al.*, 2018). Additionally, fear of opioid usage among healthcare providers and the public (Devi *et al.*, 2008; Bond and Knopp, 2018), reduced the accessibility of palliative medicines, and a license was needed to administer Morphine (Boit *et al.*, 2014; Bond and Knopp, 2018).

## Education

The education of health professionals and the public featured in 21 of the reviewed papers in curriculum plans; palliative care courses for healthcare providers; expert training; family caregiver training and support; and mentorship (Defilippi and Cameron, 2007; Kumar, 2007; Lemonica and Barros, 2007; Devi *et al.*, 2008; Downing, 2008; Downing and Kawuma, 2008; Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Grant *et al.*, 2011; Jack *et al.*, 2011; Dekker *et al.*, 2012; Logie and Harding, 2012; Boit *et al.*, 2014; Hartwig *et al.*, 2014; Herce *et al.*, 2014; Sedillo *et al.*, 2015; Campbell and Baernholdt, 2016; Chandra *et al.*, 2016; Bond and Knopp, 2018; Munday *et al.*, 2018; Potts *et al.*, 2019). Palliative care was incorporated into the curricula of medical, nursing and other health disciplines in Western Kenya, northern Tanzania and Brazil (Lemonica and Barros, 2007; Boit *et al.*, 2014; Bond and Knopp, 2018). In Zimbabwe, a university planned to develop a curriculum in palliative medicine (Di Sorbo *et al.*, 2010). A Kenyan paper also discussed the future interest of clinical staff to develop competence in particular areas of palliative care, such as paediatric palliative care (Sedillo *et al.*, 2015).

Hospice centres in South Africa conducted bedside training for physicians studying either a diploma or degree in palliative medicine (Defilippi and Cameron, 2007). Four papers reported that diploma students completed palliative care studies in different settings in order to enhance their confidence and skills (Defilippi and Cameron, 2007; Nanney *et al.*, 2010; Logie and Harding, 2012; Munday *et al.*, 2018). In 14 papers, palliative care training was described as being delivered to healthcare providers, social workers, home-based care volunteers (HBCVs), community health workers (CHWs) and spiritual leaders (Defilippi and Cameron, 2007; Kumar, 2007; Downing, 2008; Downing and Kawuma, 2008; Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Jack *et al.*, 2011; Dekker *et al.*, 2012; Logie and Harding, 2012; Hartwig *et al.*, 2014; Herce *et al.*, 2014; Bond and Knopp, 2018; Munday *et al.*, 2018; Potts *et al.*, 2019). Additionally, in three papers, a mentorship and supervision approach was significant in developing the scope of the provision of hospice care and assisting with accreditation processes (Defilippi and Cameron, 2007; Di Sorbo *et al.*, 2010; Herce *et al.*, 2014).

Only one paper discussed the benefit and challenges of traditional healers in palliative care (Campbell and Amin, 2014). Traditional healers are knowledgeable about local, cultural and their community problems, which enable them to solve psychosocial problems (Campbell and Amin, 2014). However, without palliative care training, there was a concern that healers may not understand the importance of holistic care and the role of other palliative care team members. Another two papers described public awareness

campaigns using poster exhibitions about home care in capital cities and some rural areas (Devi *et al.*, 2008; Chandra *et al.*, 2016). In these papers, palliative care awareness was achieved through house-to-house visits, printed pamphlets and banners displayed around the village, as well as being a topic on cultural nights (Chandra *et al.*, 2016). An exhibition of posters about home care was undertaken in a rural community (Devi *et al.*, 2008).

The main palliative care education challenges included: lack of training for traditional healers, community volunteers, family caregivers and the public (Devi *et al.*, 2008; Campbell and Amin, 2014; Chandra *et al.*, 2016). There was a lack of awareness about palliative care among community and healthcare providers (Grant *et al.*, 2011; Boit *et al.*, 2014; Herce *et al.*, 2014; Jabbari *et al.*, 2019). Educational limitations then led to difficulty in physician and nursing access to mentoring and supervision in rural areas (Di Sorbo *et al.*, 2010).

## Implementation

Strategies for implementing palliative care were described in 26 papers (Defilippi and Cameron, 2007; Kumar, 2007; Lemonica and Barros, 2007; Devi *et al.*, 2008; Downing, 2008; Downing and Kawuma, 2008; Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Campbell, 2011; Grant *et al.*, 2011; Jack *et al.*, 2011; Dongre *et al.*, 2012; Logie and Harding, 2012; Boit *et al.*, 2014; Campbell and Amin, 2014; Hartwig *et al.*, 2014; Herce *et al.*, 2014; Hennemann-Krause *et al.*, 2015; Namisango *et al.*, 2016; Jayalakshmi and Suhita, 2017; Bond and Knopp, 2018; Freire De Castro Silva *et al.*, 2018; Munday *et al.*, 2018; Shabnam *et al.*, 2018; Jabbari *et al.*, 2019; Potts *et al.*, 2019).

In LMICs, NGOs provide resources for expanding new palliative care programmes, to assist the continuity of care, as well as for integrating palliative care into the national health plans (Defilippi and Cameron, 2007; Di Sorbo *et al.*, 2010; Nanney *et al.*, 2010; Herce *et al.*, 2014). Some papers described networking and the importance of teamwork in implementation. The Continuum of Care for People Living with HIV/AIDS in Tanzania (CHAT) model provided a network among home-based community volunteers (HBCVs), and the clinical palliative care team (Nanney *et al.*, 2010); CVWs served as a bridge to link patients with the hospice staff (Jack *et al.*, 2011). In rural Western Kenya, the hospice team closely networked with the community and the palliative care team who worked in a referral and teaching hospital (Boit *et al.*, 2014); and in Sarawak (Malaysia), a palliative care team provided a service networked between the hospital and trained staff in a rural clinic (Devi *et al.*, 2008). In South Africa and rural Malawi, the integrated community-based home care (ICHC) model had strengthened the links of health institutions at local, regional and national levels and hospice members were used for the main national palliative care resources (Defilippi and Cameron, 2007; Herce *et al.*, 2014). Ten papers discussed the importance of teamwork in facilitating changes in community attitudes about palliative care (Kumar, 2007; Lemonica and Barros, 2007; Downing, 2008; Downing and Kawuma, 2008; Nanney *et al.*, 2010; Grant *et al.*, 2011; Boit *et al.*, 2014; Hartwig *et al.*, 2014; Bond and Knopp, 2018; Munday *et al.*, 2018).

Five papers focused on the use of technology to deliver palliative care services. Hennemann-Krause *et al.* (2015) evaluated the use of telemedicine for patients and family members with computer knowledge and skills, to self-assess symptom scores compared to in-person with a clinician. The use of telemedicine played a significant role in reducing travel time and increased both patient and their family member's satisfaction. Cell phones were used by CVWs to



link the patient and nurse for advice and support (Grant *et al.*, 2011; Jack *et al.*, 2011); a freestanding mobile clinical system was also used (Jack *et al.*, 2011). For those with difficulty travelling to a clinic in Malaysia, the assessment was undertaken by telephone (Devi *et al.*, 2008). In Bangladesh, telephone consultations provided a bridge between the physician and the patient, to access information from the hospital on bed availability, receiving general advice, medicines and comfort (Shabnam *et al.*, 2018).

The role of traditional healers was identified by participants as assisting with implementation in rural home-based care services (Campbell and Amin, 2014). A description of a palliative care programme in South Africa discussed the benefit of traditional healers in not only relieving pain and providing psychological care, but also guiding the cultural context for palliative care, and sharing the work of nurses and CVWs (Campbell and Amin, 2014). Caregivers in home-based palliative settings in rural South Africa also enabled patients to access traditional medicines, such as herbs for wound care (Campbell, 2011). In Sarawak, massage is a traditional acceptable practice for pain reduction (Devi *et al.*, 2008).

Service delivery challenges included: patients presenting late with advanced disease (Grant *et al.*, 2011); community dependence on traditional healers (Campbell and Amin, 2014); lack of integration of palliative care with other care needs along the continuum of care (Grant *et al.*, 2011); poverty (Boit *et al.*, 2014; Hartwig *et al.*, 2014; Herce *et al.*, 2014; Bond and Knopp, 2018; Munday *et al.*, 2018); and of the safety issues of nurses visiting homes (Campbell, 2011). Additionally, lack of hospital beds (Lemonica and Barros, 2007); cultural and language differences (Munday *et al.*, 2018; Jabbari *et al.*, 2019); access to technology (Hennemann-Krause *et al.*, 2015; Shabnam *et al.*, 2018); and limited transport access to get services (Campbell, 2011; Grant *et al.*, 2011; Jack *et al.*, 2011; Logie and Harding, 2012; Jayalakshmi and Suhita, 2017) were all current challenges.

### Strategies used to resolve challenges in LMICs

The specific strategies used in the papers to resolve the challenges of delivering palliative care were extracted using the framework provided by the WHO public health strategy for palliative care: (Table 3). The challenges to the delivery of palliative care in rural LMICs are summarized in Figure 3.

## Discussion

The purpose of this review was to describe the strategies that LMICs have used to establish palliative care in rural settings. The available literature on the implementation of palliative care models was located and summarized. The WHO public health model was used to frame the review with the local models found in the papers. The key findings of this review were the essential nature of collaboration, the availability of Morphine; education; and using networking and home visits, to improve palliative care. This discussion describes the review findings and makes comparison with studies published about rural palliative care delivery in more developed countries where the public health model of palliative care has been utilized.

Most descriptions of palliative care acknowledged the importance of collaboration between the government and the NGO, working in local and international grants, developing income-generating activities, fundraising events and an advocacy plan at national, local and district levels. In developed countries like Norway, and Spain, and in Mongolia, the regional government offered full coverage,

with the public healthcare system taking responsibility for developing palliative care documents and implementing palliative care at all levels (primary, secondary and tertiary levels) (Davaasuren *et al.*, 2007; Herrera *et al.*, 2007; Kaasa *et al.*, 2007). However, in the Eastern Mediterranean, there is a scarcity of funding for palliative care (Fadhil *et al.*, 2017). The World Health Assembly 67 (2014) suggested that palliative care be included in the definition of universal health coverage. They emphasized the need for health services to provide integrated palliative care in an equitable manner across all levels of health care with the emphasis on primary, home-and community-based care.

The reviewed papers addressed the availability of Morphine in the use of an essential list of medicines. The premise of this list is that opioids should be easily accessible where the patients primary care is delivered; Morphine should be affordable, and oral Morphine solution should be formulated when possible (Callaway *et al.*, 2018). However, in the findings of this review, in Middle-Eastern countries and in Nepal, though the essential medicine list was used and injectable opioids were available, oral Morphine was less available, accessible and was often unaffordable for the people living a long way from major cities (Silbermann *et al.*, 2012; Paudel *et al.*, 2015). Indeed, in two papers, an oncologist or anaesthetist was required to prescribe the Morphine, expanding the length of time patients waited for a prescription. In contrast, in Mongolia, all doctors have the ability to prescribe opioids and generic, cost-effective medications, including Morphine, have been made available and accessible for all patients (Davaasuren *et al.*, 2007). This indicates that although a country adopts the essential medicines list, unless underpinning principles are enabled, access to essential medicines will still be constrained.

This review highlights that implementation of palliative care in rural areas must encompass education at community level, as well as education and training of health professionals and care workers. In Nepal, Spain and Mongolia, bedside training was given to healthcare professionals, and a palliative care training curriculum was developed by the palliative care association of the country (Davaasuren *et al.*, 2007; Herrera *et al.*, 2007; Paudel *et al.*, 2015). A systematic approach to education in rural areas was the feature of an education programme in Canada. This programme developed a curriculum on palliative care education for the rural staff, patients and families, including course evaluation instruments (Spice *et al.*, 2012). As part of this programme, in-service training was delivered to staff and an online-education module on palliative care topics for interdisciplinary staff working in rural areas. In three papers of the review, palliative care was integrated into undergraduate and postgraduate courses of different health disciplines. Similarly, in Mongolia, palliative care has been incorporated in undergraduate curricula of nurses, doctors and social workers (Davaasuren *et al.*, 2007). In contrast, in Norway, palliative care is not integrated in health professional curriculum and in the Middle-East there is an acknowledged lack of palliative care training for health professionals (Kaasa *et al.*, 2007; Silbermann *et al.*, 2012).

A number of papers in this integrative review emphasized the importance of service networks between hospitals and rural clinics to deliver continuity of palliative care using community volunteers in rural areas. For instance, the use of technology expanded opportunities for education and utilization of volunteers; linkages between rural and urban settings were of benefit; and confidence in using a mobile phone specialist consultation team assisted skill levels. All enhanced the implementation of palliative care in rural areas. Similarly, in Norway and rural Spain, the palliative care programme networked across all the structures and levels of healthcare systems

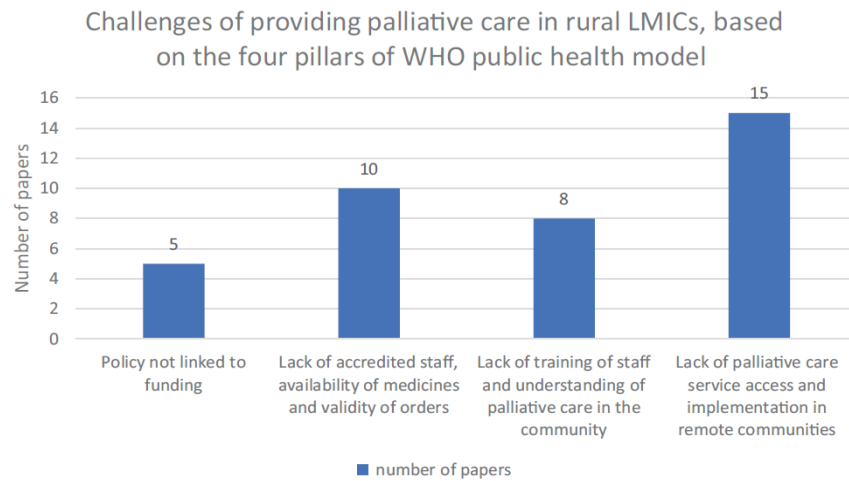
**Table 3** Strategies to address the challenges of palliative care provision in rural areas of LMICs

Challenges	Strategies to address challenges in providing palliative care in rural LMICs
Policy Policy not linked to practice or funding	<ul style="list-style-type: none"> <li>• Availability of national palliative care policy for palliative care (Bond and Knopp, 2018);</li> <li>• Collaboration between policymakers and NGOs (Devi <i>et al.</i>, 2008; Di Sorbo <i>et al.</i>, 2010; Nanney <i>et al.</i>, 2010; Logie and Harding, 2012; Boit <i>et al.</i>, 2014; Herce <i>et al.</i>, 2014). Advocacy plans at national, local and district levels (Downing, 2008; Boit <i>et al.</i>, 2014); and</li> <li>• Local and international grants, developing income-generating programmes, and fundraising events (Logie and Harding, 2012; Boit <i>et al.</i>, 2014; Bond and Knopp, 2018).</li> </ul>
Medication availability Lack of accredited staff, availability of medicines and validity of orders	<ul style="list-style-type: none"> <li>• The hospice applied to receive reimbursement through the national insurance programme (Boit <i>et al.</i>, 2014).</li> <li>• Staff education and training in Morphine administration (Nanney <i>et al.</i>, 2010; Boit <i>et al.</i>, 2014).</li> <li>• Expand the length of time of prescription validity (Devi <i>et al.</i>, 2008).</li> <li>• Preparation of an oral Morphine solution from powder in the hospitals (Grant <i>et al.</i>, 2011).</li> <li>• Permission for qualified health professionals to administer medication in the absence of doctors (Grant <i>et al.</i>, 2011).</li> <li>• Mobile phones empowered to get rapid access to clinical and social support (Devi <i>et al.</i>, 2008; Grant <i>et al.</i>, 2011).</li> <li>• Morphine available free of charge (Herce <i>et al.</i>, 2014; Bond and Knopp, 2018); the nurse provides advocacy for oral Morphine (Hartwig <i>et al.</i>, 2014).</li> <li>• Morphine included in the essential medicine list, and its accessibility was not restricted by law (Boit <i>et al.</i>, 2014).</li> </ul>
Education and training Lack of training of staff and understanding of palliative care in the community	<ul style="list-style-type: none"> <li>• Increased awareness of palliative care through community activities like visiting houses in a village, brochures and printed pamphlet campaigns for the community (Chandra <i>et al.</i>, 2016).</li> <li>• Using posters that describe home-based palliative care (Devi <i>et al.</i>, 2008).</li> <li>• Specific training to target particular audiences (healthcare professionals, community health workers, volunteers, spiritual leaders and families (Defilippi and Cameron, 2007; Devi <i>et al.</i>, 2008; Downing, 2008; Di Sorbo <i>et al.</i>, 2010; Nanney <i>et al.</i>, 2010; Herce <i>et al.</i>, 2014; Bond and Knopp, 2018; Munday <i>et al.</i>, 2018; Potts <i>et al.</i>, 2019).</li> <li>• Supervision and mentorship to palliative care providers (Defilippi and Cameron, 2007; Di Sorbo <i>et al.</i>, 2010; Herce <i>et al.</i>, 2014).</li> <li>• Palliative care incorporated in undergraduate and postgraduate of medical, nursing, dental, anaesthesia and pharmacy curricula (Lemonica and Barros, 2007; Boit <i>et al.</i>, 2014; Bond and Knopp, 2018).</li> <li>• The CHWs were very engaged in the training sessions, participated in the role play and shared stories (Campbell and Baernholdt, 2016).</li> </ul>
Implementation Service access in remote communities	<ul style="list-style-type: none"> <li>• Palliative care integrated across the continuum of care, as in successful models of care for those with HIV (Grant <i>et al.</i>, 2011; Logie and Harding, 2012), networked activity with the community and palliative care team (Kumar, 2007; Devi <i>et al.</i>, 2008; Boit <i>et al.</i>, 2014).</li> <li>• Mobile palliative care clinics in out-reach activities (Logie and Harding, 2012).</li> <li>• Technology such as mobile phones to enable rapid access; facilitate communication; integration of electronic medical record to support access to the existing system and collect data for research (Grant <i>et al.</i>, 2011; Freire De Castro Silva <i>et al.</i>, 2018); TCS (Shabnam <i>et al.</i>, 2018).</li> <li>• Community volunteers motivated and supported; and</li> <li>• An overall public health approach to provide an equitable provision of palliative care (Grant <i>et al.</i>, 2011).</li> <li>• The palliative care team members participated in-home visit (Kumar, 2007; Lemonica and Barros, 2007; Dongre <i>et al.</i>, 2012; Herce <i>et al.</i>, 2014; Jayalakshmi and Suhita, 2017; Bond and Knopp, 2018; Munday <i>et al.</i>, 2018), compassionate care (Boit <i>et al.</i>, 2014; Hartwig <i>et al.</i>, 2014), with no cost (Kumar, 2007; Jayalakshmi and Suhita, 2017; Bond and Knopp, 2018) funeral and grieving with the community, listening to their needs, respecting their values, spend time in the community (Boit <i>et al.</i>, 2014; Hartwig <i>et al.</i>, 2014).</li> <li>• Community- and home-based palliative care programme is the most cost-effective in low resource settings (Kumar, 2007; Lemonica and Barros, 2007; Downing and Kawuma, 2008; Dongre <i>et al.</i>, 2012; Herce <i>et al.</i>, 2014; Jayalakshmi and Suhita, 2017; Bond and Knopp, 2018; Potts <i>et al.</i>, 2019).</li> <li>• HBPC helped nurses to work independently, allow the patient to use traditional medicines patient to die peacefully without the decision of others (Campbell, 2011; Campbell and Amin, 2014).</li> <li>• Establishing palliative medicine, clinics, educating families and healthcare providers, key persons should be involved, and the patients want to die at home, due to this, palliative care should be widely accessible and integrated to both inpatient and outpatient services (Herce <i>et al.</i>, 2014; Jabbari <i>et al.</i>, 2019).</li> </ul>

(Herrera *et al.*, 2007; Kaasa *et al.*, 2007). However, the success of networking is dependent on the flow of information between primary and specialist care services and the capacity of staff and users of the services to access information. (Evans *et al.*, 2003).

Home- and community-based palliative care was delivered through frequent home visits and included educating family and caregivers. Services were supported with community volunteers and

healthcare providers and the staff participated in funerals in rural areas (Downing *et al.*, 2010; Ddungu, 2011). In Spain, home visiting is a feature of community-based palliative care (Herrera *et al.*, 2007; Kaasa *et al.*, 2007). In addition, a review of studies conducted in LMICs indicated that community-based volunteer programmes were a crucial component of palliative care in the rural or remote areas; however, the strategies of the programmes were not clearly described (Hannon *et al.*, 2016).



**Figure 3** Challenges of providing palliative care in rural LMICs, based on the four pillars of WHO public health model.

We expected to see more evidence in the reviewed strategies for the provision of palliative care about the priority of palliative care at a policy level, the development of guidelines and incorporation of palliative care into national documents. However, this was rarely discussed as part of palliative care service development in rural areas of LMICs. The lack of attention to the policy component of the WHO Public Health Model, may contribute to issues of sustainability. There was also a paucity of evaluative outcomes described in the reviewed papers (Hannon *et al.*, 2016). The previous and the updated version of WHO Public Health Model does not feature standards for evaluation or research as part of the model and a revision of this aspect in the model may strengthen the capacity of services to demonstrate the outcomes of their programmes for future funding and support (Stjernswärd *et al.*, 2007; Callaway *et al.*, 2018).

Though the findings have successfully summarized the strategies and challenges of palliative care in rural LMICs, there are limitations to the study and therefore to the weight of its findings. The review is limited to those published journal papers and reviews identified in the search. The use of other search terms (such as resource-poor countries and using grey literature) may have produced more papers. Most publications were simple descriptions of palliative care models. The findings are limited because at least 12 of the 30 papers had poor to no transparent methodology. Most of the studies contain bespoke strategies designed to fit the particular contexts for which they were developed. With a lack of repetition of evaluations and the poor quality of some studies, there is insufficient evidence supporting any particular strategy. Furthermore, the review undertaken to make comparisons for the discussion also found limited published papers that focused on rural settings and the public health model. The lack of strong evidence for strategies in rural areas of LMICs makes a strong case for further research to evaluate the strength of interventions in low resource setting.

## Conclusion

This paper has described the strategies and challenges used to establish palliative care in rural areas of LMICs. The four pillars of the WHO public health model were used to frame the findings. The

findings indicated that most of the palliative care models are dependent on NGOs for funding and palliative care was not integrated into existing healthcare systems. Medications such as Morphine are limited in most rural areas. There was little discussion for the integration of palliative care in undergraduate and postgraduate courses, despite this being a feature in more developed programmes in middle- to high-income countries. The home- and community-based models are dominant in rural areas. Consistently, recommendations were for the delivery of palliative care using teams including local community members like traditional healers, volunteer workers, family caregivers and religious, and community leaders. Networked service, technology such as computer software and mobile phones have also been used to bridge communication between patients and palliative care team in rural areas. A commonality across strategies for the development and implementation of palliative care in LMICs was a collaborative approach between government, health services, professionals and community. This may be an important feature of successful service development that should be investigated. Repeated evaluation of replicated models is essential for understanding the success of specific rural palliative care strategies. Further research on the public health model is required to strengthen the understanding of a successful model of palliative care in rural areas of LMICs.

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## Chapter Summary

The major strategies and challenges used to establish palliative care in rural areas of LMICs has been articulated in an integrative review. The four pillars of the WHO public health model were used to frame the results and to discuss the key findings. The findings indicated that rural models of palliative care are dependent on donors for financial support. A number of rural palliative care models had been highlighted. The home and community-based practice are the dominant strategies of palliative care in rural areas. Medications, particularly Morphine, were not accessible in most rural areas. There were few papers describing the integration of palliative care in undergraduate and postgraduate courses. Despite service initiatives in a number of settings, this review found that palliative care was not integrated to existing health care systems. Finally, networked services, technology such as computer software and mobile phones have also been used to bridge communication between patients and palliative care teams in rural areas.

## Chapter Three: Research Methodology and Methods

### Introduction

In the previous chapter, relevant literature showed the strategies used to develop palliative care in rural developing countries. The findings of the review highlighted the strategies used to develop palliative care according to the four components (policy, drug availability, education, and implementation) of the WHO Public Health Strategy. The prominent strategies identified in the integrative review are pursued in this study, such as collaboration; networked service using mobile phones; home-and community-based palliative care service challenges, including sustainable services; dependence on donors; morphine availability; and palliative care training.

The review and research studies also emphasised the everyday challenges of palliative care service implementation in rural areas, such as a low priority given to palliative care in government policy; absence of palliative care education; inadequate availability of palliative medicines; and lack of palliative care integration into the existing health care system (Grant, Brown, Leng, Bettega, & Murray, 2011). In general, the palliative care service budget is not sustainable without funding from donors (Logie & Harding, 2012; Poyhia, Mwalumuli, Mtega, & Vegula, 2020). Understanding how, where, and why these challenges occur are the main factors that need to be considered in planning a sustainable palliative care service for all individuals in need.

Case study methodology is used to answer questions asked about ‘how’ or ‘why’ a contemporary phenomenon occurs, in situations where the researchers have little or no control over the phenomenon (Yin, 2018). The research questions focus on the current status of palliative care; and how could a sustainable public health approach can be implemented in the provision of palliative care in the region.

The case study is the chosen methodology to answer these questions for this study, as an effective methodology to investigate and understand the complex issues in real-world settings (Walshe, Caress, Chew-Graham, & Todd, 2004). A case study can involve single or multiple cases which encompass a wide variety of methods, including interviewing, observation, document review, surveys or any other single or mixed method of qualitative and quantitative research (Stewart, 2014). Specifically, this study used a multiple embedded mixed method case study design.

In this chapter, the philosophical assumptions and historical origins of the case study research are described, followed by the definition and description of case study research. A detailed description of the research methodology and methods is provided.

## Philosophical assumptions

A worldview is the basic set of beliefs that guides action, also known as paradigms (Creswell, 2018). The philosophical assumptions in research make use of paradigms and theories (Creswell & Poth, 2018). The assumptions underpinning research can be ontological, epistemological, axiological, and methodological (Creswell & Poth, 2018). Ontology focuses on the nature of reality that helps to address multiple realities; epistemology focuses on how to know the reality; axiology deals with the role of values in research; and the methodology is the process used in the research (Creswell & Poth, 2018). While many worldviews or beliefs are available in the literature, this study focusses on the following three: post-positivism, social constructivism, and pragmatism.

## Post-positivism

Positivism has been widely criticised since the inception of social science, post-positivist epistemologies (theories of knowledge) and ontologies (theories of the nature of reality), have developed in response to this criticism, particularly in relation to qualitative research (Fox, 2008). According to Fox (2008), post-positive research need not exclude qualitative (non-numerical) data. Under post-positivistic inquiry, ‘truth’ is not universally generalisable to all cases and all situations; rather, findings are viewed as contextually related (Clark, 1998). There are two contrary perspectives within post-positivism, which can be broadly described as realist and constructivist (Fox, 2008). Realism considers “there is an objective social reality that could be discerned, were social researchers to possess sufficiently sophisticated tools” (Fox, 2008, p. 8). Realists recognise that “when it comes to studying the social world, our tools (human understanding and interpretation) are inevitably value-laden, theory-laden, and context-dependent” (Fox, 2008, p. 8). “All that can be hoped for is that by continual efforts towards methodological rigour, triangulation from various data sources and meticulous analysis of data that an approximation to truth can be derived, and generalised” (Fox, 2008, p. 8).

Yin (2018) conceptualises case study research as one of several forms of social science research. Yin describes his approach to “case study as using a realist perspective, which assumes the existence of a single reality that is independent of any observer” (Yin, 2018, p.

16). However, “case study research can also excel in accommodating a relativist perspective - acknowledging multiple realities having multiple meanings, with findings observer-dependent” (Yin, 2018, p. 16). According to Yin (2018), what makes case study research distinct from experimental studies is that the case study “wants to understand a real-world case and assumes that such an understanding is likely to involve important contextual conditions pertinent to the case” (p. 15). This is consistent with the position that a post-positivist researcher views findings as contextually related (Clark, 1998; Fox, 2008).

### Social constructivism

Constructivism or social constructivism (often combined with interpretivism) is typically associated with a qualitative approach (Creswell, 2018). The social constructivist researcher often addresses the process of individuals’ interactions and focuses on the specific context in which they live and work (Creswell, 2018). In constructivism, the inquirer generates or inductively develops a theory rather than starting with a theory (as in post-positivism). In constructivism, the questions are broad and general, so participants can construct the meaning of situations. The researcher intends to make sense or interpret the meaning of others using more open-ended questions and listening carefully to what people say and do in their life settings (Creswell, 2013). Stake (1995, 2006) has an interpretive approach to qualitative case study research arguing that the situation is expected to shape the activity. According to Stake (1995, 2006), a qualitative understanding of cases requires “experiencing the activity of the case as it occurs in the contexts and its particular situation” (p. 2).

### Pragmatism

Pragmatism focuses on the outcomes of the action, situations, and consequences of research inquiry, rather than antecedent conditions (as in post-positivism). Pragmatist researchers are concerned with the application: ‘what works and solutions to problems’ (Creswell, 2018, p. 10). Pragmatists emphasise research problems and questions and all approaches to understanding the problem rather than focusing on methods (Creswell, 2018). The researcher in this worldview uses multiple methods of data collection to best answer the research question. It is typically associated with mixed research methods. Merriam’s (2009) perspective belongs to the pragmatic approach; both qualitative and quantitative approaches can be used to construct theory and acknowledge case study research.

Brown, (2008) suggests that the three approaches used by these pivotal researchers rest along a quantitative-qualitative continuum where the postpositivist methodology of Yin, (2018) sits

at the right end, Stake's (1995, 2006) interpretive design sits at the left end and Merriam's (1998, 2009) who as a pragmatic constructivist draws on both elements, and is located toward the middle.

Many methodologies are aligned with specific philosophical assumptions that guide the research process. For a long time, however, a case study has been viewed with scepticism as a research methodology because it is not ascribed to a fixed position (Harrison & Mills, 2016). Stewart (2014) suggests that since case study methodology is a broad definition for a research focus, it can be used with multiple methods and accompanying philosophical positions. The most crucial consideration in case study methodology is to ensure the researcher's selected methods correspond to their particular ontological and epistemological beliefs (Stewart, 2014).

The current study draws on the pragmatist worldview because it provides freedom of choice of multiple methods and different forms of data collection and analysis. Accordingly, this study relies on what works to solve the research problem, using a mixed method design (mixing case studies with other methods). For this reason, the researcher looks to multiple methods of collecting and analysing data (survey, interviews, and focus group discussions) rather than fixing on one single method. Finally, the researcher justifies why mixing surveys with a case study method later in the chapter.

## History of case study research

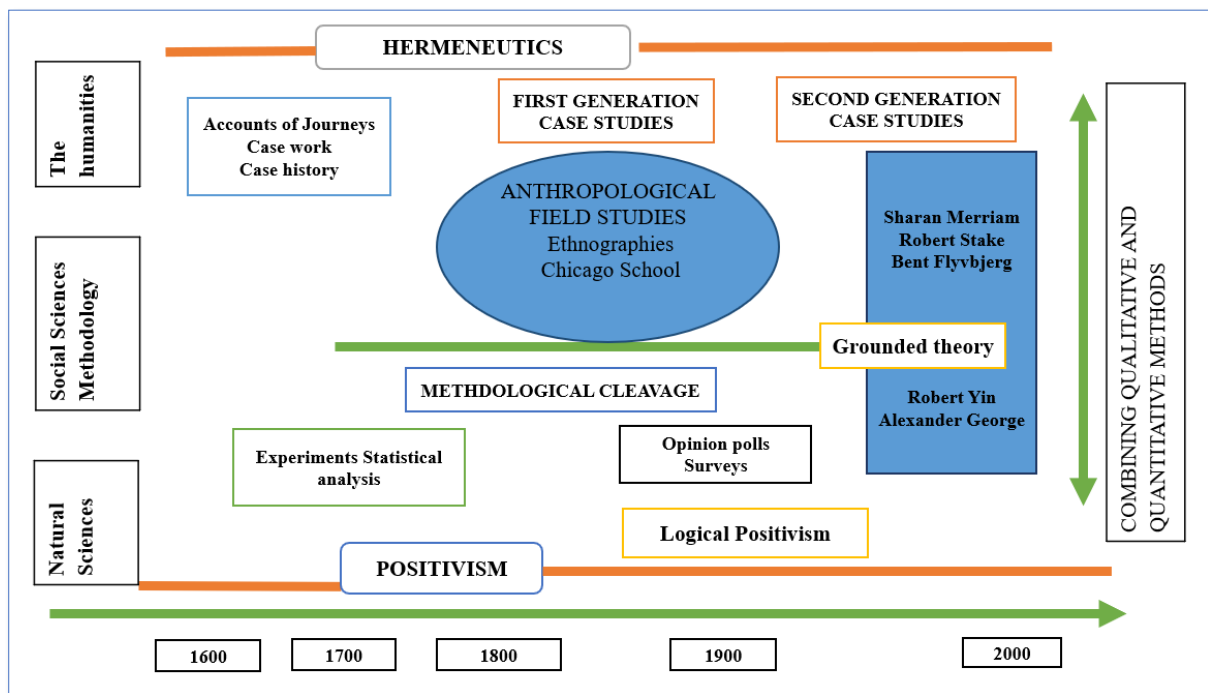
The history of case study research explores the origins of case study approaches and allows for both quantitative and qualitative approaches. Case study method has a long, renowned history as a tool of methodological investigation in many fields of academic study (Creswell, 2018; Flyvbjerg, 2011). The first-generation case studies appeared around 1900, initially conducted in the Chicago School of Sociology, where the idea of case study originated in lengthy observation (Harrison, Birks, Franklin, & Mills, 2017; Johansson, 2003; Stewart, 2014). A description of individuals has provided another source of case study research within medicine, psychology, and social work, often termed as 'casework' or 'case history' in the early twentieth century (Johansson, 2003; Stewart, 2014; Yin, 2018). The biography of Charles Darwin is considered an example of a case study from the early nineteenth century, and is evidence that case study as a research design may date back to even earlier times (Harrison et al., 2017; Stewart, 2014). Although case study research originated as a qualitative approach in anthropology and social sciences (Harrison et al., 2017), over time,

the social sciences preferred to use quantitative approaches such as surveys, experiments and statistical methods (Harrison et al., 2017; Johansson, 2003).

The second generation of case study methodology began in the late 1960s, with grounded theory as the first type (Johansson, 2003), which “merged qualitative approaches from the Chicago School of Sociology with quantitative approaches of data analysis” (Johansson, 2003, p. 7); this resulted in an inductive methodology that used detailed procedures to analyse the data. Robert Yin initiated the next step, drawing on scientific approaches to research, transferring experimental logic into naturalistic inquiry and combining this with qualitative approaches (Johansson, 2003). Yin (2018) also suggested that case study be used in several academic disciplines such as psychology, sociology, economics, political science, anthropology, social work, business, nursing and community planning. Case study research was also developed in an educational program by Merriam (1998, 2009) and Stake (1995, 2006) to evaluate curriculum design and provide relevant evidence for policy and practice decisions.

Harrison et al. (2017) summarised the history and the evolution of case study across a timeline from 1600 to 2000 (Figure 6). As highlighted in Figure 6, case studies were initially conducted in social sciences, but the domains of “logical positivism from the 1940s through to the 1960s and 1970s, meant that case study methodology was viewed with scepticism and criticism” (Harrison et al., 2017, p. 5). Grounded theory development in the 1960s led to a regeneration in case study research, in the social sciences, education, and humanities. Over the last 50 years, case study has been re-established as a reliable, valid research design for exploration of complex issues (Harrison et al., 2017).

Figure 6: Case study methodology history and evaluation adapted from (Harrison et al., 2017, p. 5)



### Definition and description of case study research

There are various definitions and understanding of case study research in the literature, but the most common are found in Yin (2018), Stake (1995), and Merriam (2009). Yin (2018) defines case study in terms of the research process; while Stake (1995) focuses on the unit of study as the case. In contrast, Merriam (2009) focuses on case study in terms of the end product of the research.

Yin's two-folded definition (2018) focuses on the scope and features of case study research. The first deals with the scope of a case study as "an empirical inquiry that investigates a contemporary ('case') phenomenon in-depth within its real-life context especially, when the boundaries between phenomenon and context are not evident" (Yin, 2018, p. 15). Context in relation to case study methodology means involving important contextual conditions relevant to the cases in order to understand the real-world setting. The second definition reveals a feature of a case study when phenomenon and context are difficult to differentiate in real-world situations. "A case study inquiry copes with the technically distinctive situations in which there may be many more variables of interest than single data points, and as one result" (Yin, 2018, p. 15). For Yin, "case study relies on multiple sources of evidence, with data needing to converge in a triangulated fashion, benefitting from the prior development of



theoretical propositions to guide data collection and analysis” (p. 15). Yin (2018) also discussed that a case study could have three research purposes-exploratory, descriptive and explanatory. “A descriptive care study is a case study whose purpose is to describe a phenomenon ‘case’ in its world context”. Explanatory case study is “a case study whose purpose is to explain how or why some conditions come to be”. Exploratory case study is “a case study whose purpose is to identify the research questions or procedures to be used in a subsequent research study” (Yin, 2018, p. 287).

The above definitions suggest that the researcher’s understandings of case studies are not limited to data collection; instead, it is an all-encompassing method which covers the logic of the design, data collection techniques and specific approaches to data analysis. Stake (1995, 2006) also suggests three purposes of case study - intrinsic, instrumental and collective or multiple case study. Intrinsic case study focuses on a particular case; instrumental case study endeavours to understand something other than the particular case; and a collective case study provides coordination between particular case studies (Stake, 1995).

In contrast, Stake (1995) defines case study as “the study of particularity and complexity of a single case, coming to comprehend its activity within important circumstance” (p. xi).

Merriam (2009) defined a case study as “an in-depth description and analysis of a bounded system ... conducting a case study is conflated with both the unit of study (the case) and the product of this type of investigation” (Merriam, 2009, p. 40).

Similar to Stake, Merriam (1998, 2009) argued that case study is characterised as being particularistic, descriptive and heuristic. “Particularistic means that case studies focus on a particular situation, event, program or phenomenon; descriptive means that the end product of a case study is a rich, ‘thick’ description of the phenomenon under study” (Merriam, 2009, p. 43). Heuristic refers to the characteristic that the study reveals information relevant to the study and stimulate the reader to think beyond the particular piece of information.

#### [A case study in palliative care research](#)

The health care system has changed over time with the increased use of advanced technology and treatments (Harrison & Mills, 2016); this has led to an increase in the complexity of health care practice and an increase in the use of case study design in nursing research (Anthony & Jack, 2009). Case study research design is an appropriate and flexible approach in social sciences as well as nursing-related fields (Stewart, 2014; Yin, 2018). Luck et al.

(2006) describe case study research as “a bridge between the paradigms” (p. 107) in health care research, particularly nursing.

Palliative care is one of the more complex, patient-focused, context-dependent and multi-professional services in the health care system (Walshe et al., 2004). Walshe et al. (2004) argue that case study research is an appropriate strategy for palliative care research, when there is a complex issue; context is central to the study, and multiple perspectives need to be recognised. Walshe et al. (2004) argue that case study research may be appropriate when there is no influential theory; when flexible design is needed; when research needs to be congruent with clinical practice; and there are challenges to the conduct of the study with other methodologies.

The case study method provides a similar pragmatic solution to a real-world research problems in palliative care services (Payne, Field, Rolls, Hawker, & Kerr, 2007). Payne et al. (2007), also indicated that the reason case study design is used in palliative care research is because of the flexibility and multiple methods of data collection.

### Strength and limitations of case studies

All research designs have strengths and limitations. The strength of case studies includes that: it uses multiple data collection methods to explore the case (Brown, 2008); there is flexibility in paradigms (Luck et al., 2006); it is useful to investigate the ‘how’ or ‘why’ types of research questions; it complements other quantitative and statistical methods (Yin, 2018); and case study design addresses complex issues (Walshe et al., 2004).

Besides the noted strengths, there are limitations in using case study research methods. These include the objection that case study is costly and time-consuming (Luck et al., 2006; Yin, 2018); there could be a lack of rigour; confusion in teaching cases; and lack of generalisability (Yin, 2018). However, there are reasonable arguments for the above limitations. For instance, Yin (2018) argues that a case study does not need to be lengthy, because it does not depend solely on ethnographic or participant observation data. Yin (2018) also argues that case studies are generalisable to theoretical propositions rather than to a population. In case studies, like an experiment, the case does not represent a ‘sample’; the researcher goal is to expand and generalise theories (analytical generalisations), not a statistical generalisation.

## Research methodology

The methodology is the lens through which the researcher views and makes decisions about the type of method used to answer the research question, and how these methods are implemented in their study (Mills & Birks, 2014). Mills (2014) differentiates methods as procedures and techniques employed in the study. This type of separate terminology has led to a lack of consensus between methodology and methods and other terms in the application of case study research. Case study is termed as a method by Yin (2018) and a methodology (Stewart, 2014); it is also called a qualitative design (Creswell, 2018), the unit of investigation (Stake, 1995, 2006), a qualitative case study (Merriam, 2009), and an approach or strategy (Walshe et al., 2004). Using case study as a methodology for this study, helps to decide the type of methods and how to apply these methods in practice.

## Research design

A research design is a logical arrangement to connect the initial research question with data collection and the conclusion (Yin, 2018). Yin suggests that researchers consider two different steps: defining the case and bounding the case. In defining the case, it be single case or multiple cases. Case studies could be undertaken with small groups, organisations, partnerships, relationships, communities, decisions, and projects or even a social unit with one person as a case (Merriam, 2009; Yin, 2018). Yin (2018) suggests that the researcher needs to clarify the case and its specific location. In this study, ‘regional palliative care’ is considered the ‘case’ and ‘Tigray’ is the location of the study.

Also, the case is a system that must be bounded by time, place, event, or activity (Creswell, 2018; Merriam, 2009; Yin, 2018). Boundaries can differ according to the case and could be geographical, organisational or the facility where the phenomenon occurs; or a set of criteria for an individual or group (Yin, 2018). In this study, the ‘case’ or ‘regional palliative care’ is bounded by the two-health care ‘Zones’, palliative care in primary and secondary levels of a health care system, particularly adult medical, surgical units in the hospital, or medical Outpatient Department, and Tuberculosis and HIV treatment in Health Centres.

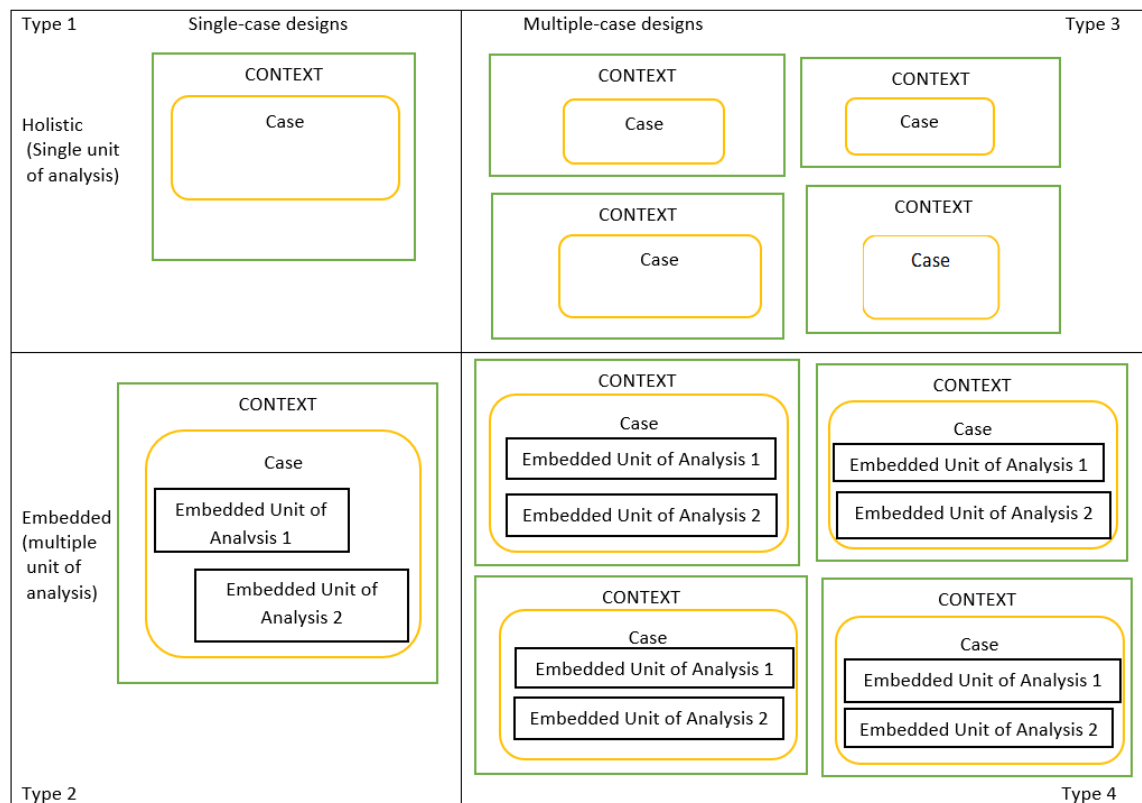
Theory or theoretical propositions have a significant role in guiding the research design, data collection and the groundwork for analytic generalisation of the study (Yin, 2018). As already described in Chapter 1, this study used the WHO Public Health Strategy, which describes palliative care as a public health issue (Callaway et al., 2018). As noted, this strategy has four major components: policies; adequate drug availability for essential

palliative care medicines, specifically opioids; education of health care providers, policymakers and the public; and an implementation plan that reflects the culture and context of the country. Blinderman (2009), recommended the WHO Public Health Strategy as a structure to guide the development of palliative care in resource-poor countries and, as such, it has informed the analysis of the literature in the previous chapter and structures the data collection and analysis.

#### *Multiple case study design (Type 3 and 4)*

There are four types of case study design: base on a 2x2 matrix: Type 1 single case (holistic) /Type 2 single case (embedded), Type 3 multiple case (holistic), and Type 4 multiple case (embedded) (Yin, 2018) (see figure 7). Yin recommends multiple case study because this involves the selection of more than one case that uses replication logic, when one or more cases can be compared (Yin, 2018). The current study used a multiple embedded case study design; embedded referring to examining the subunits of a multiple cases or organisations (Yin, 2018). The design of multiple case studies either predict similar results (a literal replication) or contrast results (a theoretical replication) (Yin, 2018). A few cases (2 or 3) might aim for literal replication of cases, while a few other cases (4-6) might predict two different patterns of theoretical replication. In this study, the two cases were chosen in order to compare the study phenomenon across the region, aiming for literal replication.

Figure 7. Types of case study design adapted from (Yin, 2018)



### *Mixed method designs: mixed case studies with other methods*

Mixed methods research allows researchers to address more complicated situations and to collect more abundant and stronger evidence than using a single method (Yin, 2018). Yin (2018) claimed that, when the case includes sub-units which are embedded, the design can be called an embedded case study design. Embedded case studies may focus on holistic data collection strategies for studying the main case and then call upon the survey or another quantitative method to collect data about the embedded sub-units of analysis.

In this study, a survey embedded within multiple case study research, that is a multiple embedded mixed method case study design, was used (Yin, 2018). Multiple case study involves the selection of more than one case that has a replication logic. Yin (2018) suggests that multiple case study design is preferable to a single one; even a two-case case study is more powerful than a single case because two cases have the possibility of direct replication and analytic conclusions. According to (Creswell, 2018), a mixed method case study design

includes the use of one or more core designs (i.e., convergent, explanatory, sequential, exploratory sequential) within single or multiple case study designs.

In using a mixed method case study, this study becomes more substantial than other methods (Yin, 2018). In the current mixed method case studies, the broader scope is focused on elucidating the status of palliative care and strategies for sustainable public health approach. Then another method, a survey, can be used to measure the level of palliative care knowledge, attitudes, and self-reported palliative care practice of nurses. In this research, the case study questions were closely coordinated with the survey method. This type of mixed method indicates complementarity as opposed to convergence (Creswell & Poth, 2018).

## Research methods

### Study settings

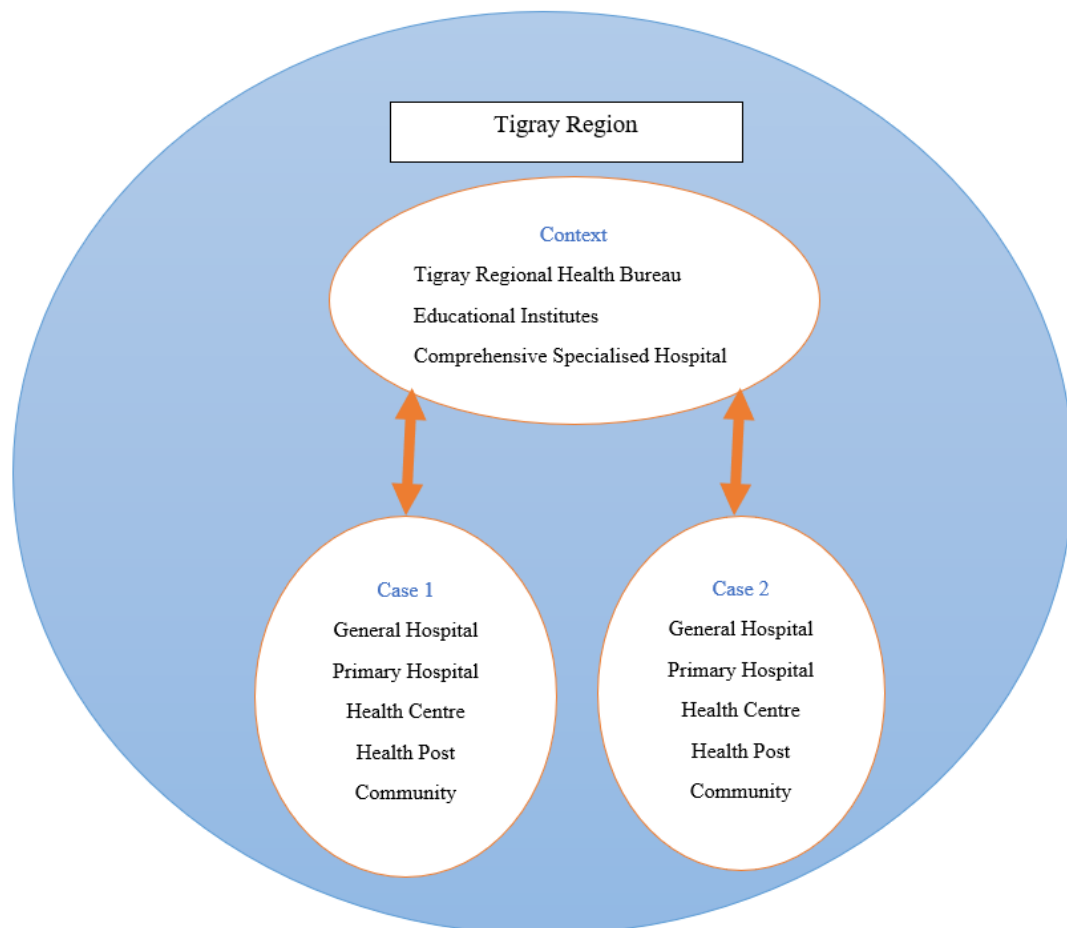
The study was conducted in one of the nine administrative regions in Ethiopia (Tigray Regional Health Bureau, 2015). As briefly described in Chapter 1, the Tigray region is located in the northern part of Ethiopia (Zeru, Berihu, et al., 2020). The total area of the region 54,569.25 square kilometres and its elevation ranges 600-2700 meters above sea level (Tigray Regional Health Bureau, 2015). Tigray has two Comprehensive Specialised Hospitals; 15 General Hospitals, 1 military General Hospital, 204 Health Centres, 20 Primary Hospitals, and 712 satellite Health Posts (Zeru, Berihu, et al., 2020). The region also has three public universities and two health science colleges owned by the regional government (Zeru, Berihu, et al., 2020). Currently, there are 189 specialist and general practitioners, 3824 diploma and BSc nurses, 485 health officers (clinical officers), 609 pharmacy technicians plus pharmacist, and 1988 Health Extension Workers in the region (MOH, 2017).

### Study participants

In addition to the focus on the case, a case study may include data from the contextual conditions surrounding the case (Yin, 2018). In this study, the context was set within the region and refers to the major policy, educational institutions, and Comprehensive Specialised Hospital. Within the context, staff were invited to participate from the Regional Health Bureau, Non-Governmental Organisation (NGO); educational institutions (representatives of Nursing, Medicine, and Pharmacy); and the Comprehensive Specialised Hospital (nurses, pharmacy, and medicine in leadership roles). The two cases represented two General Hospitals with the embedded subunits (nurses, pharmacists, medical directors); and two primary health care sectors in the region-with the embedded sub-units being healthcare

professionals (Health Extension Workers (HEWs), nurses, pharmacists, medical directors) working at Primary Hospitals, Health Centres, Health Posts); and community members living in two rural areas of the region. (Figure 8).

Figure 8: The study participants in the two Cases and the Context



### Case screening and recruitment of participants

The process of case screening needs special consideration to identify the appropriate cases for the research study (Yin, 2018). Potential participants were invited from the two cases and the context of the region. The selection procedure for the participants was:

1. The researcher identified the contact staff of each health sectors
2. The 'explanatory statement' was provided as an introduction to the researcher, prepared in English and Tigrigna

3. A contact person provided an opportunity for the researcher to meet and introduce her study to potential participants
4. The researcher gave a contact address (e-mail and phone number) for the participants for further questions. Those who agreed to participate in the interview and focus group were required to give written consent.

The data collection conducted at Group one (the nurses' survey), Group two (the leaders' interview) and Group three (community members focus group discussion). Following the selection criteria, the units of analysis or cases for data collection was arranged.

#### *Inclusion criteria for the participants:*

- ✓ Nurses who have worked in the adult medical, surgical units, oncology unit and Anti-Retroviral Treatment Clinic of hospitals for at least six months
- ✓ Medical directors, senior pharmacists, and chief nursing officers
- ✓ Nurses working in the adult Outpatient Department, Tuberculosis and HIV units of the Health Centre
- ✓ HEWs who have worked in a Health Post for at least for six months
- ✓ Community members who lived in the selected area for at least six months.

#### *Data collection tools and procedures*

A case study uses multiple sources of data and methods such as interviews, focus groups, observations, physical artefacts, a survey, archival records, and a document review (Payne et al., 2007; Stake, 1995; Stewart, 2014; Yin, 2018). This study collected data sequentially from interviews, focus groups, and surveys. However, the data collection techniques and tools remained consistent across all sites during data collection. The context data was collected first then the two cases sequentially. The surveys were translated to Tigrigna and back translated for accuracy. The interview data and the focus group discussion were translated to English for analysis.

#### *Interviews*

The interview is the most common and crucial source of evidence in the case study (Merriam, 2009; Stake, 1995; Yin, 2018). This study used face-to-face interviews with 42 participants. The interviews were conducted with two representatives of the Regional Health Bureau, seven pharmacy representatives, five doctors, four health officers (clinical officers), 17 nurses in leadership roles including Chief Nursing Officers, at all levels of health care institutions. It



also included three school representatives in leadership roles of nursing, medicine, pharmacy, one academic leader from regional health college and three HEWs in the rural Health Posts. Of the 42 participants, two nurses' interviews were not included in the analysis, because in the Comprehensive Specialised Hospital there were medical wards A and B and surgical wards A and B. So, as the interviewees were duplicate informants, we randomly excluded one each from these wards. In addition, one HEWs and one nurse from Primary Hospital were also excluded because they were similar informants. In total, 38 interview transcripts were analysed.

Participants who were leaders in their organisations were approached in person by the student researcher. The explanatory statement and consent form were distributed prior to the interview (Explanatory Statement, Appendix 1A). A framework was used to guide the interview questions (Appendix 1B). The topics of interview questions were framed based on the four components of public health strategy, being policy, education, medication availability and implementation (Callaway et al., 2018). The interviews consisted of open-ended questions about the status of palliative care service; the strategies for a sustainable public health approach to the provision of palliative care; and the challenges related to palliative care in all levels of health care settings. The interviews were conducted during business hours at participants' preferred locations (likely to be their office), taking 30-50 min — each interview was audio-recorded in the interviewees preferred language 'Tigrigna' or English. The interview guide was translated from English to the local language 'Tigrigna'. This implies that participants could easily understand the interview questions and openly responded to the questions. During the interview, the participants were asked whether the National Cancer Control Plan and guidelines were available in their organisation. The participants were questioned about how that plan had been implemented in their organisation.

### *Survey*

In this study, a self-administered questionnaire was used. The survey data included four sections: section one consisted of socio-demographic variables: including institution, age, sex, and ward, level of education, working experience, and experience for caring life-limiting ill patients. Section Two included knowledge questions adapted from the Palliative Care Quiz for Nursing (PCQN) for the knowledge test (Ross, McDonald, & McGuinness, 1996). The modified version in the Ethiopian context had 14 items using the response alternatives 'yes', 'no' and 'do not know' (Kassa, Murugan, Zewdu, Hailu, & Woldeyohannes, 2014). The instrument included eight positively (1, 4, 7, 8, 12, 13, and 14), and six negatively (2, 3, 5, 6,

9, 11) listed items. The six items (1, 2, 8, 6, 11, 13) described the categories of philosophy and principle of palliative care; seven items (3, 4, 5, 7, 9, 10, 12) pain and symptom management; and one item (14) psychological care (Ross et al., 1996). The items are scored two for *yes*, one for *no* and zero for *do not know*. The possible score ranges from 0 to 28. The highest score indicated good knowledge.

The third section of the survey was related to attitude. The tools adopted were the Frommelt Attitudes Toward Care of the Dying Scale (FACTOD) Form B (Mastroianni et al., 2015), and the modified version for the Ethiopian context (Kassa et al., 2014) was used. The modified version of the FACTOD scale, 24-items using a five-point Likert scale, was used to describe the respondent's attitude towards caring for patients with life-limiting illness. The instrument included 11 positively (3, 4, 7, 8, 10, 12, 13, 15, 16, 21, and 22), and 13 negatively listed items (1, 2, 5, 6, 9, 11, 14, 17, 18, 19, 20, 23, 24), with the response alternatives: *strongly agree*, *agree*, *uncertain*, *disagree* and *strongly disagree*. Positive items scored one (*strongly disagree*), and five (*strongly agree*), with the scores reversed for negative items. Possible scores range from 24 to 120. The FACTOD-B categories describe Fear/Malaise (items 3, 6, 18, 19, 20, 23, 24); Care of the Family ( items 13, 16); Communication (items 9, 17, 21, 22); Family as Caring (items 8, 7, 10); Relationship (2, 4, 5, 11, 12); and Active Care (items 1, 14, 15) (Mastroianni et al., 2015). A score of 50% or greater shows a more positive attitude towards caring for life-limiting ill patients. The last section included 23 items of self-reported practice-related questions adapted from related works of literature (Abu-Saad Huijer & Dimassi, 2007; Kassa et al., 2014; Nguyen, Yates, & Osborne, 2014). The instrument included closed questions and positive items scored one for 'yes' and zero for 'no', the possible scores ranging from 0 to 23. A higher score indicated better self-reported practice of palliative care.

The survey was written in English, (Appendix 2A), independently translated to Tigrigna, and back-translated into English by two bilingual native speakers. The back-translation has been compared with the original by the research supervisors and any discrepancies resolved by discussion. A total of 84 nurses working in primary and secondary levels of both Cases; and 89 nurses working in the context of Comprehensive Specialised Hospital completed the survey questionnaire. The student researcher explained the survey to the participants in regular nursing meetings. The explanatory statement survey (Appendix 2B) was distributed during the meeting. An advertisement (Appendix 2C) was posted in their wards for those not

attending these meetings. The survey was placed in a central location and took 25-30 minutes of the nurses' time and returned to a sealed box in the workplace.

### *Focus group interviews*

Focus group interviews are an opportunity to have multiple interactions conducted among the group participants to share their experience, preference, and intentions (Jirojwong, Johnson, & Welch, 2014). A guiding framework (Appendix 3A) was adapted from the literature (McIlfatrick et al., 2014) and used to elicit community members' experience of caring for people with a life-limiting illness. The focus group questions were designed to identify the strategies used to care for people with a life-limiting illness and the challenges related to caring in the rural areas of the region. The discussion was conducted in Tigrigna at the community centre and took place over 45-50 minutes. In this study, two focus group interviews were facilitated with the community members by the student researcher.

Community participants were recruited at the end of a Sunday community services gathering, via a short verbal presentation and distribution of explanatory statements (Appendix 3B). The rural community members were adult farmers (women and men), community and religious leaders who participated in district political meetings on a Sunday. The people gathered on Sundays because it is considered a holy day and a day of rest when farmers are able to participate in the meeting. The local HEWs assisted the student researcher in providing contact with religious leaders to organise this presentation. Community focus group interviews were facilitated by the student researcher with the community members using an audio-recorder. The groups occurred at the day and time suited to the participants in the community centre. The focus group interviews occurred in the context of a coffee ceremony, a traditional activity associated with community meetings.

### *Data quality*

Data quality and validity are essential components of a research study. The quality of case study design is established using four tests, such as internal and external validity, construct validity and reliability (Yin, 2018). This study did not use internal validity because it is not applicable for descriptive case studies (Yin, 2018). A discussion of strategies taken in these three tests, i.e., external validity, construct validity, and reliability is in the following sections.

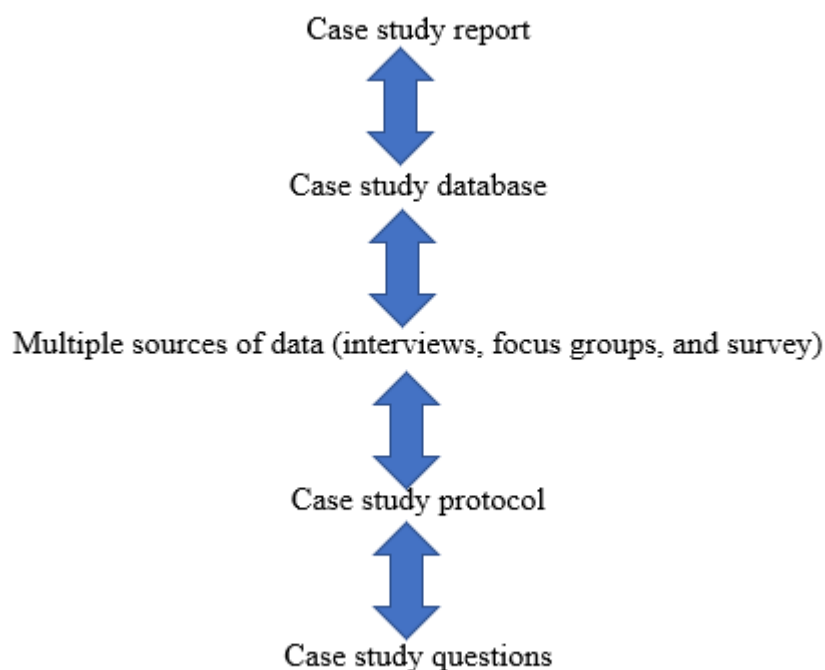
### *Construct validity*

Construct validity is one of the quality assessments which measures the concept that it is intended to measure (Yin, 2018). Yin suggests three tactics used in ensuring construct validity. These are:

1. The use of multiple sources of data, in convergent lines of inquiry; this tactic is relevant during the data collection of the study
2. To establish a chain of evidence during collecting and maintaining a chain of evidence (Figure 8), also relevant during data collection.
3. To have the draft case study report reviewed by key informants

The use of multiple sources of data is considered the strength and fundamental point of case study design, compared to other research designs. In this study, the researcher focused on the title of 'regional palliative care' with multiple sources of evidence. (see Figure 9).

Figure 9: Maintaining a chain of evidence adapted from Yin (2018)



### *External validity*

External validity deals with the degree to which the findings of the research are generalisable (Yin, 2018). For the case study design, external validity provides analytic/ theoretical generalisation rather than statistical generalisation. The two strategies used to increase external validity during research design are the use of theory in a single case and replication logic in multiple cases. In this study, two cases were used, which indicated a replication logic. The form of research questions can directly influence the strategies used in ensuring external validity (Yin, 2018). For example, many descriptive case studies deal with ‘how’ kind of questions, which is similar to the research questions in this study.

### *Reliability*

Reliability is demonstrated when the data collection procedure is repeated with the same results or it deals with minimising bias and mistakes (Yin, 2018). Yin suggested reliability be tested using three tactics such as the use of a case study protocol, developing a case study database, and maintaining a chain of evidence during data collection. A case study protocol contains the procedure and general rules to be followed when using the protocol. A protocol is desirable under all circumstances, especially in multiple case study research. The protocol has four sections: an overview of a case study; data collection procedures; protocol questions; and a tentative outline of a case study report.

### *Data management and analysis*

The collected data adhered to the University regulations and was kept permanently in a password secured electronic platform (LabArchives) at Monash University (LabArchives, 2018). Backup was secured as soon as possible following data collection. The original recording and translation/transcription was de-identified. Hard copy and the scanned consent documents were stored on LabArchives in a separate file to the data.

### *Qualitative data analysis*

Qualitative analysis was undertaken separately for each case, based on the four pillars of WHO Public Health Strategy. The data from individual interviews and focus group were recorded using a digital device and saved with participant identifier information such as One and Two for the Cases; and ‘the letter C’ for the Contexts, in order to maintain confidentiality. The audio files were transcribed by the student researcher verbatim in the language of the interview. Initially, the data were cleaned, sorted, comparing the word files with audio recorded files by another student researcher who can speak the language of the

interview to ensure data accuracy. The data analysis included putting information into different sections, providing data categories and placing pieces of evidence within such categories.

The audio recorded files were listened to repeatedly, and the transcribed data read in hard copy form in order to make notes for initial coding and to check accuracy between the recorded files and the Word files. Each participant was assigned a numerical code to ensure anonymity. A thematic analysis technique supported by a qualitative analysis software package NVivo 12 was used (Edhlund & McDougall, 2019). Thematic analysis “is a method for identifying, analysing and reporting patterns (themes) within data” (Brown, 2008, p. 79). It is an independent qualitative descriptive approach frequently used in health sciences (Castleberry & Nolen, 2018), particularly nursing research (Vaismoradi, Turunen, & Bondas, 2013). Moreover, thematic analysis is a flexible and useful research tool, provides a rich and detailed complex, account of the data (Castleberry & Nolen, 2018). Themes can be identified in one of two primary ways in thematic analysis: in an inductive or bottom-up way and in a deductive (top-down) way (Braun & Clarke, 2006) and this study used a deductive approach. The researcher coded the themes based on the four components of the WHO Public Health Strategy. The student researcher initially coded the English transcripts and, together with the supervisors, reviewed and discussed the codes.

The transcribed data has relied on theoretical proposition analytic strategies (Yin, 2018), that is the WHO Public Health Strategy with the four components. A cross-case analytic technique was used to compare cases, being ‘case-based’ rather than ‘variable-based’ approach, which focused mainly on case integrity and comparing or synthesising cases within-case patterns. This cross-case comparison occurred at the discussion stage of the thesis.

### *Quantitative data analysis*

The survey data from Group Two, was entered into the Statistical Software Package (SPSS) statistics version 25, checking for the data accuracy before analysis (Pallant, 2016). The survey was coded during the data entry to SPSS software. The coding process for the survey involved providing identifiers for each of the variables on the questionnaire. A simple, consistent approach was used, through assigning the number to represent each of the possible answers to every participant question. The process was conducted as follows:

- Coding demographic items with a number one, two, three up to the available categorical responses.
- Knowledge items for positive statements: two (yes), one (no), and zero (do not know), and reversed during negative items
- Attitude items for positive statements: one (Strongly disagree), two (Disagree), three (Uncertain), four (Agree), and five (Strongly Agree) and reversed for negative items.
- Practice items coded with a number one (yes) and zero (no)

The cases and context were re-coded variables (Case 1, 2, and Context (C)). The SPSS data was checked at least three times, and also finally re-checked for data entry accuracy by another student researcher and one of the supervisors. Descriptive statistics were conducted for demographic data and the whole scale. The data were calculated in terms of frequency, percentages, mean, and standard deviation. Measures of skewedness and kurtosis were conducted to clarify the discriminatory capacity of normal distribution. Inferential statistics were used to compare the relationship between the demographic and outcome variables in the two cases, and the context. Following advice from a statistician, data analysis was conducted to determine if there was a significant difference between the demographic variables and the outcome variables. Scatterplot, correlation, and boxplots were calculated in consultation with the statistician. As a result, non-parametric statistics were used because the variables were not normally distributed. The Kruskal-Wallis and Mann-Whitney U test was the chosen non-parametric test (Pallant, 2016). The Kruskal-Wallis test is “the non-parametric alternative to one-way between-groups analysis of variance ... used to compare continuous variables for three or more groups” (Pallant, 2016, p. 236). In this study, for the demographic variables that had three or more groups the Kruskal-Wallis test was used to compare the significant difference with the nurse's knowledge or attitude or self-reported practice. The Mann-Whitney U test is “the non-parametric alternative to the t-test ... used to test for difference between two independent group on a continuous measure” (Pallant, 2016, p. 230). In this study the Mann-Whitney U test was used to compare the significant difference between the demographic variable that had two groups with the nurse's knowledge or attitude or self-reported practice. In the other groups, the demographic variables in two cases and the context were then compared statistically to the variables (knowledge, or attitude, or self-reported practice) to determine any statistically significant differences.

Finally, the qualitative data (interviews and focus groups) and quantitative survey results were triangulated to draw a complete picture of sustainable palliative care model in the



region, and also to provide a snapshot of the current status of palliative care in the region. Triangulation “seeks convergence, corroboration, and correspondence of results from the different methods” (Creswell & Clark, 2011, p. 62). In this study, triangulation of findings was conducted through listing the survey results and the qualitative findings on the same page and a consideration of where the findings agreed (convergence), offered corroborating evidence on the same issue and appeared to contradict each other (discrepancy or dissonance) (O’Cathain, Murphy, & Nicholl, 2010). The triangulation of results was reported as part of the discussion in Chapter 7.

### Ethical considerations

Ethical issues and rights considerations are necessary for every piece of research, and the researcher has the responsibility to protect the participants from any harm and risks (Reyna, Bennett, & Bruera, 2007). The commonly accepted fundamental ethical principles related to research are beneficence, non-maleficence, autonomy, and justice (Reyna et al., 2007). Reyna et al. (2007) suggest that confidentiality and informed consent are reflected in the principle of autonomy. Autonomy refers to respect for the participants’ self-determination and their right in making a choice and taking actions based on personal values and beliefs (Reyna et al., 2007).

All interview participants gave written and informed consent. All survey participants were informed about the survey and their consent was implied when they returned a completed survey. Reyna et al. (2007) also asserted that confidentiality is an element related to autonomy because individuals have the right to control the disclosure of medical information connecting to them. Every effort was made to reduce the identification of participants in final reports by de-identifying the region, organisations, and participants. However, some organisational leaders may be identifiable by their role. The de-identified data may be used for further projects. This was stated in the explanatory statements and consent forms (Appendix 1A, 2B, 3B, 1C, and 3C).

Beneficence is doing good to improve the wellbeing of people. In palliative care research, the primary purpose is to improve the quality of life of patients and their families. The benefit of being involved in this study for the leaders, included the opportunity to reflect on current and future services for the care of people with a life-limiting illness. For nurses, the survey may have assisted in determining the education, and support nurses need in caring for people with life-limiting illnesses and they may directly benefit from this education and support in the

future. For the community members, the focus group may have been the first opportunity community members have had a chance to talk about their experience and the challenges involved when people are dying in the community. The interview allowed them to articulate their experience and to contribute to their community awareness, in particular, the importance of addressing suffering in the community.

Non-maleficence is related to beneficence which means minimising harm or doing well for participants. In this study, there was a low risk of harm for leaders working in the Regional Health Bureau, educational institute, and hospitals, as the focus of interviews was on policy, service structure and delivery, rather than personal experience. For nurses, the survey was about the nurse's knowledge, skill, and attitudes, and the risks of harm to them was low; the return of the questionnaires was also voluntary. However, the risk for the community focus group participants might have been higher because they may have chosen to discuss personal experiences, the recollection of which might have been distressing. In the rural regions of Ethiopia, where these groups were conducted, there are few health services and no counselling service for these people. Distress when discussing the death of family members or friends is a regular part of grief and was anticipated in these interviews. Thus, an experienced nurse accompanied the researcher to provide emotional support to members of the group who needed it and after the discussion; the researcher also an experienced nurse, provided debriefing to members of the group who had been distressed. In these communities, it is a usual practice that the community support their grieving members. Thus, a focus group of community members was an appropriate and supportive forum for discussion about these issues.

Finally, the researcher should balance the participants' needs and social needs and burdens during the study period (Reyna et al., 2007). In this study, the leaders and community members were provided with a written consent form to sign (Appendix 1C and 3C). The student researcher or another community member read the explanatory statement and consent form for the group members because of literacy issues. The participants had the chance to have their questions answered before signing the consent form. Illiterate community members provided their consent by marking the consent form with their thumbprint, a standard practice in Ethiopia. The interviews did not commence until written consent was provided and to support informed consent, both the consent form and the explanatory statement were prepared in English and Tigrigna.

The survey was paper-based and returned anonymously in a sealed envelope and placed in a box on the ward to protect confidentiality. Only the organisational code was noted in the paper. The individual participants have remained anonymous. Participant consent for the survey was implied by the completion of the survey and lodging it in the box on the ward. For this reason, the potential risk was minimal, and participants may even have benefited from participating in the study.

Ethical approval was gained from the Monash University Research Ethics Committee (MUREC) (13402 and Appendix 4). Since the data are collected from Ethiopia, the second ethical approval sought was from Mekelle University, Health Research-Ethical Review Committee (MU-HRERC).

## Chapter Summary

In this Chapter, the research design used for this study is discussed in detail, together with several crucial decisions guiding the overall process of the study. The researcher decided to choose case study research because it is in an appropriate strategy for palliative care research when there is a complex issue; the context is central to the study; and multiple perspectives need to be recognised. In this study, a survey was embedded within multiple case study research, that is a multiple embedded mixed method case study design was used to answer the complex research questions. Several fundamental components involved with the requirements of the case study were addressed in this Chapter. The Chapter also detailed how to conduct a case study, starting from the philosophical assumptions, history of the case study; description of the case study; case study confusion with the terms methods and methodology. The strengths and limitations of this design have been addressed, as well as justification for the selection.

The case study methodology fits within the philosophical background, including a postpositivist, pragmatic, and constructivist or interpretive approach. The survey and qualitative data were collected in rural and regional Ethiopia. SPSS statistics version 25 was used to analyse the survey data. Thematic analysis was supported by the qualitative analysis software package NVivo 12, used for the qualitative data. Ethical approval was given from Monash University and, since the data were collected in Ethiopia, the second Ethical Approval was received from a University in the study region.

## Chapter Four: Context Results

### Introduction

As discussed in the previous Chapter, ‘the Context’ refers to participants recruited from the Comprehensive Specialised Hospital, educational institutes and Regional Health Bureau. The survey data was collected from nurses working in an oncology unit, an Anti-Retroviral Therapy (ART) clinic as well as medical and surgical wards of the Comprehensive Specialised Hospital. Chapter Three described the survey data, a self-administered questionnaire with four sections. The first section contained socio-demographic variables, followed by the knowledge test modified from Palliative Care Quiz for nursing (PCQN) then, the attitudes-related question from the modified version Frommelt Attitudes Toward Care of the Dying Scale (FACTOD) Form B; and lastly, the self-reported practice items developed from different bodies of literature.

The interviews of the Context were collected from two Regional Health Bureau representatives, five head nurses, one pharmacy head, one medical and one nurse leader of the Comprehensive Specialised Hospital. The interviews also included representatives (Pharmacy, Nursing and Medicine) of each educational institute school and a nurse lecturer from the regional health college. Of the 14 interviews conducted, a total of 12 were analysed. Two nurse interviews were randomly excluded from the analysis because they were duplicate representative informants.

The collected survey data were analysed using Statistical Software Package (SPSS) version 25, followed by qualitative analysis supported by NVivo version 12. The results in this Chapter are reported in two sections: the survey results and then the qualitative results, presented in the following sections.

### Survey results of the Context

The survey was distributed to the nurses working in the oncology unit, the ART clinic, and the medical and surgical wards of the Comprehensive Specialised Hospital. In the Context, out of 124 surveys distributed to nurses working in a Comprehensive Specialised Hospital, 89 were completed, with a response rate of 71.8%. The survey results are presented in six sections. The first section summarises the socio-demographic variables (except age) using frequency and percentages. Age of nurses is described, using mean and Standard Deviation (SD). The second section reports the nurses’ level of knowledge about palliative care,

followed by the nurses' attitudes to palliative care. The final part of the survey presents the nurses' level of self-reported palliative care practice. The last two sections demonstrate the correlation between the knowledge, attitudes, and self-reported practices; and identifies the demographic variables that had significant association with these variables.

### Socio-demographic variables

The first section of the survey includes the description of sociodemographic variables. The mean age of the recipients was 30.11 years (SD, 5.42). The majority, (84, 96%), had a Bachelor of Science in Nursing (BSc) degree. In palliative care education, (58, 66%) indicated they had completed palliative care education in undergraduate, and postgraduate courses. Fifty-seven (65%) had not undertaken in-service training to assist them to apply palliative care theory to practice (see Table 4.1).

**Table 4.1**  
**Demographic variables of nurses working in the Context (n=88\*)**

<b>Variable</b>	<b>Frequency (%)</b>
<b>Institution</b>	
Specialised Hospital	89 (71.8%)
<b>Sex</b>	
Female	62 (70.5)
Male	26 (29.5)
<b>Clinical area</b>	
Medical ward	41 (46.6)
Surgical word	34 (38.6)
Oncology	10 (11.4)
ART	3 (3.4)
<b>Nursing experience</b>	
1-4 years	41 (46.6)
5-9 years	29 (33.0)
Ten years and above	18 (20.5)
<b>Experience in palliative care</b>	
None	17 (19.3)
<1 year	13 (14.8)
1-4 years	41 (46.6)
5-9 years	10 (11.4)
Ten years and above	7 (7.9)
<b>Educational qualification</b>	
Diploma in Nursing	4 (4.5)
BSc and above	84 (95.5)
<b>Palliative care in undergraduate and/or postgraduate level</b>	
Yes	58 (65.9)
No	30 (34.1)
<b>In-service training in palliative care</b>	
Yes	31 (35.2)
No	57 (64.8)
<b>Duration of palliative care in-service training</b>	
Three days - two weeks	25 (80.6)
Two weeks-one month	6 (19.4)

*\*for institution n=89, there was one survey missing values in the demographic variables*

#### Nurses' knowledge about palliative care

There were 14 items in the knowledge components of the survey. Overall, more than 45% correctly responded to the PCQN (41, 47%; ranges 5-69). The lowest number of participants correctly responded to the 'pain and symptom management' category of PCQN items (36, 41%; ranges 5-74). Half of the participants correctly responded to items in the 'philosophy and principle of palliative' category (43, 50%, ranges 25-69). The highest number of participants correctly responded to the 'psychological care' items (69, 79%). A majority of

participants responded incorrectly ‘yes’ to the statement: *Drug addiction is the major problem when morphine is used long-term* (74, 85%); and more than half the participants responded incorrectly ‘yes’ to statement two: *Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration* (44, 51%) (see Table 4.2).

**Table 4.2**  
**Nurses’ knowledge about palliative care in the Context (n=87)**

No.	Items	Yes n (%)	No n (%)	Do not know n (%)
1.	Do you know about palliative care?	69 (79.3)	9 (10.3)	9 (10.3)
2.	Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration	44 (50.6)	39 (44.8)	4 (4.6)
3.	The extent of the disease determines the method of pain treatment	78 (89.7)	5 (5.7)	4 (4.6)
4.	Adjuvant therapies (antidepressants, anticonvulsants and anti-emetics) are essential in managing pain	47 (54.0)	27 (31.0)	13 (14.9)
5.	Drug addiction is the major problem when morphine is used on a long-term basis for the management of pain	74 (85.1)	11 (12.6)	2 (2.3)
6.	The provision of palliative care requires emotional detachment	26 (29.9)	52 (59.8)	9 (10.3)
7.	During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea	57 (65.5)	22 (25.3)	8 (9.2)
8.	The philosophy of palliative care is compatible with that of aggressive treatment	28 (32.2)	50 (57.5)	9 (10.3)
9.	The use of placebos is appropriate in the treatment of some types of pain	42 (48.3)	37 (42.5)	8 (9.2)
10.	Meperidine (Demerol) is not an effective analgesic in the control of chronic pain	18 (20.7)	18 (20.7)	51 (58.6)
11.	The accumulation of losses renders burnout inevitable for those who work in palliative care	59 (67.8)	25 (28.7)	3 (3.4)
12.	The manifestation of chronic pain is different from those of acute pain	74 (85.1)	12 (13.8)	1 (1.1)
13.	Terminally ill patients have the right to choose ‘Do not resuscitate.’	46 (52.9)	38 (43.7)	3 (3.4)
14.	Terminally ill patients should be encouraged to have hope against all odds	69 (79.3)	16 (18.4)	2 (2.3)

*There were two missing values in knowledge items, 87 total participants for the knowledge test.*



A majority of participants responded incorrectly 'yes' to the statement: *The extent of the disease determines the method of pain treatment* (78, 90%); and to: *Drug addiction is the major problem when morphine is used on a long-term basis for the management of pain* (74, 85%).

However, most participants responded correctly 'yes' to the statement: *During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea* (57, 66%). In addition, more than half the participants responded correctly 'yes' to the statement: *Terminally ill patients have the right to choose 'Do not resuscitate.'* (46, 53%). A majority of participants correctly identified that the: *Provision of palliative care requires emotional detachment* was incorrect (52, 60%). Overall, 36 (41%) of participants scored 75% or greater for the modified version of the PCQN test.

#### Nurse's attitudes towards palliative care

As already described in Chapter Three, there were 23 items in the attitudes part of the survey. All participants scored 50% or greater for the modified version of FACTOD form B. A total of more than 55% correctly responded for the modified version of FACTOD-B (52, 56%; ranges 7-81). The lowest number of participants correctly responded to the 'communication' category of FACTOD-B (32, 35%; range 7-51). More than 50% of participants correctly responded to the 'relationship' items (47, 53%; range 15-77); 'fear/malaise' (49, 57%; range 24-74); and 'active care' items (54, 60%; range 38- 65). The highest number of participants correctly responded to the 'family as caring' items (78, 88%; range 74-81) followed by 'the care for the family' category of items (71, 79%; range 63-78). The majority of participants correctly disagreed/strongly disagreed with item one: *Palliative care should only be given for dying patients* (58, 65%). More than half of participants also correctly disagreed/strongly disagreed with item six: *The length of time required to give nursing care to a dying person would frustrate the nurse* (46, 52%). In addition, most of the participants correctly disagreed/strongly disagreed with the item that indicated: *As a patient nears death, the nurse should withdraw from his/her involvement with the patient* (65, 73%). A majority of participants correctly agreed/strongly agreed with item 16: *Nursing care should extend to the family of the dying person* (78, 88%) and item 13: *Nursing care for the patient's family should continue throughout grief and bereavement* (63, 71%). Most participants also correctly agreed/strongly agreed with item 15: *Addiction to pain relieving medication should not be a concern when dealing with a dying person* (65, 73%) and item four: *It is beneficial for the chronically sick person to verbalise his/her feelings* (77, 87%).

However, a majority of participants incorrectly agreed/strongly agreed with item 17: *When a patient asks, “Am I dying?” I think it is best to change the subject to something cheerful* (75, 84%) and item nine: *The nurse should not be the one to talk about death with the dying person* (58, 65%) (see Table 4.3).

**Table 4.3**  
**Nurse's Attitudes towards palliative care (n=89)**

<b>No.</b>	<b>Items</b>	<b>SA</b>	<b>A</b>	<b>U</b>	<b>D</b>	<b>SD</b>
<b>1</b>	Palliative care is given only for a dying patient.	15 (16.9)	10 (11.2)	6 (6.7)	23 (25.8)	35 (39.3)
<b>2</b>	As a patient nears death; the nurse should withdraw from his/her involvement with the patient.	10 (11.2)	7 (7.9)	7 (7.9)	18 (20.2)	47 (52.8)
<b>3</b>	Giving nursing care to the chronically sick patient is a worthwhile learning experience.	45 (50.6)	29 (32.6)	6 (6.7)	4 (4.5)	5 (5.6)
<b>4</b>	It is beneficial for the chronically sick person to verbalise his/her feelings	52 (58.4)	25 (28.1)	3 (3.4)	7 (7.9)	2 (2.2)
<b>5</b>	Family members who stay close to a dying person often interfere with a professional's job with the patient	31 (34.8)	32 (36.0)	11 (12.4)	9 (10.1)	6 (6.7)
<b>6</b>	The length of time required to give nursing care to a dying person would frustrate me	12 (13.5)	21 (23.6)	10 (11.2)	24 (27.0)	22 (24.7)
<b>7</b>	Families should be concerned about helping their dying family member make the best of his/her end of life	52 (58.4)	27 (30.3)	6 (6.7)	2 (2.2)	2 (2.2)
<b>8</b>	The family should maintain as healthy environment as possible for their dying member.	57 (64.0)	24 (27.0)	4 (4.5)	2 (2.2)	2 (2.2)
<b>9</b>	The nurse should not be the one to talk about death with the dying person.	26 (29.2)	32 (36.0)	7 (7.9)	12 (13.5)	12 (13.5)
<b>10</b>	The family should be involved in the physical care of the dying person.	52 (58.4)	22 (24.7)	9 (10.1)	2 (2.2)	2 (4.5)
<b>11</b>	It is difficult to form a close relationship with the dying person.	17 (19.1)	24 (27.0)	15 (16.9)	14 (15.7)	19 (21.3)
<b>12</b>	There are times when death is welcomed by the dying person.	21 (23.6)	24 (27.0)	16 (18.0)	14 (15.7)	12 (15.7)
<b>13</b>	Nursing care for the patient's family should continue throughout grief and bereavement.	35 (39.3)	28 (31.5)	9 (10.1)	10 (11.2)	2 (7.9)
<b>14</b>	The dying person should not be allowed to make decisions about his/her physical care.	22 (24.7)	19 (21.3)	10 (11.2)	21 (23.6)	17 (19.1)
<b>15</b>	Addiction to pain-relieving medication should not be a concern when dealing with a dying person.	32 (36.0)	33 (37.1)	10 (11.2)	10 (11.2)	2 (4.5)
<b>16</b>	Nursing care should extend to the family of the dying person.	48 (53.9)	30 (33.7)	7 (7.9)	2 (2.2)	2 (2.2)

<b>17</b>	When a patient asks, “Am I dying?” I think it is best to change the subject to something cheerful	48 (53.9)	27 (30.3)	7 (7.9)	5 (5.6)	2 (2.2)
<b>18</b>	I am afraid to become friends with chronically sick and dying patients	15 (16.9)	15 (16.9)	8 (9.0)	26 (29.2)	22 (28.1)
<b>19</b>	I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	19 (21.3)	24 (27.0)	8 (9.0)	16 (18.0)	19 (24.7)
<b>20</b>	I would be uncomfortable talking about impending death with the dying person.	23 (25.8)	33 (37.1)	9 (10.1)	14 (15.7)	10 (11.2)
<b>21</b>	It is possible for nurses to help patients prepare for death.	24 (27.0)	27 (30.3)	11 (12.4)	14 (15.7)	13 (14.6)
<b>22</b>	Death is not the worst thing that can happen to a person.	21 (23.6)	23 (25.8)	9 (10.1)	17 (19.1)	17 (21.3)
<b>23</b>	I would feel like running away when the person died.	12 (13.5)	6 (6.7)	8 (9.0)	18 (20.2)	45 (50.6)
<b>24</b>	I would not be assigned to care for a dying person	14 (15.7)	13 (14.6)	6 (6.7)	21 (23.6)	35 (39.3)

## Self-reported palliative care practices

The final part of the survey questionnaire collected data on self-reported palliative care practice. The majority (77, 87%) of participants scored lower than 75% for the self-reported palliative care practices questions. Although (55, 62%) of participants indicated they provided care for people with life-limiting illness through counselling and hygiene, a majority of the participants did not assess symptoms such as spiritual needs (69, 78%); diarrhoea and constipation (56, 63%); emotional /psychological state (53, 60%); pain; and patient education (44, 49%). The highest self-reported practice medication administration practice was tramadol (56, 63%), followed by morphine (52, 58%) (see Table 4.4).

**Table 4.4**  
**Self-reported palliative care practices (n=89)**

No	Items	Yes f (%)	No f (%)
<b>Caring for people with a life-limiting illness practice</b>			
1	Counselling	55 (61.8)	34 (38.2)
2	Hygiene	55 (61.8)	34 (38.2)
3	Patient education	45 (50.6)	44 (49.4)
4	Family education	44 (49.4)	45 (50.6)
5	Family meeting	28 (31.5)	61 (68.5)
6	Multidisciplinary team meetings	25 (28.1)	64 (71.9)
7	Comfort care	23 (25.8)	66 (74.2)
8	Working with community and religious leaders	10 (11.2)	79 (88.8)
<b>Application of assessment tools</b>			
9	Fatigue	58 (65.2)	31 (34.8)
10	Pain	45 (50.6)	44 (49.4)
11	Nausea and vomiting	39 (43.8)	50 (56.2)
12	Emotional/psychological state	36 (40.4)	53 (59.6)
13	Diarrhoea and constipation	33 (37.1)	56 (62.9)
14	Spiritual needs	20 (22.5)	69 (77.5)
<b>Administering medication for chronic pain relief</b>			
15	Tramadol	56 (62.9)	33 (37.1)
16	Morphine	52 (58.4)	37 (41.6)
17	Paracetamol	37 (41.6)	52 (58.4)
<b>Using non-pharmacological management of pain</b>			
18	Distraction	51 (57.3)	38 (42.7)
19	Hot or cold compress	46 (51.7)	43 (48.3)
20	Massage	29 (32.6)	60 (67.4)

<b>Administering medication to treat symptoms</b>				
<b>21</b>	• Nausea and Vomiting	55 (61.8)	34 (38.2)	
<b>22</b>	• Anxiety and Depression	38 (42.7)	51 (57.3)	
<b>23</b>	• Diarrhoea and Constipation	31 (34.8)	58 (65.2)	

### Examining relationships between outcome variables in the Context

In the Context, a Spearman's rho correlation coefficient was used to identify the relationships among the outcome variables. There was a small, positive correlation between attitude and self-reported practice,  $\rho = .22$ ,  $n = 89$ ,  $p < .05$ , with a more favourable attitude being associated with a high level of self-reported practice (Pallant, 2016) (see Table 4.5).

**Table 4.5**  
**The correlation among the outcome variables.**

		<b>Correlations</b>			
			Knowledge	attitude	practice
Spearman's rho	Knowledge	Correlation Coefficient	1.000	-.010	-.131
		Sig. (2-tailed)	.	.929	.226
		N	87	87	87
	Attitude	Correlation Coefficient	-.010	1.000	.224*
		Sig. (2-tailed)	.929	.	.034
		N	87	89	89
	Practice	Correlation Coefficient	-.131	.224*	1.000
		Sig. (2-tailed)	.226	.034	.
		N	87	89	89
	*. Correlation is significant at the 0.05 level (2-tailed).				

### The association between the demographic and outcome variables in the Context

Of the ten demographic variables, three had a significant association: nursing experience, education level, and palliative care studies in undergraduate and postgraduate levels.

There was a significant difference in attitude with palliative care studies in undergraduate and postgraduate levels. A Mann-Whitney U test (Pallant, 2016) revealed that there was a significant difference in attitude with palliative care study undertaken in undergraduate and postgraduate courses not taken ( $Md = 80.5$ ,  $n = 30$ ) and taken ( $Md = 86$ ,  $n = 58$ ),  $U = 599$ ,  $z = -2.39$ ,  $p = .017$ ,  $r = -0.3$ . This indicated that those nurses who had studied palliative care in either undergraduate or postgraduate courses had a more positive attitude towards palliative care than those who had not taken a course.

Higher self-reported palliative care practice was also significantly associated with higher education qualifications. A Mann-Whitney U test (Pallant, 2016) revealed a significance difference in the level of self-reported practice associated with educational qualifications; Diploma (Md = 4.5, n= 4) and a Bachelor of Science in Nursing and above (Md = 10, n = 84),  $U = 291.5$ ,  $z = 2.49$ ,  $p = .013$ ,  $r = 0.3$ .

Self-reported palliative care was significantly associated with years of nursing experience. A Kruskal-Wallis Test (Pallant, 2016) revealed a statistically significant difference in self-reported practice levels across three different age groups (Gp1,  $n = 41$ : 1-4 yrs, Gp2,  $n = 29$ : 5-9 yrs, Gp3,  $n = 18$ ,  $\geq 10$  yrs),  $X^2 (2, n=88) = 7.77$ ,  $p = .02$ . Those nurse with more experience recorded a higher median score (Md=14.5) than the other two groups, which recorded a median value of 10 for 5-9 yrs and 8 for 1-4 yrs of experience.

In the Context survey results, almost all participants held at least a Bachelor's degree in nursing and the majority of participants had learned about palliative care in their undergraduate and postgraduate courses; but most participants had not received in-service palliative care training. Overall, a number of participants had low levels of knowledge and poorer self-reported practice; however, all participants possessed positive attitudes towards palliative care. In addition, there was a small positive relation between attitude and self-reported practice: participants who had more favourable attitudes towards palliative care were associated with higher levels of self-reported practice. The participants who had Bachelor's degrees and higher levels of education, and greater years of nursing experience were more likely to have higher self-reported practice than those who had a Diploma and fewer years of experience. In addition, those participants who studied palliative care in either undergraduate or postgraduate level had more positive attitudes than those who had not.

### Qualitative results of the Context

The interviews to collect data for the Context were conducted at the Regional Health Bureau; educational institutes; and a Comprehensive Specialised Hospital. Interviews were conducted with representatives from the leadership teams of Medicine, Nursing and Pharmacy in a Comprehensive Specialised Hospital, University, and regional college: a total of 12 interviews with nine males and three females. Participants described the status of palliative care policy, palliative care education and training; availability of medication and palliative care implementation in the Regional Health Bureau, educational institutes, and



Comprehensive Specialised Hospital, discussing the challenges and opportunities related to the delivery of palliative care in their settings.

The process of translating the interviews was discussed in Chapter 3. They are utilised verbatim in this and the following chapters, with the text clarifying the intent and meaning of the quote in square brackets.

From the interviews, three major themes emerged: *palliative care policy and guidelines*; *palliative care education and training*; and *palliative care implementation*. The themes and subthemes of the Context are described in this next section (see Table 4.6).

**Table 4.6**  
**Context themes and sub-themes**

Themes	Sub-themes
Palliative care policy and guidelines	<ul style="list-style-type: none"> <li>• Policy status of palliative care and the availability of palliative care guidelines and related documents</li> </ul>
Palliative care education and training	<ul style="list-style-type: none"> <li>• Palliative care integration into curricula</li> <li>• Professional and community awareness and perception of palliative care</li> </ul>
Palliative care implementation	<ul style="list-style-type: none"> <li>• Using mass media to promote palliative care</li> <li>• Pain management</li> <li>• Providing care</li> <li>• Resources related opportunities and challenges</li> </ul>

### Palliative care policy and guidelines

As already discussed in Chapter One, there is a National Palliative Care Guideline, and palliative care is included in both the National Cancer Control Plan (NCCP) and the Health Sector Transformation Plan (HSTP). In order to determine how these plans and guidelines translated in the region, the interviewees were asked to reflect on what they understood about them. This theme reflects what they recognised and where policy and guidelines were available in the different parts of the Context. Participants also described their perceptions about whether there was a priority for palliative care as well as the focus on palliative care by policymakers in the regional government. This theme includes one aspect: *Policy status of palliative care and the availability of palliative care guideline and related documents* in health care settings.

### *Policy status of palliative care and the availability of palliative care guidelines and related documents*

In examining the policy status of palliative care, it is highlighted if, and how, participants recognised the presence of palliative care in the national health policies and guidelines and their reflections on the shifting priorities from communicable to non-communicable diseases and palliative care. The justifications for prioritising palliative care are also addressed.

Participants identified palliative care as a priority for health policy. The Regional Health Bureau representative described how Ethiopia's health policy was designed. Previously, the country's priority health issues were communicable diseases, maternal and child health:

*... palliative care is not neglected by the government. The issue is about priority ... policy developed considering, one thing, the majority problems of the community. The second thing, it considers the available resource ... existing infrastructure, existing system ... So, previously the main killer disease was malaria ... communicable disease ... children did not get a vaccination, mothers did not get the antenatal care and did not get assistance service for giving birth. At that time, without addressing this, you cannot talk about non-communicable disease ...*

(Participant CRHBR)

Participants described what they viewed as evidence that palliative care is a priority in the region. Some participants further emphasised indications of the need to prioritise palliative care, in the ageing population and the increasing incidence of non-communicable diseases (NCDs) being described as important drivers:

*... when you see the population pyramid ... our life expectancy is increasing, we have high prevalence ... of NCDs... In general, we have obvious reasons that I am saying palliative care [should be] a priority ...*

(Participant CNGOR).

Resulting from the increasing incidence of NCDs, the country and regional priority was described as shifting. Participants indicated that because there are now more deaths related to NCDs, palliative care is gaining focus in the region:

*... our country or our region is in transition stage, from those we know for a long period of time, that is, the communicable disease, to the new Chapter, what we call ... non-communicable disease ... [For example], I have seen one study in our region ...*

*which indicates 35% of death is due to non-communicable disease. 30% is communicable disease. So, the transition indicates the priority is changing ...*

(Participant CRHBR)

However, one of the educational institution participants claimed that, even though the incidence of NCDs had increased, the priorities had not changed in health care organisations in rural communities, whereas in the General Hospitals and Primary Health Care Units, priority was still being given to communicable diseases:

*... in the Health Centre or hospitals ... [health professionals] were not giving focus to palliative care ... palliative care should be given for chronic patients ... [however] ... poor attention was given by the policy makers of the [regional] government ... the policy focused on communicable disease ...*

(Participant CRCR)

So, despite acknowledgement of palliative care policy at a regional leadership level, palliative care may not be a current priority for health professionals working at the patient care level.

However, other participants argued that palliative care should not be a priority, because there was still a shortage of clean water and basic health care equipment which required priority over palliative care:

*... of course, now the non-communicable diseases are coming as a priority ... [however] ... palliative care is ... a luxury ... because we need to provide the basic health care ... in Ethiopia, most of the population [live in rural area], farmers [have] nobody [to] care of them. They do not have clean water to drink let alone [to talk about] palliative care ...*

(Participant CSH2)

The following participant emphasised that palliative care was a lower national priority than other specialities because rural people in Ethiopia had basic unmet needs:

*As a school of medicine ... we do not have anaesthesiologist ... [and] intensivist ... So, there are many specialists that needed priority ... there are other many priorities again such as programs ANC [Antenatal care], maternal hospital delivery, the communicable diseases, the children illnesses ... So, I am not saying palliative care is not important, it is important ... I will put palliative care as second or third line...*

(Participant CSH2)

In relation to availability of palliative care documents, participants working in senior leadership roles in the Context had information about the inclusion of palliative care in the national health policies and guidelines. These senior leaders included staff in the Comprehensive Specialised Hospital, the Regional Health Bureau and the NGO. For example, the NGO representative explained where palliative care was included in the country and at regional levels:

*Countrywide palliative care policy is launched ... this means palliative care is included in the national health policy ... palliative care is also included [under] the department of curative and rehabilitation [service] ... in the Regional Health Bureau*

(Participant CNGOR).

The Regional Health Bureau representative further clarified how and in which national document, palliative care was included:

*... as a country and as a region, it [palliative care linked with cancer] is [at an earlier stage], now starting ... palliative care for cancer gets emphasis now in the five years plan and is started ...*

(Participant CRHBR)

In general, leaders had information about the presence of palliative care in the national health policies and guidelines, whilst the nurses working in the wards of the Comprehensive Specialised Hospital and the educational leaders were less clear. These participants indicated that they had no information about the presence of palliative care in the national health policies and guidelines. For example, one educational leader explained that although he knew what palliative care was, he did not know if palliative care existed in the national health policy:

*... we [doctors] wish to have palliative care policy ... [However] I have never heard a palliative care policy from our government ... So, for me, I do not think there is a clear, functional palliative care policy in practice right now ...*

(Participant CSH2)

The nurses working in the wards of the Comprehensive Specialised Hospital were unfamiliar with a palliative care policy and indicated there were no policy plan which included palliative care in their ward. They further elaborated that the consequences of not having a palliative care policy meant that those patients in need of palliative care, went unaided. They believed

that, when appropriate policy was made available, health professionals would be able to implement the service:

*... no policy plan came to our ward. There is nothing indicates to provide the palliative care service ... when we get such chronic cases, we need to help them, but we do not have policy that indicates ... palliative care, we send them, [the patient] to their home. We did not help them ... if the government provide emphasis on it [palliative care], nothing is impossible ...*

(Participant CTHWNH3)

Awareness of the national health policies and guidelines on palliative care does not appear to have filtered down to those nurses working at the ward level of the Comprehensive Specialised Hospital, nor to educational leaders in educational institutes.

When participants were asked to describe what documents were available in their settings, some indicated that they had access to the National Palliative Care Guideline and related documents, saying they knew where to access them. However, others had no awareness about such documents.

The Regional Health Bureau participant explained the inclusion of palliative care in the NCCP and the HSTP documents:

*... as a starting point, we start something, for the next two to three years, 50% of health care facility will start working on palliative care is our initial point which is included as a direction in the guideline ... palliative care included in the five years [health service transformation] plan ...*

(Participant CRHBR)

In addition, the National Palliative Care Guideline and related documents were only described as available by the Regional Health Bureau and the Comprehensive Specialised Hospital leadership participants. The medical and nurse leaders described how the palliative care guideline was only available to hospital leaders in soft copy form, indicating that it had not been distributed to other staff:

*... we had the materials like a guideline. All the materials, the guideline is available with the palliative care committee ... I have softcopy to use for myself the palliative care guideline ... we did not distribute palliative care guideline to the wards in a hard copy form ...*

(Participant CTHND).

The three educational leader participants stated that the pain management guideline was available in their school, indicating that they had the opportunity for free internet access that allowed them to download them:

*... I do have pain management guideline but not palliative care ... the palliative care document can be found from the internet ... In the internet or with the in-service coordinator there may be palliative care guideline.*

(Participant CSH1).

However, the educational college participant and the Comprehensive Specialised Hospital clinical ward leaders were unaware of the availability of pain management or palliative care guidelines:

*... we do not know about the documents [palliative care] ... we do not have updated documents in this institute. So, the alternative we have is, searching in the internet [internet access from the town] ... if there is national guideline, we must know that, but this is the problem.*

(Participant CRCR).

These responses suggest palliative care documents are available with a few leaders but have not been widely distributed to the professionals working at ward level of the Comprehensive Specialised Hospital.

### **Palliative care education**

In this theme, participants talked about where palliative care education was provided and to whom the education was delivered. They also explained how professionals and the community understood and perceived palliative care. Participants further elaborated on the inclusion of palliative care in the health care curricula and how the lecturers provided emphasis on palliative care in the learning processes. They also responded to questions about education of the wider population using mass media. This theme consists of four sub-themes: *palliative care integration into curricula; professional and community awareness and perceptions of palliative care; and using mass media to promote palliative care.*

### *Palliative care integration into curricula*

The Context participants described how and where palliative care was included in health professionals' curricula. They also elaborated how the lecturers focused on teaching and evaluating students, and the focus provided by doctors on these topics in seminars. The challenges to, and opportunities for, the inclusion of palliative care in curricula were also described.

Context participants working at the university said that palliative care was not included in the undergraduate Nursing, Medicine, and Pharmacy curricula. For example:

*... in undergraduate program there is no palliative care as a specific Chapter or topic ... Palliative care is not specifically integrated in the curriculum.*

(Participant CSH1).

In addition, a Comprehensive Specialised Hospital medical leader explained that the curriculum was nationally standardised across Ethiopia, indicating that inclusion of palliative care content was not a mandatory requirement:

*... the curriculum is revised nationally every 5 years and ten years ... There are professionals who believe to integrate [palliative] in medicine curriculum. We [school of medicine doctors] have no power to do that [the integration] ... it [integration of palliative care to the curriculum] ... should be done national ... There are also some initiatives. But not yet harmonised until now ...*

(Participant CTHD).

However, the medical and nursing educational leaders described palliative care as being incorporated in some postgraduate specialties such as the Masters of Adult Health Nursing and a speciality in surgery:

*For postgraduate, for surgery, there may be [palliative care], but I do not think it is adequate ... Palliative care is not only doing surgery or giving medicine ... you may find palliative care as a chapter, in Western textbooks.*

(Participant CSH2).

Palliative care was part of the diploma curricula in the regional health college where nurses and primary health providers were trained. Palliative care was part of the Diploma of Nursing and Midwifery curricula and the lecturers were teaching about palliative care:



*We are teaching students here [in the regional health college] to nurses and midwifery about how to provide care for chronic disease patients starting from hospital admission up to post-mortem care ... palliative care is included to the curriculum.*

(Participant CRCR).

Participants described the challenges in teaching palliative care at the university and regional health colleges. They clarified that teaching and evaluating students about palliative care depended on individual staff members' level of interest. Some lecturers provided focus and evaluated the students, and some did not, with one educational leader explaining that providing emphasis on teaching students about palliative care was an individual choice:

*... I am surgeon, I treat patients, I teach about palliative care, but it is not a systematised or organised way ... Individually, we are providing our compassion care to dying patients, ... I am going to decide whether to teach palliative or not, it is individual decision ... in seminars we do not give such attention palliative care in general. Even in exams ... palliative care has never been [on] our agenda.*

(Participant CSH2).

In addition to a lack of personal motivation to teaching palliative care, lecturers may not have had the knowledge. Because the regional health college lecturers had no updated formal information about palliative care, they had been trying to teach nurses and midwives by searching for palliative care information on the internet:

*...the instructor may not teach them with the experienced knowledge we are reading and searching what palliative care and details.*

(Participant CRCR).

The lecturers acknowledged that whilst students were taught about palliative care, it was often difficult for them to implement their theoretical knowledge in clinical practice settings:

*... when students had clinical placement in the hospital, they have no power to provide awareness with their topic of interest [for example palliative care], they are following the institute program [hospital or health care settings] ... professional and the industry students are unbalanced [have less power] ... because the staff did not know palliative care*

(Participant CRCR).

This participant suggested that awareness and attitude of professionals, communities, and the administrative staff about palliative care required attention.

Some participants described the opportunities to enhance awareness about palliative care. The NGO representative thought that there were unemployed or retired nurses who could provide palliative care, and that the universities and colleges in the region had the ability to provide training for health care professionals:

*... we have universities, colleges ... [in the region] that can [provide] training ... we have a lot of nurses who did not get the opportunity to be employed ... we need to train these nurses ... we can recruit them in palliative care service ... Even the retired nurses are not a simple thing, we can use them, they can be a mentor ...*

(Participant CNGOR)

Thus, despite palliative care being integrated into the diploma curriculum of nurses and some postgraduate specialists of medicine and nursing, there were challenges in translating the theory they had learned into practice in clinical health care settings. Providing attention to teaching and evaluating students' knowledge about palliative care also depended on individual lecturer's interest and thus inconsistent.

#### *Professionals' and community awareness and perceptions of palliative care*

Participants clarified how they thought professionals and the community understood palliative care and highlighted their attitudes towards palliative care.

Some participants said that the nurses working in hospitals and Primary Health Care Units lacked awareness about palliative care. This lack of awareness among registered nurses may result in students who have some knowledge about palliative care being unable to put their theoretical knowledge into practice in these health settings. For example, a lecturer in the regional health college claimed that the nurses working in the hospitals had no information about the term 'palliative care'. The health education provided by the hospital staff to the community only focused on communicable diseases:

*Palliative care has no focus by the way even in the Health Centre or hospital ... if you say palliative the nurses may ask you back what is palliative?... So, there is lack of awareness in nurses ... nothing is applicable in the hospitals so there is unmatched there. So, if I teach my student and I send to the hospital, ... the nurses did not know about it ... Even they [nurses] did not accept as palliative care is part of the*

*profession ... the health education [in Hospitals and Health Centre] is about these communicable diseases ...*

(Participant CRCR).

Additionally, the NGO representative described that although there was a palliative care department in the Regional Health Bureau, the staff working in this department may not understand the meaning of the term ‘palliative care’:

*... there is a focal person for rehabilitation and palliative care ... But even for those focal persons palliative care is not clear.*

(Participant CNGOR)

Not only nurses, but also doctors were described as having low palliative care awareness in the Comprehensive Specialised Hospital, with the medical leader describing a general lack of awareness among health care professionals:

*... even now the main challenge is awareness starting from the doctors, they only focused on the pathology and treatment ... the professionals have lack of awareness in the whole palliation, psychosocial and spiritual care. If we have awareness, we can own it and they [professionals] can start to work on it. So, awareness is the problem...*

(Participant CTHD).

Some participants described the reason why professionals have low awareness of palliative care; the doctor working in the Comprehensive Specialised Hospital suggesting that poor teaching methods were responsible:

*... the way we use to enhance awareness ... I need to say we have to be out of the traditional meeting kind of training [lectures] ... the training should not be given by compiling all the trainees together like a meeting, we have to use in different direction kind of training [training with clinical placement] ...*

(Participant CTHD).

The training strategy should include some clinically-oriented ways of teaching, rather than just lectures. In addition, the nurses working in the Comprehensive Specialised Hospital’s clinical wards suggested to include follow-up and sharing of their experiences after the training:

*... training alone is meaningless. So, what I recommend is after they trained ... they have to start practically activity ... Even after they [the trained professionals] came from the training, they have to guide and share their experience [to] their colleagues ... The other thing is before the training, it is better to prepare all the necessary materials then the trained staff will directly start to implement ... there should be follow-up ...*

(Participant CTHWNH2)

Palliative care awareness was not only perceived as low among health care professionals, but also in the community. The Comprehensive Specialised Hospital's education leader of medicine and the clinical nurse leader both said that professionals had a low awareness of palliative care, let alone the community:

*... I guess it [palliative care] is not available in the community. Let alone to the community, palliative care awareness is not available in the professionals. Even the name palliative care by itself is new for the professionals ...*

(Participant CTHWNH2).

The Regional Health Bureau representative expressed a similar opinion, with the following participant emphasising the low awareness of palliative care in both communities and the professionals working in rural areas:

*What we call it in English 'health literacy'. The health literacy of the community toward palliative care is too low. Let alone the community erm the farmer erm we have up to 70-75% of our community are living in rural area, the educated community [diploma nurses] even did not know and understand about the palliative care ...*

(Participant CRHBR)

This participant explained that the health professionals provided an emphasis on health education of preventable diseases, but not palliative care:

*... being a poor country, we provide health education to the community to prevent those preventable disease by the community, themselves ... Considering all this, the community by themselves helps to enhance their health, our principle is, we can reduce 70-80% of the diseases through health education of the community ...*

(Participant CRHBR)

So, there was a lack of palliative care awareness described among both health care professionals and community in the region.

In addition to awareness, some participants suggested that professionals and the community should have a more positive attitude towards palliative care, clarifying how community awareness and attitudes affected health care professionals' attitudes. For example, the Comprehensive Specialised Hospital medical leader and the NGO representative said that professional attitudes towards palliative care are more likely to change if the community awareness of, and attitude towards, palliative care is enhanced:

*... the main problem is to leave from the previous way of working. Though it is good or bad ... If we have not had a good attitude in washing our hand outside [at home or out of hospital], we cannot change, when we came to the hospital. So, I believe it is not only the hospital work. In general, the country ... Most of the time they [the community] are resistant ...*

(Participant CTHD).

Some participants explained how professionals felt when their patients deteriorated. The Comprehensive Specialised Hospital clinical nurse leader and the NGO representative elaborated that when professionals focus on patients' helplessness and sadness, they are less likely to act in a helpful way:

*... when you see the patient in the beginning ... and their progress. We have our own [professionals] satisfaction and when we get a recurrent, you feel distress psychologically affected ... when they become end stage, you [the professional] feel sad ... when you see severe pain patients and if you are not doing anything it has its own psychological problem ...*

(Participant CTHWNH1).

In addition, an education leader of medicine suggested that the professionals should start thinking about how to provide care for those in need of palliative care, promoting more positive thinking on how to provide care for dying:

*... we need to think of those people who are dying with cancer and then like. We have to start when we start thinking about them carrying about them, then when we try to increase the standard of care this agenda will come ...*

(Participant CSH2).

The Comprehensive Specialised Hospital nurse leader said that care is changing for patients with cancer, being less likely to be resigned to dying. They were said to be viewing options for treatment more positively and following their chemotherapy regimens. Palliative care awareness though was viewed differently – suggesting this depended on the determinants of health literacy like employment and education:

*... there is a change in ... attitude ... [towards] palliative ... For example, ... Previously, if the patient diagnoses with cancer, they become hopeless and they prefer to go to holy water and others... So, when we see the patient follow-up, chemotherapy compliance ... it is increasing from time to time ... However, palliative care awareness exactly in the community, it depends working level, education level...*

(Participant CTHND).

Similarly, another nurse leader of a Comprehensive Specialised Hospital ward explained that the community, especially those who have more educational background, were asking questions about their diagnosis, with the participant describing how the professionals manage patient and family questions about cancer:

*... most of the patients and their family especially those who are educated asked questions about their diagnosis. But when we treat cancer, it is for three things. One for curative, second to stay in its place, and the third one is to relive from pain and other symptoms. That is how we explain, and we tell their stage of the disease...*

(Participant CTHWNH1).

However, doctors were challenged when talking with the patient about their diagnosis. For example, a Comprehensive Specialised Hospital doctor elaborated that they were in a dilemma about whether to tell the truth when a patient was diagnosed with chronic incurable disease. This participant believed that telling the truth may depend on the doctor's attitude, with some doctors discussing the patient's diagnosis with the family, and others not. Despite this, he suggested there was improvement in telling the real diagnosis:

*... in here [Ethiopia], most of the patients are dependent on someone [their relatives]. So, permission is mandatory. Not only in palliative, in any kind of treatment, we involved family. There are individuals [doctors] who can tell the truth ... For instance, for aged people when they know their disease is cancer, they may consider as a big punishment from God ... Telling the truth is personal ... But from the previous, now is better...*

(Participant CTHD).

Another doctor also believed that there were challenges in telling the real diagnosis to the patient and family, elaborating that professionals were not telling and disclosing information to the community:

*... we cannot communicate our society, study has not been done, I am just assuming based on my years of experience, but there is a problem of disclosing their diagnosis. For example, the number of months survive we do not tell, we do not tell the possible options of treatment...*

(Participant CSH2).

However, the Comprehensive Specialised Hospital nurse leader explained that the nurses and doctors were telling the truth after discussions with the family. This participant explained the challenge they faced when the professional sought to tell the truth, to inform patient and family of the right diagnosis:

*... we are talking with the attendants or family care givers about the patient case, so the family said please do not tell this for our patient like this. However, sometimes the patients ... want to know their case... So, we may tell them [the patient] ... during [the clinical] round... Both, the doctor and nurse ... tell the truth together... Some of the patients accept the truth and some of them may not. It depends on individuals...*

(Participant CTHWNH3).

The doctor participant and the nurses working in the Comprehensive Specialised Hospital further clarified the strategy of how the professionals communicated to the patient and family without telling the truth of their diagnosis; that telling in a strategic way helped the patients not to invest unnecessary money and resources:

*... We just tell them [the patients] you have a disease without, specifying what it is, and take this medicine. Then they [the patients] provide a trust to us to take the medications ... we told them [the patient and the family] not to go to another place because it has an economic factor [not to go to hospital because care is costly]. So, we informed them [the patient and the family], this is the last treatment ... So, ... we told [the patient and the family] this is beyond our capacity [beyond the doctor's capacity to treat in the hospital] ... and discharge them to their home...*

(Participant CTHD).



However, another participant indicated that though some patients knew the real diagnosis and prognosis, the family wanted further advice and transferred them from one hospital to other. This participant elaborated that the community had low levels of palliative care awareness:

*... beyond the referral, the patients and their families invest unnecessary money displacing their family, wastage of time, money, for not getting the curative service, ... Even though [the family] are treated and know the truth, because of the community have not a strong palliative care awareness, again... there are some occasions that family took the patient to different local hospitals...*

(Participant CRHBR)

Indications from participants in the Context suggest that professional and community attitudes towards chemotherapy are changing. However, the level of palliative care awareness among the community depended on the health literacy of the patients and the family members. For this reason, the doctors had a challenge to communicate about the real diagnosis with the patient and family members.

#### *Using mass media to promote palliative care.*

In Ethiopia, mass media is used to promote health-related issues to educate the community. Radio is used in rural areas and television for people living in urban areas to inform the community about communicable diseases. Participants were asked about the promotion of palliative care using mass media, in order to determine the challenges, as well as how well they considered it had been used to promote palliative care.

Palliative care was described as an unattractive topic to discuss in media like television and radio. Nevertheless, it was also acknowledged that it was still an important topic to discuss as the following educational leader of medicine illustrates:

*... no, when I have media interview, I do about my procedures and diseases, it is not fun topic to discuss about dying patient ... or terminally ill patient. We do not discuss that, but I think it is a very good topic to discuss because in every household, there are people with cancer patient they need palliative care. Taking about palliative care will help lots of people, I think ...*

(Participant CSH2).

The Comprehensive Specialised Hospital nurse leader described how the community sought information despite little media coverage about palliative care:

*...our media are not working in palliative care. So, we cannot say there is awareness in media, but the information is given in different ways that is why the follow-up increased ...*

(Participant CTHND).

The medical leader clarified why palliative care was not promoted using mass media, confirming that palliative care was not in the media because such services were not available in the Comprehensive Specialised Hospital:

*... we did not provide awareness using media for the community. One of the means to provide [palliative care] awareness is media. We believe this and other different things were not strongly implemented ...*

(Participant CTHD)

Without having a palliative care clinic, providing awareness of palliative care was not viewed as helpful, because there was little to offer people:

*... it is easy to advertise. We can advertise with radio do this and do not do that. It is one thing to understand the disease being in their place. But, to come here [Comprehensive Specialised Hospital] and get the service, we need a palliative care clinic ... We have a very crowded place in our hospital...*

(Participant CTHD)

Palliative care was not promoted using mass media in the region, despite some viewing it as an important aspect to discuss; without practical palliative care services in the hospitals, participants felt there was little value in publicity about palliative care.

### **Palliative care implementation**

The third theme describes the current status of palliative care service delivery in the region. Participants described what care is available, including the use of morphine for pain management. They also clarified the available resources and challenges in implementing palliative care. These sub-themes are: *pain management, providing care, resource related opportunities and challenges.*

#### **Pain management**

This sub-theme described how health professionals managed the severe pain of patients diagnosed with incurable disease. The Comprehensive Specialised Hospital participants

described their initiatives to treat pain, including prescribed medication and clarifying the challenges and enablers of using morphine as an analgesic in their settings. As described in Chapter One, palliative care and pain management training were given to physicians, nurses, and pharmacists. To identify how in-service training influenced the participants in their practice, participants were asked to explain the focus of their training and how it then impacted their practice. They also reflected on where the training was provided, which professions were trained, and the outcomes of training.

Participants working in the Comprehensive Specialised Hospital indicated how some professionals were dismissive of complaints from patients about pain. For example, a Comprehensive Specialised Hospital pharmacist perceived that pain was not only ignored in the Comprehensive Specialised Hospital, but there was also a cultural taboo that suggested that patients ought not complain about pain. This participant explained that health professionals had this cultural attitude and so discouraged patients who wanted to talk about their pain:

*... I am clinical pharmacist ... I had round with senior physicians. If the patient suffering with pain, being senior, they told him “your ancestors passed lots of war, why you complain with this simple pain” ...*

(Participant CTHP).

This type of response to a patient’s pain was considered to demotivate patients from expressing their feelings of pain in the hospital.

Participants described how the cultural values and proverbs of the community affected the patients in not complaining about pain. They also explained how some community members neglected pain and did not consider treatment requiring a need to go to health care settings. For example, the pharmacist further explained how some community members used cultural proverbs that influenced individuals not to go to the hospital for pain treatment because ‘strong’ people tolerate pain:

*... if someone is suffering with pain, they [people in the community] call it, “Is not you are hero”? [suggesting to the person tolerate their pain] kind of other things...*

(Participant CTHP).

Similarly, the NGO representative confirmed the cultural barriers and proverbs that affected the community, so individuals were discouraged from discussing their pain:

*... pain is ignored in our country ... If you ask, have you had pain, they will reply it is being aged. [a part of aging] the community attitude towards pain is poor, they think that it is difficult to live without pain. They discourage for those who explained about their pain. In men's ... Do you think a man can have pain? that is what they say, this are cultural barriers we have...*

(Participant CNGOR)

These community and health professional attitudes all demotivated patients to express their feelings of pain to their families or health professionals.

However, some participants described an opportunity developed to address the cultural attitudes towards pain. The Pain-Free Hospital Initiative (PFHI) was a strategy used to treat pain through hospital-based health professionals' training. Participants clarified that PFHI was launched in different Ethiopian hospitals, including the Comprehensive Specialised Hospital of the study setting. The staff of the Comprehensive Specialised Hospital used the exemplar of the Menelik hospital where PFHI was practiced in the capital city of Ethiopia, to set up their own initiative:

*... there is a government initiative ... called pain free hospitals, and this is led by Ministry of Health ... For example, in Addis Ababa, Menelik hospital is the role model and they have a good initiative. We need to take as an exemplary for that and to apply in our institution.*

(Participant CTHD)

By adopting this initiative, the Comprehensive Specialised Hospital developed pain management training and follow-up activities. Participants described how hospital-based pain-management training was delivered in four rounds to a selected nurses, pharmacists, and doctors in the Comprehensive Specialised Hospital.

*... we provided training four times ... to implement the whole WHO [World Health Organization] pain ladder ... Now, not all of them are trained ... the trainings were given consequently ... nurses, pharmacy and even physicians ... But we prioritise them ... we try to train ... at least one... from every department ...*

(Participant CTHP)

Some participants acknowledged that the palliative care training was limited to pain management and confined to the Comprehensive Specialised Hospital staff:

*... a lot of training was given in pain management, but I do not think so, to all health care facility. Pain management training was not given downward. It was given to the big hospitals [general and Comprehensive Specialised Hospital] ... we have not tried to train Health Extension Workers to give the service yet ...*

(Participant CNGOR)

In addition, the education leader of the School of Medicine described how the school is preparing for the future, to establish a palliative care department by nominating seven specialists for pain management fellowships in the Comprehensive Specialised Hospital:

*In the future [palliative care] department will be established ... once the department established, seven doctors are taking training ... [these are] ... internists ... surgeons ... they will become change agents ... [the training] focused on pain management not palliative care ... they will start working in a team form...*

(Participant CSH2).

Despite training offered to several disciplines, nurses working in the clinical wards of the Comprehensive Specialised Hospital indicated that neither pain management nor palliative care training was delivered to hospital staff:

*... nurses were not trained in palliative care. So, when we came to the training, we have no training at all ... There are a lot of training here [Comprehensive Specialised Hospital], but the trainees were given to primary health care. So here [Comprehensive Specialised Hospital] the training rate is very poor. It is better to say none.*

(Participant CTHWNH3)

For this reason, not all the hospital staff were trained in pain management. In addition, although training was given to some health professionals, these staff left the hospital without an opportunity to implement their knowledge, because once they graduated, they moved on to other settings:

*... all the doctors are not trained especially the resident [postgraduate] and intern [graduate], there is high turnover staff especially in doctors, as a teaching hospital, that is a major challenge. Because ... they will graduate and going [leave the hospital]*

(Participant CTHND)

In addition to the issue of trained staff leaving before using or sharing their knowledge, staff struggled to find health care resources to incorporate the theory they had learned in the training, into their practice:

*... before six months, nurses were trained in our ward ... The trained professional was not putting their knowledge into practice ... [because], the trained professionals lack materials to implement the service Then after the trained staff change their ward because of [hospital staff] rotation.*

(Participant CTHWNH2)

The sustainability and continuity of the training and follow-up was described as a further issue:

*... now palliative care is not included from the components of in-service training ... Either formally through training or informally the professionals have the information ... previously ... there was a few trainings available ... recently no training was given.*

(Participant CTHND).

For example, participants described that in 2017, pain management training supported by the Centres for Disease Control and Prevention (CDC) had been given to different disciplines from the region, but in the subsequent year (2018), pain management training was not in the calendar of in-service training in the hospital:

*... pain management trainings were given to the hospital's staffs, nurses and academic staff. This in-service training program [was] coordinated by CDC ... palliative care is one of the listed in the program ... But this year, I do not know, there is no palliative care training given it is not [even] listed ...*

(Participant CSH1)

The participants indicated that training should continue, with regular follow-up in the clinical health care settings.

One participant referred to their Comprehensive Specialised Hospital quality care committee which had conducted a survey to assess the training outcomes. They found that there was some improvement in pain management in clinical practice, following this initiative:

*... in our hospital we have a quality care committee, they provide a survey to assess the level of pain management ... those quality officer including from our profession,*

*first they are making baseline assessment ... in the pilot area ... they conducted a survey to describe the status of pain management ... the pain satisfactions [of the patient] is improved ...*

(Participant CTHND).

For example, the pharmacist and the medical leader of the Comprehensive Specialised Hospital described that before their training, morphine had expired before being used, mostly because there was a fear of the side effects; and there was a general lack of information about its availability in the hospital (lack of communication between the pharmacy and the prescribers). Following the pain management training, the doctors described being more confident in prescribing morphine:

*... the Federal staff started to provide palliative care training ... the previous problems of morphine were clearly stated in pain management training. So, we can say this all is strongly improved.*

(Participant CTHD)

Despite morphine availability for prescription, concern was expressed that not all doctors were prescribing:

*... a lot of doctors are prescribing morphine ... So, it is improving... every year, there is a change ... it is better than the previous ...[however] until now, there are doctors who did not know the availability of it [morphine] ... Even though it is available, the doctors fear to prescribe...*

(Participant CTHD)

Participants clarified that there are doctors who fear prescribing morphine because they perceived it had respiratory suppression side-effects:

*... when we provide training, I was one of the trainers, the doctors requested naloxone antidote to prescribe morphine. The doctors' believed that ... morphine has a side effect on respiratory distress ... a senior specialist when they heard morphine, they say no, simply ... it should not be prescribed...*

(Participant CTHP)



Participants were asked why, when morphine was available, it was only available in hospitals. The Regional Health Bureau indicated that the Ethiopian standard only allowed morphine availability in hospitals where there are doctors who can prescribe the medication:

*... it [morphine] can avail in the hospitals, Primary Hospitals and above. We have doctors in Primary Hospitals. We have seen it [morphine] in the General Hospitals and Comprehensive Specialised Hospital ... GP [General Practitioner] can only prescribe/ order morphine and other opioids.*

(Participant CRHBR)

In addition, final year medicine students were also described by a clinical nurse as being able to prescribe morphine:

*... interns [final year graduation class of medicine students], General Practitioner and above can prescribe morphine. So, starting from the interns, General Practitioner and senior can prescribe it...*

(Participant CTHWNH3)

Due to the above limitations, not all doctors working in the Comprehensive Specialised Hospital setting were utilising morphine for the relief of patient pain.

There was a difference of opinion between the doctors and clinical nurses working in the Comprehensive Specialised Hospital regarding the prescription of morphine for patients at home. The doctors described how, when a patient is discharged from the hospital, they are provided with morphine prescriptions to last for a number of months:

*...we prescribe morphine when the patient discharged to their home, all of us [doctors] provide the tablet or suspension of morphine for three months ...*

(Participant CTHD)

In addition, the nurse working in the oncology unit described how morphine syrup was prescribed to those patients who had severe pain when they were discharged from the hospital. This participant also clarified that morphine was prescribed for the patients' home in the Out-Patient Department:

*In our setup we are giving to the patients who had severe pain in a syrup form. Even in OPD they give them morphine to [home]. We also give them. Those who have severe pain we inform them how to take the medicines [at home].*

(Participant CTHWNH1)

However, a nurse working in a surgical ward of the Comprehensive Specialised Hospital explained that their patients were given other, milder analgesic medications to take home:

*... now, morphine is not as such familiar, we did not prescribe to their [the patient] home ... When they [the patient] discharged from here [in a ward] still now the patient took tramadol, paracetamol, and diclofenac to their home ...*

(Participant CTHWNH3)

Although doctors working in some units of the Comprehensive Specialised Hospital prescribed morphine to patients for when they were at home, this was not a universal practice.

There were doctors who thought that morphine was the safest and cheapest drug for severe pain. These participants also justified the importance of morphine for dying patients despite potential side-effects:

*... morphine does not have addiction the one that addict is pethidine. A person who is dying with three months or four months if becomes addicted, what is the problem? So, I think it will be justifiable a person to give whatever kind of addicting the drugs...*

(Participant CSH2).

Morphine was described by some participants as not only safe, but also one of the cheapest drugs in the region. For example, the pharmacist and the senior doctor from the Comprehensive Specialised Hospital reported that morphine was affordable by the community in the region:

*... it [morphine] is not expensive. Even it is cheap ... We do not have a problem in our case to afford these medications. Even the patient has no problem to afford this...*

(Participant CTHP)

However, participants from inside and outside the hospital disagreed, saying that for members of the community, morphine was expensive compared to the average daily expenses of individuals. This participant also said that while morphine was available in hospitals, and in some commercial pharmacies, there are general challenges in morphine availability:

*... the price again it [morphine] is expensive compare to people income, so I would not say morphine are available ... in the cities, there are certain private pharmacies who*

*bring morphine ... by one way the other, but we do not have a continuous supply of morphine in the hospital.*

(Participant CSH2)

This was supported by a nurse in Comprehensive Specialised Hospital who stated:

*... availability of medication right now, it is almost none. Most of the medicines are not available ... Even most of the time, they [the family] bought for one ampoule morphine in an expensive money from private pharmacy 300 Ethiopian Birr...*

(Participant CTHWNH3)

For those who cannot afford medications, some participants suggested there was a health insurance initiative that might help to solve the financial burden:

*... it [morphine] does not have more problem with affordability. Especially if the patients come with the health insurance, we can address the affordability problem in hospitals using that, it is not as such difficult ...*

(Participant CRHBR)

Despite these challenges, participants reported that while morphine was prescribed in the Comprehensive Specialised Hospital, however re-prescription in the community, where there were fewer doctors was not possible. The Ethiopian standard does not allowed nurses, or assistant physicians to prescribe morphine outside hospital settings:

*... morphine is not allowed to prescribe in Health Centres because doctors are not there, when we go downward ... We only have a health officers [clinical officers] which mean an assistant of physician.*

(Participant CRHBR)

Even though nursing regulations allowed them to prescribe pain medication to relieve mild to moderate pain, nurses in the Comprehensive Specialised Hospital were reluctant to prescribe. For example, the nurse director from the Comprehensive Specialised Hospital indicated that nurses could prescribe Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) but not opioids:

*... the policy did not have a restriction to order pain medication except opioids. The nurse should not wait until the doctor comes if the patient was suffering with pain. Erm ... we have a wrong perception that every medication should be order by the*

*doctors. Even we have been asked in the high level, they said the nurse can prescribe particularly for mild and moderate pain ...*

(Participant CTHND).

Despite acknowledging that patients suffer with pain while waiting for the doctor, nurses remained reluctant to prescribe pain medication. For those patients who had prescribed orders, nurses administered the prescribed medication, including morphine in the Comprehensive Specialised Hospital, based on the doctors' order:

*... when we administer medicines, we are administered based on the doctor ordered. When they [the doctors] ordered, like anti-pain [morphine] IM or such kind ...*

(Participant CTHWNH2).

They clarified that they administered morphine although they had not undertaken pain management training:

*... we just simply administer morphine; the nurses administer without training ... The syrup and tablet, the patient can take it easily. But we inform the nurses to administer morphine slowly through the IV [Intravenous] line ...*

(Participant CTHWNH3)

One nurse participant expressed concern that it was important to have updated information through training on how to administer morphine. This participant elaborated that there was value in having a clinical pharmacist in the hospital ward who assisted nurses in administering the drug.

*... it [training] how to administer morphine is necessary, but when you work cooperatively, we have clinical pharmacy with us, they guide the nurses, when the nurses need help, if we administer the medicine in this way, the patients can be beneficial. We are working in a team ...*

(Participant CTHWNH2).

However, when morphine was not available in the pharmacy, the nurses discussed with the doctors' alternative available pain medications such as tramadol before they administered any medication:

*... when we had patients with severe pain ... we administered tramadol because it is better available than morphine based on the doctors ordered ... We are selecting the*

*terminally ill patients who have severe pain, so we are trying to provide morphine for them ...*

(Participant CTHWNH1)

Nurses followed prescriptions for analgesics and advocated for pain management when prescribed medications were unavailable.

The Pharmaceutical Fund and Supply Agency (PFSA) is a governmental pharmaceutical agency that distributes medications to all health sectors of the region. The participants explained that the national PFSA recommended pharmacy ordering requirements, that the Comprehensive Specialised Hospital pharmacist should purchase medications every quarter; however, the pharmacist elaborated that morphine was not consistently available from the PFSA. For example, when the pharmacist requested 100 boxes of morphine from PFSA, the pharmacist may receive a small proportion of that; an insufficient quantity for the quarter. Due to this, the pharmacist requested morphine from PFSA more frequently than recommended in the hope of obtaining more:

*... as a policy we need to buy medications quarterly ... But the situation did not invite you to do that. Not every quarter, we bought every day ... because when you ask quarter medication from [our main source] PFSA [Pharmaceutical Fund and Supply Agency] there are a situation they gave you for four days or four weeks ...*

(Participant CTHP)

Morphine is included in the Essential List of Medicines of the Comprehensive Specialised Hospital, but is inconsistently available in the pharmacy. The pharmacist confirmed that morphine supplies were inadequate:

*... we have essential list of medicines. It is published in a book form ... We need to avail morphine in all forms injectable, tablet and syrup. Now we are trying to avail both ... injectable and tablet ... But morphine syrup is not completely available ... Especially with paediatric antidote.*

(Participant CTHP).

Despite the Ethiopian pharmaceutical industry being capable of manufacturing morphine syrup, currently there is a lack of foreign currency required to support the importation of the morphine ingredients:

*...we had our own domestic fabric [morphine manufacturing plant] in Addis Ababa, but the ingredients are coming from the abroad countries/ imported ... because of the hard currency increases ... they could not find morphine ingredient ...*

(Participant CTHP).

Therefore, the lack of morphine was not only the challenge of a Comprehensive Specialised Hospital; there were quantities insufficiently available all over the country. Participants also clarified the difficulty in dividing morphine in tablet form into the prescribed milligrams as an additional challenge. For example, in one case, the morphine tablet was formulated in 30 mg and the doctor had prescribed 5 mg. The Comprehensive Specialised Hospital pharmacist described how the patients had struggled to break morphine into the required dose or to take many tablets up to the required dose:

*... morphine prescribed in a 5mg, but we provide the patient 30 mg [available 30 mg tablets]. Now, when the patient divide [the tablet], it is not in a scientific way ... For example, erm if the patient wants to split in to four ... The patients may split into ten. The patient may divide it [morphine] into 7mg ... We could not find a medication starting with 5 mg up to now ... Being 30 mg, it makes us a difficult ...*

(Participant CTHP).

So, despite the fact that some morphine was available in the hospital pharmacy store in the form of a tablet, the provision of specific accurate formulations for smaller doses was not available.

### *Providing care*

In this sub-theme, participants described how the professionals viewed the status of palliative care implementation in their settings. They acknowledged the care given to chronically ill patients in the Comprehensive Specialised Hospital and charity organisations. Participants recognised that physical care, pain management and psychosocial supports were provided in the Comprehensive Specialised Hospital. Some participants also described the care given at home, including the volunteer services provided by charitable organisations. They also described the challenges and opportunities related to providing palliative care at home and in the Comprehensive Specialised Hospital. When participants discussed the provision of palliative care, they were careful to indicate that it was only available to a particular group of patients, clarifying that the palliative care initiative introduced to the region was confined to the care given for patients with HIV, describing how and why palliative care was provided,

both in their home and the Comprehensive Specialised Hospital. For example:

*... palliative care initiatives were started in HIV as a major program. Even as a term, palliative care becomes familiar with HIV ... To relieve the severe pain in this case, palliative care was given as an independent service. Especially, in those health sectors that only give HIV service...*

(Participant CRHBR)

Participants suggested that the palliative care focus being solely on HIV patients was because the NGOs provided economic support for this care and treatment:

*There are many projects working in that area [HIV care and treatment]. There are also professionals recruited to provide the care ... because in HIV... there is NGO such as CDC and others that provide financial support ... That is why, professionals provide emphasis in palliative care [HIV] ...*

(Participant CTHND).

Despite participants describing palliative care being delivered for HIV patients, some working in Comprehensive Specialised Hospital argued that palliative care was not delivered in the ward, nor was information offered to patients diagnosed with other incurable illnesses. This participant explained how health professionals provided information when patients were diagnosed with incurable illness and their family asked about care options:

*... in the governmental hospitals, nothing is done [palliative care service]. When the patient and family asked where to go? The response is, we have finished, you have to go to your home and your family can look after you, that is how we replied ... the challenge we have is, when the patient [were] discharged from the hospital, they did not get palliative care advice from the doctor and other health professionals...*

(Participant CTHWNH3)

However, other participants indicated that despite palliative care not being implemented as a whole service, aspects of palliative care like physical care, pain management and psychosocial support were available to patients in the Comprehensive Specialised Hospital. For example, the medical leader of Comprehensive Specialised Hospital said that health professionals in the Comprehensive Specialised Hospital provided pain and symptom management as a priority:



*... the nurses working in oncology unit are administering cancer medicines, vomiting and pain medicines which [is] one parts of palliative care ... Most of the time we only focus on pain or pathology of the disease. We did not focus on ... psychosocial, spiritual, and other problem ...*

(Participant CTHD).

The clinical nurses' leader working in the surgical ward of the Comprehensive Specialised Hospital explained the nurses' focus on physical care, as they provided nursing care in the clinical wards:

*... starting from admission, ... we [nurses] simply give physical [care] ... otherwise we did not provide holistic kinds of palliative care ... We admit the patient and treat their case then discharge them ... The [available] care in the ward can be with feeding, bed bath, and positioning every two hours to prevent bed sore... these are our duties...*

(Participant CTHWNH3).

This participant and the clinical nurse leaders of oncology unit suggested that holistic palliative care was not provided in their settings, justifying the focus on care being treatment of their cancer:

*... we are not delivering full palliative care, just in a certain way. This is a unit [oncology]. It is not a ward ... The patient is only taking chemotherapy and leaving to their house ... we never had a ... death. We are not following to the end stage of cancer. Either the patients ... suffer with pain and other symptoms at home, or they may admit in other wards...*

(Participant CTHWNH1).

In addition to the physical care provided in the wards, some participants highlighted that nurses provided psychological support in Comprehensive Specialised Hospital wards. For example, the clinical nurse leaders of the Comprehensive Specialised Hospital said that the nurses provided counselling as a psychological support, by encouraging patients to focus on the positive aspects of the care they were receiving:

*... as a nurse ... we can only counsel the patients; we have nothing beyond that ... we provide psychological care by counselling ... We counsel them by saying at least if we relieve your pain, it is big thing...*

(Participant CTHWNH1).

However, this participant added that, currently, their ability to talk to patients and spend time explaining care and support increased their workload:

*... now, we have patients load and a few health professionals. We are not explaining them in detail ... As much as we can, at the beginning we explain what it is ...*

(Participant CTHWNH1).

Some participants described that in addition to physical care and psychological support, social and financial support was provided by social workers in the Comprehensive Specialised Hospital. For example, the nurse leader of the Comprehensive Specialised Hospital elaborated how the social workers communicated with the hospital administrative staff and charity organisations to manage family challenges:

*... social workers ... are working in solving financial problems [of the patient] ... some patients have no money to get treatment. So, they communicate with the patients, how to solve such types of problems, to provide free service in the hospital, they check ... whether the patient have [financial] problem or not. Those orphans or anyone without relatives, they connect them to the funding organisations and different associations...*

(Participant CTHND).

However, some participants seemed to be unaware of the availability of social workers in a Comprehensive Specialised Hospital. For example, a clinical nurse leader noted that they had no information about the role of social workers in the hospital. This participant clarified how the oncology staff provided some financial support to the patient and family as needed:

*... we do not have spiritual and social care ... we provide economic support for those who have difficulty to buy the medications, either we try to convince the pharmacist to get medication for free or we support them financially [from the health professional's personal resources] ...*

(Participant CTHWNH1).

Therefore, despite a lack of holistic palliative care, some participants described physical care, pain management, psychosocial and some limited ad hoc financial support being implemented for patients admitted in the Comprehensive Specialised Hospital. However, as

noted, others described the limitations of palliative care with it only being available for HIV patients.

When patients were discharged from the hospital, participants indicated that some searched for alternative options for care at home, like private care services, which are available in the region's capital. This participant described that home care was expensive and without it, there were few other options for care:

*in [name of the region] we only have one home-based-care: family clinic ... it is in [the name of the capital city] ... [name of the private clinic] ... have home-based care. It is business and unaffordable, but at least it can be a choice for those who can pay.*

(Participant CNGOR).

Some participants noted a few religious and charity organisations that provided volunteer care in the region:

*... missionaries of charity [Mother Teresa] sisters, ... have [four] centres that found in the [towns of the region] ... The other one is, one religious organisation established in the [capital city of the region]. They motivated and cooperated volunteer peoples ... I do not think it is a standard palliative care service...*

(Participant CNGOR).

The NGO representative further described the opportunities supporting home care using volunteers, explaining the cultural norms in respecting the elderly and providing social support to those with chronic illness, especially for those with no one to look after them. So, volunteer care was a supportive opportunity in the context:

*... our culture [teaches] individuals to be kind for sick, and old age peoples. We have volunteer peoples. For example, the university students are so excited to provide care because it [care] is not only delivered with the health professionals ...*

(Participant CNGOR).

Despite physical care, pain management and psychosocial and financial supports being delivered in the Comprehensive Specialised Hospital, participants said that palliative care was not integrated into the existing health system, suggesting a lack of communication between the federal and regional health staff as the main reason. For example, the pharmacist working in the Comprehensive Specialised Hospital said there was lack of networking between their hospital and the Regional Health Bureau. This participant clarified the

importance of working together in the regional health settings, in sharing their experience and managing pain:

*... our focus was not only with the pain management but ... in others too ... we do not have a communication channel with the regional health facility ... It was good if we have connection with the Regional Health Bureau. The pharmacists in Comprehensive Specialised Hospital can help in any aspect ... we can give updated information and training in pain management. We can also help them with sharing manuals ...*

(Participant CTHP).

The Comprehensive Specialised Hospital doctor further elaborated how integration was important, not only for palliative care, but also with other health care activities in the hospital. This participant also described integration as including palliative care within the existing health care system. As well, his suggestions were to work at the community level beyond the Comprehensive Specialised Hospital, not only with integrating palliative care, but working with communicable disease prevention:

*... integration is a major problem ... it [palliative care] is not only that. There is infection prevention as a major one. We are very poor ... the community ... are benefiting from infection prevention. They [the community] are not yet taking this. We cannot make a unique island in the hospital only. It should be integrated to the community ...*

(Participant CTHD)

In addition, the educational leader of the school of Medicine suggested that palliative care should not only be available in the Comprehensive Specialised Hospital, but also included in the Health Extension Workers (HEWs) activities in community Health Posts. This participant recommended starting palliative care in one of the regional hospitals:

*... we should integrate [palliative care] ... with Health Post, Health Centre, General and Primary Hospitals. It should not be limited to the referral hospital. To begin the program, we need to start [palliative care] in a big hospital ...*

(Participant CSH2)

Other participants argued that the regional health services were already connected with the Comprehensive Specialised Hospital; for example, the integrated referral service from the

hospital to the Health Post. The Regional Health Bureau representative described the network between the health care level and the standard of care in each health sector and clarified community awareness of the standard of care:

*... our referral system by itself starting from the bottom Health Post, Health Centre, Primary Hospital, General Hospital then Comprehensive Specialised Hospital has a [network] ... we have a standard in every sector ... at the bottom, it is health education. In the Health Centre, it has its own standard ... our community know about it.*

(Participant CRHBR).

Referral between the different levels of the health service settings was also described as a feature of integrated settings. Patients were referred from the Comprehensive Specialised Hospital to General Hospitals closer to home, for palliative care and close follow-up, showing communication between the federal staff in the tertiary setting and the regional health care staff:

*We back refer to the General Hospitals ... to provide follow-up there, we inform the patient, "the service you need in this hospital is done," in a written form ... please help the patient in providing palliative care service and follow-up to the hospitals but not to the Health Centres.*

(Participant CTHWNH3).

Participants described not only the referral system but also that there was a networked health care system in the region which helped reduce communicable diseases and maternal and child health deaths. For example, the Regional Health Bureau representative clarified how the health system was networked from region to community, resulting in a reduced number of patient deaths in the region. This participant further explained how this system showcased the region as an exemplar for the world, and that this could be used to include palliative care in the existing health system:

*... we have linked health system starting from the region up to the bottom 'Kebele' [district] ... Especially in relation to reduction of mother and child death, reduction of communicable disease, we have a good experience reducing death and disease that makes us famous and talking about it in the world. This experience comes from the system that we build. We can also use the system to non-communicable disease. We have a system that can address to both ...*

(Participant RHBR).

In addition, the NGO representative described a strong and networked system, even though palliative care was not included in the existing system, recommending strengthening the existing system by recruiting palliative care professionals in each health sector of the region:

*I do not think so; palliative care is integrated to the existing system ... I recommend not to have a new system. We have a golden system. It is connected end to end. We need to [strengthen] the Health Post... We can employ a nurse who can accommodate palliative care at Health Post. We should make strong the Health Post by recruiting professionals who can deliver palliative care, but a new system may not sustain ...*

(Participant CNGOR).

The Regional Health Bureau representative suggested working to integrate palliative care into the existing system, further explaining the role of Health Extension Workers (HEWs), engendering community trust by close contact with the households, and just as NCDs and mental health were integrated into the existing HEW activities, so could palliative care:

*... [in our region] in each 'Kebele' [district] ... we have Health Extension Workers ... the research conducted in ... Health Extension Workers trust, indicated that more than 80-85% are trusted worthy ... the first Health Extension Workers had 16 components now we add two programs, non-communicable diseases, and mental illness ... so, we already have the system, the thing is ... we need to integrate ... those [palliative care] guidelines into the system ...*

(Participant CRHBR).

The integration of palliative care into HEW activities was an important opportunity as there were different team members in the community that could support the Health Extension Workers' duties:

*... we also have a team community; we have Health Development Army. We have female's voluntary team, farmers, and young ... The bottom platform health system, the base is not easy. Not only this having a system ... the Health Extension Workers are acting as a family with the community because they have been working for a long time with them.*

(Participant CRHBR).

However, other participants argued that much work was required on the existing system, even suggesting a new system. For example, health initiatives sent from the federal ministry of health may not be easily applicable within the health institution which provides patient care. This participant suggested that the initiatives should come from the hospitals or Primary Health Care Units and that they should be tested and checked at that level:

*... the system should be changed ... [it] should not be established by someone ... the initiatives should come from us [the Comprehensive Specialised Hospital staff] ... There are a lot of initiatives come to our office ... Just it looks like prescription ... we copy and paste without tasting ... just simply do it, kind of work. Even we know it is beneficial, but the system differs from place to place and from the community to the community. system should be improved ...*

(Participant CTHD).

Thus, a positive perception of the opportunities to include palliative care in the existing health system were evident, especially using the region's networked system.

#### *Resource-related opportunities and challenges*

This sub-theme highlighted the participants' perceptions about the opportunities and challenges related to resources. These participants reflected their views about financial and human resources, palliative care guidelines, mobile phone technology, and a palliative care clinic that facilitated the implementation of palliative care within health settings.

Some participants clarified that resources were needed such as human resources, a separate clinic, and guidelines for palliative care. Resources needed to be available before palliative care could be implemented. For example, the Regional Health Bureau and NGO representative suggested that the implementation of palliative care required trained staff, medication, and other health care resources, which were currently not available:

*... palliative care needs ... skilled health professionals, supply, when we say supply, it can be an appropriate medicine for palliative care. It can also be an equipment to work on it, there are a lot of different things. Those kinds of equipment, not yet fulfilled...*

(Participant CRHBR).

In addition, the challenge of inadequate financial resources for the provision of palliative care was identified. Financial resources referred to the budget allocated for palliative care training,



medications, as well as implementing and establishing the palliative care department. For example, the educational leader of medicine described the financial challenges in providing training and establishing the department, suggesting that, as a poor country, there were many challenges requiring priority:

*... the barriers ... [is] ... resource ... because to trainee individuals about the importance of palliative care ... [to] establish, department [and] provide the service... we need to have money ... But the country right now is in serious financial shortage ... we are a very resource constrained country ... we have so many priorities as a country ...*

(Participant CSH2).

Despite the palliative care initiative commencing at the Comprehensive Specialised Hospital, some participants said the government had not allocated a budget for implementation. They suggested that the budget should have been included with the initiatives. For example:

*... we have limited budget, and it could not be sustainable ... When [palliative care and other] initiative come from ministry of health, there should be an integration with the ministry of finance and economic development. When you bring initiative to implement that there [would be good] to have its own budget ... we are using from the available budget ... That is why the quality is poor.*

(Participant CTHD).

Some participants also described how a shortage of funding affected the purchase of requested medications in the Comprehensive Specialised Hospital, meaning that staff had to prioritise medications:

*... there is a budget problem [to buy] the medications as you want ... we have a separated lifesaving medication. We give these medications as a priority then if we have a remaining money, we jump to the next ... First, we buy the vital medications then essential and after that we go to the non-essential ones ...*

(Participant CTHP).

In addition, participants clarified that there was a financial challenge which affected the importing medications from abroad:

*... 90% medications are imported ... no medication supply at all ... we have scarcity of hard currency ... So, having this challenge ... it is difficult to provide continuous palliative care ...*

(Participant CRHBR).

Despite there being financial challenges in the Comprehensive Specialised Hospital, some participants explained the opportunities that helped to reduce the community financial challenge, including a health insurance initiative that motivated the community to receive timely health care services. The Regional Health Bureau representative clarified how the health insurance initiative in the community helped:

*... we are starting health insurance as an opportunity ... in our region, 45% community already registered now. In this insurance, we are planning to reach into 80% in this year. So, if 80% of the community are registered, so they will not have the reason to stay in their home and say I will not go to the hospital because of money. They only pay once a year and it is 240 ETB [\$9.37 AUD] ...*

(Participant CRHBR).

Participants suggested the community should engage in health insurance for early and ongoing health care access, including palliative care.

Participants also highlighted the challenges related to having a visible presence of palliative care. Participants working in the Comprehensive Specialised Hospital elaborated on the importance of having a separate palliative care clinic and that this challenge was a disincentive to professionals in delivering palliative care in the hospital. For example:

*... there is no separate room to start palliative care up to now ... they [palliative care trained staff] did not implement it practically ...*

(Participant CTHWNH2).

In addition, the NGO representative justified why there was no palliative care clinic in their settings, explaining how a separate palliative care clinic would be supportive for the regional hospital:

*... if we open a palliative care centre for the chronic cases, it can be strong, and the hospital can get relief. It is a win-win situation ...*

(Participant CNGOR).

Other opportunities have emerged to solve the building challenges; in the regional capital, the cancer centre building was being built and may have a separate palliative care clinic:

*... we have plan. We know where the place should be, we have a construction. We are planning to make it [palliative care] there [on the big cancer centre with 300 beds].*

(Participant CTHD).

So, participants supported a separate and visible palliative care clinic to develop palliative care.

Other participants saw appropriate, skilled human resources as likely to be available in the Comprehensive Specialised Hospital. The medical doctors described the opportunity of having specialists and sub-specialities in multi-disciplines, particularly an oncologist, in providing palliative care in the hospital:

*... we have oncologist ... They are delivering a good palliation ... we have good health professionals in different disciplines ... Now the sub-speciality is also increasing ...*

(Participant CTHD).

This participant indicated there was a developing palliative care team in the Comprehensive Specialised Hospital:

*... we have a palliative care team ... we have ... three kinds of committee. One ... pain free, second the thing which emphasised in cancer, we have individuals who focused on palliative care treatment and the third one is we have individuals who start fellowship from American MD [Medical Doctor] cancer centre ...*

(Participant CTHD).

The Comprehensive Specialised Hospital nurse leader further elaborated on the team disciplines and how they were selected, describing the focus of the team members so far:

*... the palliative care team is made up of doctors from different disciplines, anaesthesia, nurse, and others ... The team developed based on the training they took ... Even though they [the committee] planning to work a lot of activity, now they particularly focused on pain and counselling service ...*

(Participant CTHND).

Other participants argued that the palliative care team was not yet developed, perceiving that a palliative care team needed to have skilled staff in different professions, and this was not well organised:

*... it [palliative care] ... teams should be established ... So, we do not have such organisation in our case ... psychologist need to be there, oncologist, surgeon, internist and some social worker and spiritual people ... we do not have ... all this team ...*

(Participant CSH2).

Mobile phones were used to communicate between the community and health professionals about the HIV patients' issues. Participants described the importance of connecting through mobile phone technology in supporting the palliative care team's work in home care with the nurse leader describing how mobile phones were used when caring for HIV patients at home:

*... this [the mobile phone] technology works only in HIV patients ... They [professionals] go to their house, even follow-up. If the patient lost, the professionals called them ...*

(Participant CTHND).

Mobile phones are also used in the oncology unit to communicate and provide follow-up for their patients. A nurse clarified the challenge for sustainability of using such technology:

*... previously ... we called the patient and asked the reason to discontinue the medication ... Even indirectly they [the family] get our phone number and they called us and asking what they can do ... But now ... because of patients' overload, it is difficult to call the patient ...*

(Participant CTHWNH1).

Other participants argued for the use of mobile phone technology in the health care system, with the Comprehensive Specialised Hospital medical leader and the Regional Health Bureau representative describing their experience in using mobile phones in maternal and child health. They said that mobile phone technology was a good idea, but not yet practically implemented, suggesting more work on palliative care before integrating this technology:

*... technology is good, we have the idea ... [theoretically] it is good to use [mobile phones] ... [however] ... it is not working in the actual practice ... We have started*

*this technology in mother and childcare. We can shift later but first we need to focus here [developing palliative care] in the region ...*

(Participant CRHBR).

So, despite some technology being available in the Comprehensive Specialised Hospital, not all professionals supported mobile phones in the health care service.

In the Context, despite a few leaders believing that palliative care was included in the national health care policies, participants working at the patient level and the educational leaders were unaware of them. Although a few leaders perceived palliative care should be a priority because of the high incidence of NCDs and ageing in the region, others argued that palliative care should not be a priority because of unmet basic needs and that health professionals provided the focus on treatable and communicable diseases. There were no palliative care guidelines in the hospital wards and educational institutes, except in the case of a few leaders of the hospital and Regional Health Bureau.

Participants indicated that the diploma qualified nurses had completed education in palliative care. However, palliative care was not included in undergraduate and postgraduate curricula of Nurses, Medicines, and Pharmacy. Some participants described that there were varying degrees of palliative care knowledge among health care professionals, administrative bodies, and community members. Lack of clinical application included in the teaching of palliative care was described as a major challenge to the provision of palliative care. Pain management training was provided to some health care professionals working in Comprehensive Specialised Hospital and educational institutes. However, trained professionals were not practising their theoretical knowledge because the training was not supported by practical activity.

In the Comprehensive Specialised Hospital pain was managed based on severity and included morphine. However, morphine was not consistently available in the hospital pharmacy because there was a lack of medication in the PFSA. The Ethiopian regulation policy only allowed doctors to prescribe morphine and despite morphine availability, all doctors were not prescribing because of perceived side effects. Other doctors believed that morphine was the cheapest and safest medication. If morphine was unavailable, sometimes they prescribed tramadol as an alternative for severe pain management. The country regulations prohibit nurses from prescribing morphine.

Palliative care implementation commenced in the region with HIV patients, because of an

NGO project, which provided financial support, for palliative care service in hospital as well as at the HIV patient's home. A charity and a religious organisation also provided volunteer care in the region. Other than this, the whole palliative care service was not implemented for other chronic diseases. Professionals working in the Comprehensive Specialised Hospital provided physical care, pain management, psychosocial support to chronically ill patients.

There were opportunities and challenges related to resources for implementing palliative care. These were the human and financial resources, communication using mobile phone technology, medications, and a palliative care clinic. In the Comprehensive Specialised Hospital, there was an opportunity for trained professionals such as nurses, doctors, specialists, and sub-specialists, as well as unemployed and retired nurses who could provide palliative care. There were also universities and colleges that helped to train these professionals. A health insurance initiative in the region was thought to assist the community members to solve their financial claims; and provide funding for pain management initiatives in the Comprehensive Specialised Hospital. In addition, there had been some attempts to integrate palliative care with the existing health care system and to use mobile phone technology in palliative care for the future. However, insufficient budgets for consistent morphine supplies, and lack of a palliative care clinic in the hospital inhibited further development.

## Chapter summary

In this Context Chapter, the results of survey and qualitative results have been presented. The demographic results described the nurses' age, gender, clinical area, nursing and palliative care experience, educational level, palliative care in undergraduate and postgraduate level, in-service palliative care training and its duration, together with the level of knowledge, attitude, and self-reported practice. The correlation among these variables and the demographic variables that had been significantly associated with the outcome variables have also been identified. In the qualitative results, the interviewees reflected on the status of palliative care policy; education; availability of morphine, and palliative care implementation in a Regional Health Bureau, a Comprehensive Specialised Hospital, and educational institutes.

Some of the survey results were supported by the qualitative findings. The results of the survey showed that nurses had inadequate knowledge and self-reported practice of palliative care. In the qualitative findings, despite there being some palliative care and pain management training provided to a few nurses, there was a lack of palliative care awareness

among nurses and other professionals working in health care settings. In addition, the training strategies were not a clinically-oriented way of teaching, affecting the nurses' capacity to practise the theoretical knowledge they had received in the training.

In the survey, the nurses who had a positive attitude had higher levels of self-reported practice. While in the qualitative results, despite the professionals having positive attitudes towards palliative care, they had not applied holistic palliative care because they lacked palliative care awareness and health care resources.

Most participants in the survey agreed erroneously that drug addiction was a major problem for long-term management of pain using morphine. However, the qualitative findings indicated that some doctors believed that morphine was the cheapest, safest, and most important medication for dying patients, despite potential side-effects.

The survey results showed that all nurses had positive attitudes towards palliative care. Most survey participants and the qualitative findings from some doctors agreed that the side effect of morphine should not be a concern for dying patients. Although some of the doctors preferred to prescribe morphine for chronically ill patients, it was not consistently available in the pharmacy store. This is because there was a lack of morphine from the main supply source (PFSA).

The qualitative results provided a valuable source of information about the in-service palliative care training and the presence of palliative care in undergraduate and postgraduate curriculum. The demographic results indicated that a majority of nurses had not received in-service palliative care training. Similarly, the qualitative findings indicated that a few professionals were trained in pain management, rather than palliative care. In addition, more than half the nurses who completed the survey indicated they had undertaken palliative care studies in undergraduate and postgraduate level; whereas, in the qualitative findings, participants indicated that palliative care was not included in undergraduate and postgraduate curricula.

In the qualitative results, despite palliative care being implemented for HIV patients in the region, holistic palliative care was not implemented for non-HIV patients, except some aspects of care in the Comprehensive Specialised Hospital. However, National Palliative Care Guideline and NCCP were developed. Palliative care was also included in the national HSTP. This plan and other policies and palliative care guidelines were only available from a few leaders of the Comprehensive Specialised Hospital and the Regional Health Bureau

representatives. Palliative care may not have been a priority for the professionals working at the patient level and in educational institutes, because they had no information about palliative care policies and guidelines.

There were challenges and opportunities related to resources for palliative care. In the region, there were some opportunities for developing palliative care related to health insurance; pain-management; universities/colleges; in-service palliative care training; and using un-employed, graduated and retired nurses. In the Comprehensive Specialised Hospital, there were additional opportunities for human resource such as nurses, doctors, and specialists who could implement palliative care. Although the professionals described positive attitudes towards palliative care, they believed there was a lack of palliative care awareness in the Context. The palliative care-trained professionals were also unable to practically implement their theoretical knowledge. This was because the training was not supported with practical clinical strategies. There was also the lack of health care materials, inadequate budget; lack of separate palliative care clinics; and lack of consistent palliative care training, to implement a quality palliative care service. The presentation of the survey, and qualitative results of Case 1 will continue in Chapter Five.



## Chapter Five: Case 1 Results

### Introduction

Like the previous results chapter on the Context, this chapter consists of two sections reporting on Case 1; the survey results and the qualitative results of Case 1. As already described in Chapter Three, Case 1 refers to participants from the General Hospital, Primary Hospital, Health Centre, and Health Post and rural community members in the 'Zone'. In Case 1, the survey participants were nurses recruited from the General and Primary Hospitals, and the Health Centre. The collected survey data were analysed using SPSS Version 25. In the qualitative phase, interviewees were recruited from the leaders of the General and Primary Hospitals, Health Centre, and Health Post. The focus group members were recruited from members of the rural community. The qualitative data analysis was supported by NVivo version 12 software.

### Survey results of Case 1

Firstly, the response rate and the socio-demographic characteristics of Case 1 are reported using tables, frequency, percentages, mean and standard deviation. Then, the nurses' level of knowledge, attitudes and self-reported practice are presented using frequency and percentages, followed by the correlation between these variables. The demographic variables that had a significant association with the outcome variables are also identified.

### Socio-demographic variables

In all, 40 surveys were distributed to nurses working in the General and Primary Hospitals, and Health Centre, and 35 (87.5 %) were completed. Statistical analyses were performed on the final 35 surveys. Of 35 nurses who completed the questionnaire, the majority (24, 68.6%) were female, and the mean age of the respondents was 34.97 years (SD=8.95; ranges, 23-57 years). More than half of the participants held a BSc degree (18, 52%), and (28, 80%) had not undertaken in-service palliative care training. The majority of nurses had not undertaken palliative care in undergraduate courses (21, 60%). (see Table 5.1).

**Table 5.1**  
**Demographic variables among nurses working in Case 1 (n=35)**

<b>Variable</b>	<b>Frequency (%)</b>
<b>Institution</b>	
General Hospital 1	25 (71.4)
Primary Hospital 1	5 (14.3)
Health Centre 1	5 (14.3)
<b>Sex</b>	
Female	24 (68.6)
Male	11 (31.4)
<b>Clinical area</b>	
Surgical ward	14 (40.0)
Medical ward	11 (31.4)
Out Patient Department, Tuberculosis clinic and emergency	6 (17.2)
Anti-Retroviral Therapy	4 (11.4)
<b>Nursing experience</b>	
1-4 years	13 (37.1)
5-9 years	7 (20.0)
10-14 years	6 (17.1)
15 and above	9 (25.7)
<b>Experience in palliative care</b>	
None	16 (45.7)
1-4 years	9 (25.8)
5-9 years	5 (14.3)
Ten years and above	5 (14.3)
<b>Educational qualification</b>	
Diploma in Nursing	17 (48.6)
BSc and above	18 (51.5)
<b>Palliative care in under and post graduate level</b>	
Yes	14 (40.0)
No	21 (60.0)
<b>In-service training in palliative care</b>	
Yes	7 (20.0)
No	28 (80.0)
<b>Duration of palliative care in-service training</b>	
Three days-two weeks	6 (85.7)
Two weeks-one month	1 (14.3)

### Nurses' knowledge about palliative care

As for the previous Context survey, the knowledge components were 14 items from the modified version of PCQN. Overall, a total of more than 40% correctly responded to the modified version of PCQN (15, 43%; range 1-30). Like the Context, 'pain and symptom management' was the lowest correctly responded category of PCQN (13, 38%; range 1-24). More than 40% of participants correctly responded to the 'philosophy and principle of

palliative care' category (15, 42%; range 6-24). The highest number of participants correctly responded to the 'psychological care' category (30, 86%). The majority of participants responded incorrectly 'yes' to item three: *The extent of the disease determines the method of pain treatment* (34, 97%); and to item two: *Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration* (23, 66%). In addition, most of the participants responded incorrectly 'yes' to the item that described: *Drug addiction as the major problem when morphine is used long-term* (24, 68.6%); and more than half responded incorrectly 'no' to item that showed: *Terminally ill patients have the right to choose 'Do not resuscitate.'* (18, 51%).

However, a majority of participants responded correctly 'no' to the item that indicated: *Provision of palliative care requires emotional detachment* (21, 60%); and correctly identified during: *The terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea* (22, 63%). Of the total participants, 12 (34.3%) scored 75% or greater for the modified version of PCQN test. (see Table 5.2).

**Table 5.2**  
**Nurses' knowledge about palliative care in Case 1 (n=35)**

No.	Items	Yes n (%)	No n (%)	Do not know n (%)
1.	Do you know about palliative care?	24 (68.6)	6 (17.1)	5 (14.3)
2.	Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration	23 (65.7)	11 (31.4)	1 (2.9)
3.	The extent of the disease determines the method of pain treatment	34 (97.1)	1(2.9)	0
4.	Adjuvant therapies (antidepressants, anticonvulsant and anti-emetics) are essential in managing pain.	16 (45.7)	13 (37.1)	6 (17.1)
5.	Drug addiction is the major problem when morphine is used on a long-term basis for the management of pain	24 (68.6)	5 (14.3)	6 (17.1)
6.	The provision of palliative care requires emotional detachment	8 (22.9)	21 (60.0)	6 (17.1)
7.	During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea	22 (62.9)	12 (34.3)	1 (2.9)
8.	The philosophy of PC is compatible with that of aggressive treatment	13 (37.1)	19 (54.3)	3 (8.6)
9.	The use of placebos is appropriate in the treatment of some types of pain	20 (57.1)	14 (40.0)	1 (2.9)
10.	Meperidine (Demerol) is not an effective analgesic in the control of chronic pain	11 (31.4)	4 (11.4)	20 (57.1)

<b>11.</b>	The accumulation of losses renders burnout inevitable for those who work in palliative care	27 (77.1)	6 (17.1)	2 (5.7)
<b>12.</b>	The manifestation of chronic pain is different from those of acute pain	24 (68.6)	11 (31.4)	0
<b>13.</b>	Terminally ill patients have the right to choose ‘Do not resuscitate.’	14 (40.0)	18 (51.4)	3 (8.6)
<b>14.</b>	Terminally ill patients should be encouraged to have a hope against all odds	30 (85.7)	5 (14.3)	0

#### Nurse’s attitudes towards palliative care

As already described in the Context results, the attitude components had 24 items from the modified version of FACTOD-B. Overall, more than 65% of participants correctly responded to the modified version of FACTOD-B (23, 67%; range 5-34). Like the Context, the lowest number of participants correctly responded was the ‘communication’ (10, 29%; range 5-21) part of the FACTOD-B. A total of 70% or greater participants correctly responded to the ‘relationship’ items (24, 70%; range 17-33); ‘fear/malaise’ (25, 71%; range 12-33); and ‘the care for the family’ items (25, 71.5%; range 20-30). ‘Family as caring’ was the highest correctly responded category of FACTOD-B (32, 91%; range 29-34) following by the ‘Active care’ category (27, 76%; range 22-31). Like the Context participants, all participants of Case 1 (100%) scored 50% or greater for the FACTOD. Most participants correctly responded (disagreed/strongly disagreed) with the item that states: *Palliative care is given only for a dying patient* (31, 89%); and the item: *As a patient nears death; the nurse should withdraw from his/her involvement with the patient* (32, 91%). The majority of participants also correctly responded (agreed/strongly agreed) to item 16: *Nursing care should extend to the family of the dying person* (30, 86%); and item four that proposes: *It is beneficial for the chronically sick person to verbalise his/her feelings* (33, 94%).

However, most participants incorrectly (agreed/strongly agreed) with item 17: *When a patient asks, “Am I dying?” I think it is best to change the subject to something cheerful* (29, 83%); and also, with item nine: *The nurse should not be the one to talk about death with the dying person* (25, 71%). (see Table 5.3).

**Table 5.3**  
**Nurses attitudes towards palliative care (n=35)**

No.	Items	SA	A	U	D	SD
1..	Palliative care is given only for a dying patient	0	1 (2.9)	3 (8.6)	26 (74.3)	5 (14.3)
2.	As a patient nears death; the nurse should withdraw from his/her involvement with the patient.	0	3 (8.6)	0	19 (54.3)	13 (37.1)
3.	Giving nursing care to the chronically sick patient is a worthwhile learning experience.	27 (77.1)	6 (17.1)	0	2 (5.7)	0
4.	It is beneficial for the chronically sick person to verbalise his/her feelings.	28 (80.0)	5 (14.3)	2 (5.7)	0	0
5.	Family members who stay close to a dying person often interfere with a professional's job with the patient.	5 (14.3)	10 (28.6)	1 (2.9)	16 (45.7)	3 (8.6)
6.	The length of time required to give nursing care to a dying person would frustrate me.	11 (31.4)	4 (11.4)	1 (2.9)	16 (45.7)	3 (8.6)
7.	Families should be concerned about helping their dying family member to make the best of his/her end of life.	27 (77.1)	6 (17.1)	0	2 (5.7)	0
8.	The family should maintain as healthy an environment as possible for their dying member.	24 (68.6)	10 (28.6)	0	1 (2.9)	0
9.	The nurse should not be the one to talk about death with the dying person	19 (54.3)	6 (17.1)	5 (14.3)	5 (14.3)	0
10.	The family should be involved in the physical care of the dying person	22 (62.9)	7 (20.0)	1 (2.9)	4 (11.4)	1 (2.9)
11.	It is difficult to form a close relationship with the dying person.	8 (22.9)	5 (14.3)	1 (2.9)	14 (40.0)	7 (20)
12.	There are times when death is welcomed by the dying person	7 (20.0)	10 (28.6)	3 (8.6)	13 (37.1)	2 (5.7)
13.	Nursing care for the patient's family should continue throughout grief and bereavement	15 (42.9)	5 (14.3)	4 (11.4)	10 (28.6)	1 (2.9)
14.	The dying person should not be allowed to make decisions about his/her physical care	7 (20.0)	3 (8.6)	3 (8.6)	14 (40.0)	8 (22.9)

15.	Addiction to pain-relieving medication should not be a concern when dealing with a dying person	23 (65.7)	4 (11.4)	5 (14.3)	3 (8.6)	0
16.	Nursing care should extend to the family of the dying person	26 (74.3)	4 (11.4)	1 (2.9)	4 (11.4)	0
17.	When a patient asks, "Am I dying?" I think it is best to change the subject to something cheerful	24 (68.6)	5 (14.3)	0	6 (17.1)	0
18.	I am afraid to become friends with chronically sick and dying patients.	3 (8.6)	1 (2.9)	3 (8.6)	18 (51.4)	10 (28.6)
19.	I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	8 (22.9)	5 (14.3)	2 (5.7)	10 (28.6)	10 (28.6)
20.	I would be uncomfortable talking about impending death with the dying person	12 (34.3)	10 (28.6)	1 (2.9)	8 (22.9)	4 (11.4)
21.	It is possible for nurses to help patients prepare for death	15 (42.9)	6 (17.1)	2 (5.7)	5 (14.3)	7 (20.0)
22.	Death is not the worst thing that can happen to a person.	3 (8.6)	5 (14.3)	3 (8.6)	15 (42.9)	9 (25.7)
23.	I would feel like running away when the person died.	2 (5.7)	1 (2.9)	2 (5.7)	18 (51.4)	12 (34.3)
24.	I would not be assigned to care for a dying person	2 (5.7)	1 (2.9)	1 (2.9)	24 (68.2)	7 (20.0)

## Self-reported palliative care practices

The self-reported practice section of the survey had 23 items. In the self-reported palliative care practice, 31 (88.6%) participants scored lower than 75%. Although 28 (80%) of participants provide care for people with life-limiting illnesses through family and multidisciplinary meetings, only 6 (17.1%) participants were working with community and religious leaders. Twenty-two participants (63%) indicated that they assessed pain; however, only three (8.6%) of the participants assessed spiritual needs. The highest self-reported practice was the administration of tramadol 31 (89%) followed by paracetamol 19 (54%) and the lowest scored was morphine administration (2 (5.7%)). (see Table 5.4).

**Table 5.4**  
**Self-reported practice of palliative care nurses (n=35)**

NO	Items	Yes (%)	No (%)
<b>Caring for people with a life-limiting illness practice</b>			
1	Family meeting	28 (80.0)	7 (20.0)
2	Multidisciplinary team meetings	28 (80.0)	7 (20.0)
3	Counselling	26 (74.3)	9 (25.7)
4	Comfort care	20 (57.1)	15 (42.9)
5	Hygiene	17 (48.6)	18 (51.4)
6	Patient education	17 (48.6)	18 (51.4)
7	Family education	18 (51.4)	17 (48.6)
8	Working with community and religious leaders	6 (17.1)	29 (82.9)
<b>Application of assessment tools</b>			
9	Pain	22 (62.9)	13 (37.1)
10	Diarrhoea and constipation	20 (57.1)	15 (42.9)
11	Nausea and vomiting	19 (54.3)	16 (45.7)
12	Emotional/psychological state	13 (37.1)	22 (62.9)
13	Fatigue	9 (25.7)	26 (74.3)
14	Spiritual needs	3 (8.6)	32 (91.4)
<b>Administering medication for pain relief</b>			
15	Tramadol	31 (88.6)	4 (11.4)
16	Paracetamol	19 (54.3)	16 (45.7)
17	Morphine	2 (5.7)	33 (94.3)
<b>Using non-pharmacological management of pain</b>			
18	Hot or cold compress	25 (71.4)	10 (28.6)
19	Distraction	23 (65.7)	12 (34.3)
20	Massage	7 (20.0)	28 (80.0)
<b>Administering medication to treat symptoms</b>			
21	Nausea and Vomiting	26 (74.3)	9 (25.7)
22	Diarrhoea and Constipation	19 (54.3)	16 (45.7)

23	Anxiety and Depression	11 (31.4)	24 (68.6)
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### Correlation between outcome variables in Case 1

The relationship between the outcome variables was investigated using Spearman's rho correlation coefficient (Pallant, 2016). Preliminary analysis was performed by scatterplot which found a violation of the assumptions of normality and linearity (Pallant, 2016). There was a medium, negative correlation between knowledge and self-reported practice,  $\rho = -.36$ ,  $n = 35$ ,  $p < .05$ , indicating a high level of knowledge associated with a low level of self-reported practice. There was also a medium, negative correlation between attitude and self-reported practice,  $\rho = -.44$ ,  $n = 35$ ,  $p < .01$ , indicating a more favourable attitude was associated with a lower level of self-reported practice. (see Table 5.5).

**Table 5.5**  
**Correlation between the outcome variables in Case 1.**

Correlations					
Spearman's rho	Knowledge	Correlation Coefficient	Knowledge	attitude	practice
			1.000	.117	-.358*
		Sig. (2-tailed)	.	.505	.035
		N	35	35	35
	Attitude	Correlation Coefficient	.117	1.000	-.442**
		Sig. (2-tailed)	.505	.	.008
		N	35	35	35
	Practice	Correlation Coefficient	-.358*	-.442**	1.000
		Sig. (2-tailed)	.035	.008	.
		N	35	35	35

\*. Correlation is significant at the 0.05 level (2-tailed).

\*\*. Correlation is significant at the 0.01 level (2-tailed).



In Case 1, more than half of the participants held a Bachelor's degree in nursing. The majority of nurses had not received palliative care education in their undergraduate courses and had not taken in-service palliative care training. Most participants were found to have knowledge deficits and lower levels of self-reported practice. There was a medium negative correlation between knowledge and self-reported practice, with participants who had higher levels of knowledge associated with lower levels of self-reported practice. All participants had positive attitudes towards palliative care. In addition, there was a medium negative correlation between attitude and self-reported practice: participants who had more favourable attitudes were associated with lower levels of self-reported practice.

### Qualitative results of Case 1

The Case 1 interviews were conducted at the General Hospital; Primary Hospital; Health Centre; and Health Post, with the leadership team of nursing, medicine and pharmacy in General and Primary Hospital, the medical director and pharmacy head in the Health Centre and the Health Extension Worker in the Health Post. A focus group discussion with eight females in the rural community member group was also conducted. A total of 13 interviewees, six males and six females participated in Case 1. The interviewees clarified the status of palliative care policy; palliative care education and training; availability of medication and palliative care implementation at the General and Primary Hospital; Health Centre and Health Post of Case 1. They also described the challenges and opportunities related to the delivery of palliative care in their health care settings.

From the interviews conducted in Case 1 three major themes were identified; *palliative care policy and guidelines; palliative care education and training; and palliative care implementation*. Each theme can be broken down into several sub-themes (see Table 5.6).

**Table 5.6**  
**Case 1 themes and sub-themes**

Themes	Sub-themes
Palliative care policy and guidelines	<ul style="list-style-type: none"> <li>• Policy status of palliative care and the availability of palliative care guidelines and related documents</li> </ul>
Palliative care education and training	<ul style="list-style-type: none"> <li>• Palliative care training</li> <li>• Professional and community awareness of palliative care</li> </ul>
Palliative care implementation	<ul style="list-style-type: none"> <li>• Pain management</li> <li>• Providing care</li> <li>• Resources related to opportunities and challenges</li> </ul>

### Palliative care policy and guidelines

As described in the background to the study and in the previous Chapter, there is a National Palliative care Guideline and national health care plans that includes palliative care. In order to identify how the policy and guidelines had been implemented in Case 1, interviewees were asked to clarify the availability of palliative care policy and guidelines. In this theme, the interviewees from the Case 1 explained what they recognised about the policy and from whom palliative care documents were available. The interviewees also reflected on their perceptions about the priority of, and focus on, palliative care by policy makers from the government and the professionals working in their settings. This theme includes one sub-theme: *Policy status of palliative care and the availability of palliative care guideline and related documents* in their health care settings.

#### *Policy status of palliative care and the availability of palliative care guidelines and related documents*

Participants in Case 1 reflected on their perception about the presence of palliative care at the national health care policy level. In this sub-theme, participants highlighted how the palliative care policy was recognised by professionals in Case 1. They also elaborated on why they believed the government had a low focus to palliative care.

In Case 1, participants reported that palliative care was not included in the national health policies and guidelines and none of the palliative care-related policies were available in their settings:

*... palliative care is not available in the policy level. It [palliative care] is not coming as a policy to the institutions ... there is no policy design to implement palliative care ...*

(Participant 1GHD)

In addition, one Health Centre participant recounted that there was no focus on palliative care in their centre; he thought it would be beneficial to focus on palliative care, but it required policy designed to implement it:

*... we did not give focus on palliative care ... if we think as a centre ... [palliative care], it will be good. [However], we are doing nothing ... there is no palliative care policy designed ... still now we are not implementing palliative care ...*

(Participant 1HCHO)

Another Primary Hospital leader clarified that the policy provided priority and focus to communicable disease and maternal and child health specialists:

*The policy ... focus is on prevention activity and nutrition, family planning and delivery for mothers. In general, the main policy focused on the prevention activity but with this the palliative care ... we are working based on the available materials ...*

(Participant 1PHHO)

The General Hospital medical leader added that the consequence of a low focus to palliative care in preference to curative care from the policymakers meant that health professionals in the region were reluctant to provide palliative care in their settings:

*... starting from the federal ministry of health ... the Regional Health Bureau ... and administrative level... did not give focus on palliative care ... so, the professionals working in the health care levels neglected palliative care ... they give priority on the government focused activities ... which means provide focus in the curative activities in the hospital and prevention in Health Centres ...*

(Participant 1GHD)

The Health Extension Workers (HEWs) also described the lack of government support and direction as the reason why they give less attention to palliative care:

*... the government did not give priority to palliative care ... we have a lot of activities to implement. We are focusing on high burden type of diseases [communicable disease] We do not have a government direction to focus on palliative care ...*

(Participant 1HEWHP)

In Case 1, participants expressed the view that palliative care was not incorporated in the national health policies and the policymakers provided priority and focus to curable and preventable diseases rather than palliative care. The health professionals believed they followed the guidance of the government in the focus on their services.

As described in Chapter One, there was a National Palliative Care Guideline and a National Cancer Control Plan (NCCP) and Health Sector Transformation Plan (HSTP). In order to recognise if these documents or other related documents were available, participants were asked to reflect on the available documents and with whom the documents were located in their settings.

Participants in Case 1 indicated that there were no National Palliative Care Guidelines available in their sub- region, except a few documents that included palliative care. They referred to a pain management guideline, Ethiopia Hospital Service Transformation Guideline (EHSTG), and World Health Organization (WHO) Module in a PowerPoint form that were only available for the leadership of the General Hospital (see Table 5.7). The participants indicated that no palliative care documents were available in either the Health Centre or the Health Post.

**Table 5.7**  
**Available palliative care and related document in Case 1**

<b>List of palliative care and related document</b>	<b>Awareness and Availability</b>	<b>Neither Aware nor Available</b>
Pain management guideline	<ul style="list-style-type: none"> <li>• Medical and nurse leader in General Hospital</li> <li>• Clinical nurse leaders in General Hospital</li> </ul>	<ul style="list-style-type: none"> <li>• Primary Health Care Unit (Primary Hospital, Health Centre and Health Post) participants</li> <li>• Pharmacy leader of the General Hospital</li> </ul>
EHSTG (Ethiopia hospital service transformation guideline).	<ul style="list-style-type: none"> <li>• Nurse leader of the General Hospital</li> </ul>	<ul style="list-style-type: none"> <li>• Medical leader; clinical nurse leader; and pharmacy leader of the General Hospital</li> <li>• Primary Health Care Unit (Primary Hospital, Health Centre and Health Post) participants</li> </ul>
WHO palliative care training ppt	<ul style="list-style-type: none"> <li>• Medical leader of the General Hospital</li> </ul>	<ul style="list-style-type: none"> <li>• Nurse leader; clinical nurse leader and pharmacy leader from the General Hospital</li> <li>• Primary Health Care Unit (Primary Hospital, Health Centre and Health Post) participants</li> </ul>

Therefore, except for a few palliative care-related documents available only to the leadership participants of the General Hospital, no National Palliative Care Guidelines or documents were readily available in Case 1.

### **Palliative care education and training**

This theme highlighted how the participants in Case 1 perceived education and training related to palliative care. They also elaborated on where and to whom palliative care training was given in their settings. Participants also talked about their perceptions of how the professionals and community understood palliative care. This theme consists of two sub-themes: *palliative care training*; *professional and community awareness of palliative care*.

#### ***Palliative care training***

Participants in Case 1 explained that palliative care training was only provided to professionals working in the Anti-Retroviral Treatment (ART) clinic (a part of the General

and Primary Hospital), and Health Centres. For example, a medical leader working in the General Hospital was one of the trainers who provided palliative care training to the professionals working in the ART clinics of the General Hospital and Primary Health Care Units. This participant justified that the training only focused on professionals working in ART clinic because it was organised by the NGOs:

*... in-service palliative care training ... using the WHO power point was conducted ... I have been a trainer for one to two days ... the training was [organised] by the CDC [Centres for Disease Control] which is an NGO project focus on HIV ... to ART [Anti-Retroviral Therapy] service professionals ... it [in-service palliative care training] is not available [more widely] ... Because ... pre-service ... still [now] palliative care is not given and not incorporated in the curriculum...*

(Participant 1GHD)

The nurse leader of the General Hospital suggested that palliative care training was provided to only a few professionals working inside the General Hospital:

*... in-service palliative care training was given to one or two professionals of the hospital ... the training was provided within the hospital ...*

(Participant 1GHND)

Other participants argued that the in-service training was about pain management rather than palliative care. The clinical nurse leader of the General Hospital explained that pain management training was given to one of the nurses from their ward:

*One nurse was trained in pain management not palliative care training ... she shared her experiences with other health professionals ...*

(Participant 1GHWNH1)

However, other participants working in Primary Hospital and Health Centres had not received training for either palliative care or pain management:

*... No training at all ... we have more than 20 to 30 senior experienced professionals ... nothing is available in palliative care training ...*

(Participant 1PHND)

Despite few professionals having undertaken palliative care and pain management training in the General Hospital, no such training was available in the Primary Health Care Unit.

### *Professionals and community awareness of palliative care*

Like the previous Context Chapter, participants explained how health professionals and the community understood the term ‘palliative care’. In this sub-theme, participants described the opportunities and challenges related to professionals and community awareness of palliative care.

Participants indicated that professionals working in Case 1 lacked awareness about palliative care, except for a few professionals working in the ART clinic. For example, the medical leader of the General Hospital described how professionals did not understand the term ‘palliative care’ and did not understand why patients were referred to less resourced or experienced services such as Health Centres, for palliative care:

*... the professionals did not understand the concept of palliative care ... those professionals who are working in ART may have a certain information ... [For example] when the doctor ... referred cancer patients to the Health Centre for palliative care ... They [professionals] think why this killer disease has been sent for us [the hospital] ... they think it needs a higher institution ...*

(Participant 1GHD)

Those participants working in the Primary Health Care Unit acknowledged they lacked awareness about palliative care and needed further information:

*... we do not have detailed information how to provide care for the chronic patients ... we did not get any updated information ... we need highlight how to provide palliative care.*

(Participant 1PHND)

Community members as well as professionals had poor understanding about palliative care. However, some participants explained that the community members who had follow-up care in ART clinics may have been given some palliative care information. For example, a nurse leader clarified that the health professional working in ART provided palliative care education to HIV patient:

*... the ART professionals provide awareness to the community [ART patients and family] ... we inform them, but we are not providing detailed information about palliative care to the community ...*

(Participant 1GHND)

The medical leader also described how little the community understood about incurable diseases. They said that the community members had misinformation about these diseases and lacked palliative care awareness, turning to traditional spiritual healing methods if told they had an incurable disease:

*... a few people have a little information ... as cancer is a killer and not cured, that is the only thing they know ... they have no palliative care information at all. If the doctor informed the patient and family, that the patient's diagnosis was incurable ... they prefer to go to the holy water*

(Participant 1GHD)

However, some participants described the opportunity for health education in relation to incurable diseases. They clarified that health education was given by HEWs and other health care staff to encourage cancer screening and early intervention. For example, the HEWs described where and how they provide education to the community:

*... we provide health education to prevent mother to child transmission ... the communicable disease such as HIV ... and cancer ... we inform them the importance of ... pre-cervical cancer screening. We also tell the community that all cancer is not killer when it is detected early, it will be curable ... We provide health education in the community meeting or in the church ...*

(Participant 1HEWHP)

Some participants suggested that it was the lack of professional palliative care awareness that contributed to the low palliative care awareness in the community, this participant suggesting that the priority was to enhance the professional's awareness:

*... the health professional should have awareness and we can transfer our awareness to the community ... So, we do not provide any health education about palliative care to the community. Even the health professional did not know it [palliative care] ... we know nothing about palliative care...*

(Participant 1GHWNH1)

Although a few ART clinic health care staff and HIV patients and families had limited information about palliative care, indications from participants of Case 1 suggest that in general, professionals and community members lacked awareness of palliative care:



## Palliative care implementation

Participants highlighted how health professionals provide care for the patients diagnosed with incurable disease in health care settings. They further reflected on where the family took the ill person, when the doctor informed the patients and family that the disease was no longer treatable in the hospital. The opportunities and challenges in implementing palliative care were also described. This theme is described by three sub-themes: *pain management*, *providing care and resources related opportunities and challenges*.

### *Pain management*

Participants in Case 1 perceived that pain-management was an important aspect of palliative care implementation in health settings. In this sub-theme, participants clarified how severe pain was managed, the challenges in relation to availability, accessibility, affordability, prescription, and administration of opioids, particularly morphine.

Participants in Case 1 clarified that morphine was not included in the General Hospital's list of medications and was not available in their settings. Some participants described that despite morphine being available in the country, it is not accessible in General Hospitals. For example:

*... country level, morphine is available ... [however] ... In our institution [in the General Hospital], morphine is not available. Even it is not included in ... the drug list ... in most of the General Hospitals, morphine is not available...*

(Participant 1GHD)

The pharmacist working in the General Hospital expressed the opinion that morphine is not appropriate to prescribe for severe pain:

*... it [morphine] is related with cancer ... here [in General Hospital] there are no cancer patients ... when the patients have severe pain, the doctors prescribe pethidine because morphine is not safe ... and it has a side effect ...*

(Participant 1GHP)

However, the medical leader of the General Hospital argued that morphine is a safer drug than pethidine. This participant explained that they only prescribed pethidine to relieve severe pain for cases where pain was not expected to be ongoing:

*... Morphine is the only safe drug ... We are only prescribed ... pethidine ... in maternal delivery to relive pain ... but for cancer patients ... we are not prescribed pethidine as a pain management. Pethidine is not recommended...*

(Participant 1GHD)

This participant further elaborated that morphine was not only a safe drug but it was also one of the cheapest drugs in the region:

*... when I was prescribing in the other hospitals, it [morphine] is not expensive, they [the community] can afford it ... morphine is cheap, it does not have a problem with affordability.*

(Participant 1GHD)

When morphine was not available in the pharmacy store, participants commented that alternative pain medication such as tramadol was prescribed for patients who had severe, chronic pain. For example,

*Here [in our hospital] we only have tramadol ... when we have a patient with severe pain, we have no choice, we prescribe NSAIDs. Then we prescribe tramadol that is what we have ... if the patient pain does not respond with tramadol, they will suffer with pain ...*

(Participant 1GHD)

The leader of the Health Centre also described that morphine was unavailable in their setting. He said that tramadol was the main medication used because the country regulations did not permit prescription of morphine in Health Centres:

*... we do not have morphine ...tramadol is our top anti-pain ... if severe pain happened, we refer them. We could not prescribe morphine. The Health Centre standard did not allow us to prescribe it ...*

(Participant 1HCHO)

At the Health Post, the HEW claimed that the only pain medication available in their setting was paracetamol:

*... when we are walking home-to-home, we always have anti-pain [paracetamol] in our bag ... We do have patients diagnosed with hypertension ... cervical cancer ...*

*hepatitis [who had severe pain] ... they took anti-pain [paracetamol] medicine from our clinic ... we only have paracetamol ...*

(Participant 1HEWHP)

The challenge was not only availability of morphine, but also there a lack of other medications such as tramadol in the central pharmacy store in Case 1. For example, the pharmacists described that they purchase medications every quarter from the PFSA, but they were not consistently available. This participant further elaborated why they prefer to purchase medications from PFSA:

*... medications are cheap in PFSA ... [however] ... not consistently available from the source, PFSA ... we buy medication from PFSA every three months ... if there is no medication in the source, we buy a few medications from private which is very expensive...*

(Participant 1GHP)

So, although doctors prefer to prescribe morphine in General and Primary Hospitals, it is not included in the available drug list of the hospitals. Morphine was also unavailable in Health Centres and Health Posts because the country's standard regarding Health Post services did not allow the purchase, storage or prescription of morphine:

### *Providing care*

Participants elaborated on how professionals provided care to patients diagnosed with incurable disease in the health care settings and at the patients' homes. Participants described how palliative care was implemented for HIV patients. They said that physical care, pain-management, and psychosocial supports were provided in the General and Primary Hospitals, and the Health Centre. Some participants also described the family's role in providing care at home and taking their sick relatives to hospital and alternative care sites. They also elaborated on the challenge and opportunities related to the care given at home and in the health care settings.

Participants acknowledged that palliative care was implemented for HIV patients in the hospital as well as at the patients' home. They also described how palliative care was not provided to patients diagnosed with other incurable disease in the hospital:

*... we provide palliative care ... in ART. But not linked palliative care to the wards in the hospital ... we are not implementing [palliative care] or home care other than HIV*

*patients ... those who are critical in relation to stage 4 HIV patients, professionals provide care up to the patients' home.*

(Participant 1GHD)

This participant further clarified the reason why palliative care focused in HIV patients:

*the main focus of ... palliative care is HIV [ART] ... in ART, they [professionals] went to their [patient's] home, because there is a concern and attention and a small fund from CDC ...*

(Participant 1GHD)

Despite participants clarifying that palliative care was provided for HIV patients, some participants indicated that palliative care was not delivered in the hospital, that professionals were reluctant to acknowledge the palliative care needs of patients:

*... I prefer to say almost palliative care is not implemented ... I think when the patients arrived in palliative care stage ... as a system it [palliative care] is totally ignored service.*

(Participant 1GHD)

However, this participant also clarified that though palliative care was not implemented as a whole service, there was some psychological support and pain management available in hospitals. His concern was that this care and support was provided without a conscious understanding of palliative care:

*Palliative care is a broad science ... when the doctor provide advice, we think that this is part of palliative care, even when the patients are in a hospital, they may get anti-pain [pain medication], we can say there is partial part of palliative care activity implemented ... Not intentionally and thinking the professional to provide palliative care ...*

(Participant 1GHD)

Some participants further clarified the nursing care provided to the patients in the hospital did not consider the concept of holistic palliative care, that physical nursing care was provided, with little consideration of other support. The clinical nurses' leader working in the General and Primary Hospitals described the detailed nursing care from the patient's admission to discharge:

*... we are providing care until the patient discharge from the hospital ... we administer medication and measuring vital sign ... and advice for the patient. But it is not based on what you said [palliative care] ... we also provide physical examination to assess pain and consider as the fifth vital sign ... We never give the patients emotional, psychological support ... we even never think about it [palliative care].*

(Participant 1GHWNH1)

Similarly, some participants considered palliative care as equivalent to pain management, so that the hospital wards were practicing pain assessment as a part of vital signs:

*... when we say palliative care in wards, it is pain management, and this is considered as the fifth vital sign. So, we are working ... in managing pain of the chronic patients ... in the ward ...*

(Participant 1GHND)

Some participants described stories of patients who self-referred to the Primary Hospital for care up to the end-of-life; in the case below, their preference being to die at the hospital. This participant explained how the professionals provided care in this setting:

*... when they discharged from the [general] hospitals they came to here [Primary Hospital] and want to get care ... Even though they are dying, they want to die in our hospital, or they need care for dying ... We are ... providing care and support ... The health professional provides positioning not to develop bed sores, keeping clean, to take meals on time: if there is an economic problem, we link to those who can help patients.*

(Participant 1PHWNH1)

In addition, some participants working in a Health Centre shared their experience in providing what they described as palliative care. The Health Centre leader said that sometimes patients were referred from the hospital to the Health Centre for palliative care, describing a case where the professionals provided care in their centre, focusing on the patient and family wishes to die at home and then facilitating it:

*... the doctors ordered to get palliative care service in the nearby Health Centre, and the doctor inform them not to cost much for the family ... there was one mother, her age is 85 or 90 ... the referral paper said give her palliative care ... we provide care such as prevention of bedsores, bed making, timely medication administration, we have*

*been checked vital sign ... we do this all ... the family see that she is dying and request to take the patient to her home, then she passed away ...*

(Participant 1HOHC)

Patient care in the health care settings was not limited to physical care. Some participants also clarified that they attempted to provide emotional support to chronically ill patients and their family members:

*... we give psychological support for the patient, the family may be discouraged, they may be hopeless, the patient may have severe pain, so we inform the family not to be like that, we tell them to provide care for their patient as much as they can.*

(Participant 1HEWHP)

Some of the focus group participants described a story of the patient who had chronic disease at home. They said that although the patient was repeatedly admitted and treated in the General Hospital, there was little that could be done, and he finally died:

*... the patients who were suffering [at home] with ... abdominal tumour [liver disease] ... for 10 years ... four neighbours carried the patient on foot to the hospital ... He took a lot of medications ... the patient was treated in hospital many times ... but no change ... finally, he passed away ...*

(Participant 1RFG)

They described that if a patient had family members, they did not always look after the patient at home; they may not even provide a greeting. This participant indicated that such family members may only participated in the funeral ceremony:

*... let alone to look after at home or to take the elder to the hospital, they do not want to say good morning ... there are a lot of elderly and sick people and no one looks after them ... They suffer until end of life in their house ... not only one [or] two [but] many ... The thing they do is they may participate in funeral ceremony ... because of money ... nowadays, the health care is expensive ... the family would take the dead body to buried in the church.*

(Participant 1RCFG)

The HEWs agreed that some patients were isolated from care, without family carers and further elaborated the challenges:

*... those who have no son or daughter are suffering at home ... no one is looking after them, when their son or daughter gets married they did not even say hi to their chronically ill family ...*

(Participant 1HEWHP)

However, some participants argued that some did share the care of their sick relative. Other participants highlighted the family duty in taking the patient to the hospital and providing care at home:

*The patients live with their wife and children in their house ... their brothers and sisters, those are the one who look after the patient ... For example, if the patient wants to get open air, they help him to be outside ... the family are preparing food ... washing the patient's clothes that is what family can do ... protecting them from cold, make them warm with blankets ... the family provide care at home until the time of death ...*

(Participant 1RCFG)

Some participants acknowledged that the family were not only providing care at home, but took them to hospital and engaged with other alternatives such as traditional healers and holy water sites:

*When the patient has pain and other symptoms the family took the patient to the hospital, if no improvement there, they took him to holy water and if it is beyond that the family took the patient to the traditional healers. After that ... the patient will suffer at home ... the family try all their best... if he died, it is closed ...*

(Participant 1RCFG)

One medical professional further clarified why the family took the patients to the alternatives described. This participant believed that spiritual rites such as holy water were important sources of palliative care support because the priest provides psychological, spiritual support:

*... if the doctor told the patient and the family that the case is not cured, the patient and family go to the holy water. Until the end of their life, they will stay there... palliative care is given in the holy waters... though they have pain, the priest provides psychological and spiritual support ... But here [our hospital] we are saying this is the last treatment, so this is more painful ...*

(Participant 1GHD)

Therefore, despite there being some families who had financial challenges in caring for their sick relatives, a number of participants acknowledged the significant family role in providing care at home and taking patients to health care settings and different alternative care settings until the end of life.

#### *Resource related to opportunities and challenges*

This sub-theme elaborated participants' reflections on the challenges and opportunities relating to resources available for the provision of palliative care in Case1. These participants described their perceptions of financial and human resources, palliative care guidelines, mobile phone technology, and a palliative care clinic that might facilitate palliative care implementation in health settings.

Some participants believed that there were financial resource challenges impeding the provision of palliative care. They said that despite patients getting health care in some health sectors, there was a lack of funding to get the health care they needed in hospitals. They also suggested that health care services should be provided at no cost to the patient:

*... let alone to health care even to basic needs, to get ... food is difficult ... They want to go to the hospital ... they have no money ... even though they [son or daughter] love their father and mother, they could not have greeting to their parents because of money ... nowadays, the health care is expensive ... how do I bring 2000, or 3000 ETB. [for example] ... it is good to have free health care service...*

(Participant 1RCFG)

Some participants described that a health insurance initiative was identified as available to the community in Case 1, which required everyone in the community to pay a premium. The opportunity of having a health insurance initiative in their setting was still available to those community members who were unable to pay, as the government voided the payment for health insurance, for them:

*... the government are helping with the health insurance for 174 patient who cannot afford the insurance money ...*

(Participant 1HEWHP)

Despite this initiative, some participants described the challenges of paying for the insurance by all members of the community.



*... the community request to return their health insurance money ... they said that the leaders are not paying for insurance kind of questions, this is the challenge.*

(Participant 1HEWHP)

Financial support for those in need in the rural community was described by The HEWs as available from the government and also from community members. This participant described how the community provided support to HIV patients.

*... we have social affairs from every community they contribute 24 ETB [from the farmer pocket] for HIV patients ... The HDAs [Health Development Army] mobilise the financial support ... we motivate the community to help her by [contributing] cereals and money ... the community provide some food for HIV... The government also help with food for HIV patients ... Free medication for HIV patients...*

(Participant 1HEWHP)

The clinical nurse leader of the General Hospital also explained how the health professionals sometimes provided financial support to fund those who were referred to the Comprehensive Specialised Hospital, but were in financial stress:

*... if this patient has no money and wants to be discharged, the professionals are helping some money ... the health professionals are providing economical support as I mentioned before the doctors 100 ETB, and nurses 5 or 10 ETB [from their own pocket]*

(Participant 1GHWNH2)

One doctor of the General Hospital suggested that there was an opportunity for NGOs to provide financial support for palliative care, recommending a partnership between NGOs and the government:

*There are NGOs who are interested to work in it [palliative care] though not the focus of the country ... I don't think the NGOs get the chance to be more motivated [about palliative care] from the government ... because CDC [Centres for Disease Control and Prevention] ... focus on HIV ... There should be a small budget allocated to provide palliative care ...*

(Participant 1GHD)

In addition to financial support, a community network might help to provide social support and raise funds in the rural community for palliative care:

*... the community on the ground can provide social care ... there is social activity at the rural area, there is one to five networks [network of groups, each with a community leader and 5 community members] ... collect some cereals and economic support by collecting money...*

(Participant 1PHHO)

Some participants further described that different groups (associations) reflecting the cultural values of the community were used to help chronically ill patients with no relatives to look after them; these groups were an important support:

*... we have a good culture; the community can help each other for the chronic patients who have no family ... we have 'Mahber' or [association] ... The group have 25-30 members ... The community may visit chronic patients ... they are also motivated to help each other ... the neighbour can carry the patient to the hospital ...*

(Participant 1HEWHP)

Some participants saw that the challenges to the provision of palliative care were not only financial. The significant health system challenges already described impact on what palliative care can be provided, the following participant suggesting that the system should be improved:

*We have to develop a system. To establish a system, we may not need a special centre and a health professional ... the government did not have a focus on palliative care ... as a system it [palliative care] is not applicable ...*

(Participant 1GHD)

Palliative care is not led by government, so integrating it into the existing health extension activities was a difficulty, with one participant proposing that care centres were required to meet the needs of older people:

*In the past, it was focused on communicable diseases, but now ... it is 18 components ... the non-communicable disease ... is incorporated ... We do not have a government direction to provide palliative care ... the government should provide focus and build ... an aged and orphan care centre ...*

(Participant 1HEWHP)

In addition, those working in General and Primary Hospital said that a separate palliative care unit within the hospital was needed. This participant explained that the major cancer centre of the country was providing a chemotherapy service but not palliative care:

*... there should be separate palliative care unit ... But in Ethiopia [there are] a few cancer centres. These centres are not prepared or designed for palliative care, I used to be involved in cancer centre ... I know it, patients had chemotherapy [then] they went to their home, that is it. Still these centres have no palliative care service.*

(Participant 1GHD)

A lack of palliative care trained staff was also identified by those working in General and Primary Hospitals as an important challenge to palliative care implementation:

*It [palliative care] starts from the diagnosis ... providing counselling ... necessary supports, making to be pain free until the end of life ... the hospital direction did not motivate professionals to deliver palliative care ... we send the patient to their home, that is what we are doing ... this causes guilty feeling ... [the professional] not feeling good psychologically ...*

(Participant 1GHD)

This participant said that assessing patients for palliative care needs was more time-consuming than the care of other patients and so doctors are reluctant to spend that time:

*Everyone knows how palliative care is needed and it is a basic thing, but with the policy direction and lack of health professionals ... [affected not to provide care] ... [for example,] the doctor assessed around 60 patients per day ... in here [in General Hospital]. [compared] to the [standard] ... it is three to four times. So, the professionals become reluctant to start palliative care ...*

(Participant 1GHD)

As well as the care of patients requiring palliative care being time-consuming, the nurse-patient ratio did not accommodate additional work, affecting the ability of nurses in the clinical wards of the General Hospital to provide palliative care:

*Our main challenge is the professional and the nurses are not appropriate, it [nurse-patient ratio] is 1 nurse to more than 20 patients. Especially at night time 1 or 2 nurse for 40 to 50 patients ... some nurses may provide care, and some may not because it is personal ...*

(Participant 1GHWNH1)

Not all staff were committed to providing palliative care if it is perceived as additional to their current work:

*... the professionals thinking palliative care as additional work. So, they want to work the usual activities ... the professionals were left alone to add palliative care meaning they did not even implement all their obligated activities...*

(Participant 1GHD)

This participant also suggested that there should be a leadership commitment to enhance the clinical and professional commitment:

*... the main thing it needs political commitment. Clinical commitment without political commitment is meaningless. So, these things should be done. If there is [political] commitment, here [in our hospital] it is very simple...*

(Participant 1GHD)

The transport of patients to hospital was also indicated as a challenge. Some participants suggested an ambulance service for chronically ill patients should be developed beyond the current ambulance service for pregnancy and childbirth:

*The patient went to hospital by being carried on their shoulder ... we need to pay for transportation ... there is no free transport... Even for the dead body you have to pay. ... there should be ambulance for chronically ill patients or farmer ...*

(Participant 1RCFG)

Mobile phones were described as an opportunity to improve health services for patients with chronic illness. Participants highlighted how the community used mobile phones to get an ambulance. They also acknowledged the importance of mobile phones for patients, as well as building a network between the health care centres. Some participants explained how the community communicated with HEWs using mobile phones. For example, the HEWs and the focus group participants described that the community members or the Health Development Army (a community led support group) had the phone number of HEWs and the Red Cross. They further explained why they called these numbers:

*... most of the time, we use ambulance for pregnant mothers, for those who give birth. ... The community have our phone number and Red Cross number. If our phone is not*

*working, they call Red Cross directly ... The community or the Health Development Army called us ... If the patients have no family, the neighbour called us for ambulance.*

(Participant 1HEWHP)

Some participants suggested mobile phone contact between the health professionals might improve understanding about referrals and provide an opportunity for explanation about a patient's condition and needs. For example, the medical leader of the General Hospital explained that when there was confusion about referral, the doctor was able to reassure the Health Centre staff about the rationale for the transfer using their mobile phone:

*... when we ... referred cancer patients to the Health Centres ... for palliative care ... they [health professionals] see their diagnosis, they refer back to us because they think cancer cannot be treated in the Health Centre ... the doctor discussed using mobile phone with the professional about it ...*

(Participant 1GHD)

The clinical nurse leader explained how the professionals working in different health sectors networked using mobile phones to improve their understanding of a patient's condition:

*... the patients and family request an appointment by calling a [hospital] phone number. We have [name of the referral service] office. When the patient came from Health Centre by referral then the doctors give feedback ... the hospital is linked with the Health Centres. Even they [professionals] are calling and asking information...*

(Participant 1GHWNH2)

So, mobile phones are being actively used in the community to raise attention to patients' issues and for health professionals to communicate between each other, and this indicates mobile phones could be used for future palliative care support.

The qualitative results indicate that palliative care-related policies were not available in Case 1. The participants believed that policy priority and focus was for preventable and curable diseases rather than palliative care. Due to this reason, the professionals working at the patient level were reluctant to deliver palliative care in their settings. There were no National Palliative Care Guidelines available in Case 1, except a few palliative care-related documents located with the leadership participants of the General Hospital.

In Case1, despite in-service palliative care or pain management training being provided for

ART staff and a few nurses in medical and surgical ward of the General Hospital, participants claimed that health professionals working at the Primary Hospital and Health Centre had not received any of this training. Some trainees also argued that the training was pain management rather than palliative care. The community members other than those patients with HIV and their families, lacked information about palliative care. Additionally, palliative care was not included in the medical students' curriculum in Case 1 health care settings.

Morphine was not available in this case, with some participants believing that it was not safe to prescribe. Even when they did prescribe it, it was not included in the General Hospital's drug list. Thus, professionals in the General and Primary Hospitals, as well as the Health Centre prescribed tramadol to manage severe pain. However, paracetamol was the only pain medication available at the Health Post.

In Case 1, palliative care was solely delivered for HIV patients both in their home and health care settings, mainly because the NGOs provided financial support for HIV care and treatment. However, professionals working in the General and Primary Hospitals, and the Health Centre provided physical care, pain management and psychosocial support to chronically ill patients without a conscious understanding of holistic palliative care. If the sick person had family to provide care at home, they often took them to the hospital and to other alternative care sites. But not all families provided care to their sick relatives, primarily because of financial and other problems.

There were opportunities and challenges related to resources for palliative care implementation. In Case 1, mobile phones were used to communicate between the rural community, health care providers, and the Red Cross and the ambulance service. Professionals working in different health care settings also used mobile phones to communicate about patients' issues. There was a health insurance initiative available in the community but a gap in implementation, because not every community member had paid the premium. However, there was some financial support from the rural community, government and NGOs for HIV patients. The rural community had an association and networks that helped to raise funds and social support; and the health professionals sometimes provided financial support to the patients referred to hospital. However, participants in Case 1 were concerned that palliative care was not integrated into the existing health care system because policymakers provided little focus on palliative care. Thus, there was concern that there was no palliative care unit; a lack of palliative care-trained professionals; a lack of ambulance service; and also, a lack of professional and political commitment for palliative care.

## Chapter Summary

In Case 1, the survey and qualitative results have been presented from the collected and analysed data sources including survey, interview, and focus group discussion.

The survey results of Case 1 demonstrated that most of the nurses had insufficient knowledge and self-reported practice of palliative care. In the qualitative results, participants perceived that health professionals lacked palliative care awareness except ART staff, HIV patients and family members. Participants described that palliative care as only available for HIV patients in the hospital and at the patients' homes. In addition, the participants described that in-service palliative care and pain management training was provided to ART staff and a few professionals working in General Hospital. Similarly, the survey results indicated that a majority of nurses had not undertaken in-service training.

The survey results indicated that almost all nurses had not administered morphine borne out by the qualitative results, where participants claimed that morphine was not available in Case 1. Participants described that severe pain was managed using tramadol in the General and Primary Hospitals, and Health Centres; and paracetamol was the only available analgesic medication in the Health Post. Despite that some aspects of physical care, pain management and psychosocial support were implemented in the health care settings, there was a lack of awareness of the holistic philosophy and practice of palliative care service.

Despite their lack of knowledge and self-reported practice, all nurses in Case 1 had positive attitudes towards palliative care. Despite the demographic variables not being significantly associated with knowledge, attitudes or self-reported practice, there was a correlation among these outcome variables. Higher levels of knowledge were significantly correlated with a lower level of self-reported practice; and participants who had higher levels of positive attitude was significantly correlated with lower self-reported practice. Despite palliative care and pain management training being provided for a few professionals, policy makers provided little support or focus on palliative care, resulting in professionals working at the patient level not being motivated to implement palliative care. The qualitative results indicated perceptions of the lack of palliative care in the country's health policy, as well as the unavailability of National Palliative Care Guidelines, except for the leaders of the General Hospital.

There were several opportunities and challenges relating to resources for palliative care. In Case 1, there was a health care initiative that helped to minimise community financial

challenges in accessing emergency care by using a network or association. Families of sick relatives assisted in care and supported them at home and took them to hospital and alternative care sites. However, not all family were able to care for patients due to financial problems. Community members and health professionals used mobile phone technology to ease communication across the health care system. The major challenges that emerged were the lack of a palliative care unit, lack of palliative care training for professionals, the unavailability of morphine and the lack of professional and political commitment to palliative care. The results of Case 2 will be discussed in the next chapter.



## Chapter Six: Case 2 Results

### Introduction

Similarly, to the previous two results chapters, the results of Case 2 are presented in two sections. The first section describes the survey results, and the qualitative results are documented in the following section. As already indicated in Chapter Three, the survey data were collected from nurses working in General and Primary Hospitals, and a Health Centre. The collected data were analysed using SPSS Version 25. The qualitative data were collected by interview, participants being recruited from leaders of the General Hospital and Primary Health Care Units; and the focus group discussion data were collected from the rural community members of Case 2. Again, the qualitative data were analysed using NVivo 12 software.

### Survey results of Case 2

Like the survey results of the Context and Case 1, in Case 2, out of 56 survey questionnaires distributed to nurses working in the General and Primary Hospitals, and Health Centre, 49 (88%) were completed and analysed.

The demographic variables of Case 2 are presented using table, frequency, percentages, mean, and standard deviation. Then, the nurses' level of knowledge, attitudes and self-reported practice are reported using frequency and percentages, followed by the correlation between these variables. Finally, the demographic variables that had a significant association with the outcome variables are presented.

### Socio-demographic variables

Like the previous two result chapters, there were 10 socio-demographic variables in Case 2. The majority of the respondents 37 (76%) were females with the mean age of 35.49 years (SD=7.79; ranges, 24-50 years). Thirty-two (65%) nurses had undertaken palliative care in undergraduate and post graduate courses. More than half the participants had not received in-service palliative care training (27, 55%), and 33 nurses held at least a Bachelor's degree in nursing (67%) (see Table 6.1).

**Table 6.11**  
**Demographic variables for nurses working in Case 2 (n=49)**

<b>Variable</b>	<b>Frequency (%)</b>
<b>Institution</b>	
General Hospital 2	40 (81.6)
Primary Hospital 2	5 (10.2)
Health Centre 2	4 (8.2)
<b>Sex</b>	
Female	37 (75.5)
Male	12 (24.5)
<b>Clinical area</b>	
Medical ward	21 (42.9)
Surgical word	18 (36.7)
ART	5 (10.2)
OPD and emergency	5 (10.2)
<b>Nursing experience</b>	
1-4 years	11 (22.4)
5-9 years	9 (18.4)
10-14 years	6 (12.2)
15 and above	23 (46.9)
<b>Experience in palliative care</b>	
None	21 (42.9)
1-9 years	15 (30.6)
Ten years and above	13 (26.5)
<b>Educational qualification</b>	
Diploma in Nursing	16 (32.7)
BSC in Nursing	33 (67.3)
<b>Palliative care in undergraduate and post graduate level</b>	
Yes	32 (65.3)
No	17 (34.7)
<b>In-service training in palliative care</b>	
Yes	22 (44.9)
No	27 (55.1)
<b>Duration of palliative care training</b>	
Three days-two weeks	15 (68.2)
Two weeks-one month	7 (31.8)

### Nurses' knowledge about palliative care: Case 2

Similar to the previous survey results of the Context and Case 1, there were 14 items in the knowledge test. Half of participants correctly responded to the modified version of PCQN (24, 50%; ranges 5-45). Like the Context and Case 1, the lowest number of participants correctly responded to the 'pain and symptom management' category of PCQN (23, 41%; range 5-42). More than 50% of participants correctly responded to the 'philosophy and principle of care' category (26, 54%; range 18-45). The highest number of participants

correctly responded to the ‘psychological care’ items (43, 88%). The majority of participants responded incorrectly ‘yes’ to item three: *The extent of the disease determines the method of pain treatment* 44 (90%), and to item two: *Palliative care is only appropriate in situations where there is evidence of patient deterioration* 30 (61%). The majority held incorrect views about addiction problems with long term prescription of morphine (item 5) (34, 69%) and nearly half (24, 49%) of participants did not know that: *Terminal ill patients have the right to choose ‘Do not resuscitate.’* (item 13).

Most participants were more knowledgeable about item 6 that indicated: *Provision of palliative care requires emotional detachment* (31, 63%); and responded correctly ‘yes’ to item seven: *During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea* (32, 65%). Of the total participants, 21 (42.9%) scored 75% or greater for the modified version of PCQN test (see Table 6.2).

**Table 6.2**  
**Nurses’ knowledge about palliative care**

No.	Items	Yes n (%)	No n (%)	Do not know n (%)
1.	Do you know about palliative care?	45 (91.8)	0	4 (8.2)
2.	Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration	30 (61.2)	18 (36.7)	1 (2.0)
3.	The extent of the disease determines the method of pain treatment	44 (89.8)	5 (10.2)	0
4.	Adjuvant therapies (antidepressant, anticonvulsant and anti-emetics) are essential in managing pain.	17 (34.7)	27 (55.1)	5 (10.2)
5.	Drug addiction is the major problem when morphine is used on a long-term basis for the management of pain	34 (69.4)	10 (20.4)	5 (10.2)
6.	The provision of palliative care requires emotional detachment	15 (30.6)	31 (63.3)	3 (6.1)
7.	During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea	32 (65.3)	15 (30.6)	2 (4.1)
8.	The philosophy of PC is compatible with that of aggressive treatment	23 (46.9)	21 (42.9)	5 (10.2)
9.	The use of placebos is appropriate in the treatment of some types of pain	24 (49.0)	23 (46.9)	2 (4.1)
10.	Meperidine (Demerol) is not an effective analgesic in the control of chronic pain	12 (24.5)	13 (26.5)	24 (49.0)
11.	The accumulation of losses renders burnout inevitable for those who work in palliative care	29 (59.2)	18 (36.7)	2 (4.1)

12.	The manifestation of chronic pain is different from that of acute pain	42 (85.7)	7 (14.3)	0
13.	Terminal ill patients have the right to choose ‘Do not resuscitate.’	23 (46.9)	24 (49.0)	2 (4.1)
14.	Terminal ill patients should be encouraged to have a hope against all odds	43 (87.8)	5 (10.2)	1 (2.0)

### Nurse’s attitudes to palliative care

There were 24 items that assessed the nurses’ attitudes to palliative care. Overall, more than 60% participants correctly responded to the modified version of FACTOD-B (31, 63%; range 3-48). Like the Context and Case 1, the lowest number of participants correctly responded to category was the ‘communication’ part of FACTOD-B (15, 30%; range 0-27). More than 50% of participants correctly responded to the categories of ‘active care’ (29, 59%; range 25-32); ‘relationship’ (31, 64%; range 15-47); and ‘fear/malaise’ (30, 61%; range 18-48). ‘Family as caring’ was the highest correctly responded to category of FACTOD-B (44, 91%; range 42-48) followed by ‘the care for the family’ items (42, 85%; range 35-48). Almost 60% of the participants correctly disagreed/strongly disagreed with item one: *Palliative care should only be given for dying patients* (29, 59%); and with item six: *The length of time required to give nursing care to a dying person would frustrate the nurse* (28, 57%). The majority of nurses also correctly disagreed/strongly disagreed with item two: *As a patient nears death, the nurse should withdraw from his/her involvement with the patient* (33, 67%). In addition, almost all participants correctly agreed/ strongly agreed with item 16: *Nursing care should extend to the family of the dying person* (48, 98%). Most of the participants also correctly agreed/ strongly agreed with item 13: *Nursing care for the patient's family should continue throughout grief and bereavement* (35, 72%) and with item 15: *Addiction to pain relieving medication should not be a concern when dealing with a dying person* (32, 65%).

Almost 95% participants incorrectly agreed/ strongly agreed with the item: *When a patient asks, “Am I dying?” I think it is best to change the subject to something cheerful* (46, 94%) and to item nine: *The nurse should not be the one to talk about death with the dying person* (30, 61%). Like the Context and Case 1 attitude results, all participants in Case 2 scored 50% or more for the modified version of FACTOD (see Table 6.3).

**Table 6.3**  
**Nurses' attitudes to palliative care**

No.	Items	SA	A	U	D	SD
1.	Palliative care is given only for a dying patient	6 (12.2)	13 (26.5)	1 (2.0)	5 (10.2)	24 (49.0)
2.	As a patient nears death; the nurse should withdraw from his/her involvement with the patient	5 (10.2)	9 (18.4)	2 (4.1)	5 (10.2)	28 (57.1)
3.	Giving nursing care to the chronically sick patient is a worthwhile learning experience	23 (46.9)	25 (51.0)	1 (2.0)	0	0
4.	It is beneficial for the chronically sick person to verbalise his/her feelings.	29 (59.2)	18 (36.7)	1 (2.0)	1 (2.0)	0
5.	Family members who stay close to a dying person often interfere with a professional's job with the patient.	19 (38.8)	18 (36.7)	9 (18.4)	2 (4.1)	1 (2.0)
6.	The length of time required to give nursing care to a dying person would frustrate me.	3 (6.1)	9 (18.4)	9 (18.4)	15 (30.6)	13 (26.5)
7.	Families should be concerned about helping their dying family member make the best of his/her end of life	31 (63.3)	17 (34.7)	1 (2.0)	0	0
8.	The family should maintain an as healthy environment as possible for their dying member.	34 (69.4)	9 (18.4)	4 (8.2)	2 (4.1)	0
9.	The nurse should not be the one to talk about death with the dying person	21 (42.9)	9 (18.4)	4 (8.2)	11 (22.4)	4 (8.2)
10.	The family should be involved in the physical care of the dying person	30 (61.2)	12 (24.5)	5 (10.2)	2 (4.1)	0
11.	It is difficult to form a close relationship with the dying person.	7 (14.3)	12 (24.5)	8 (16.3)	12 (24.5)	10 (20.4)
12.	There are times when death is welcomed by the dying person	15 (30.6)	25 (51.0)	3 (6.1)	4 (8.2)	2 (4.1)
13.	Nursing care for the patient's family should continue throughout grief and bereavement	21 (42.9)	14 (28.6)	3 (6.1)	3 (6.1)	8 (16.3)
14.	The dying person should not be allowed to make decisions about his/her physical care	6 (12.2)	12 (24.5)	6 (12.2)	12 (24.5)	13 (26.5)
15.	Addiction to pain-relieving medication should not be a concern when dealing with a dying person	19 (38.8)	13 (26.5)	7 (14.3)	5 (10.2)	5 (10.2)

16.	Nursing care should extend to the family of the dying person	30 (61.2)	18 (36.7)	0	1 (2.0)	0
17.	When a patient asks, “Am I dying?” I think it is best to change the subject to something cheerful	33 (67.3)	13 (26.5)	3 (6.1)	0	0
18.	I am afraid to become friends with chronically sick and dying patients.	6 (12.2)	8 (16.3)	4 (8.2)	16 (32.7)	15 (30.6)
19.	I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	4 (8.2)	21 (42.9)	4 (8.2)	7 (14.3)	13 (26.5)
20.	I would be uncomfortable talking about impending death with the dying person	13 (26.5)	12 (24.5)	6 (12.2)	10 (20.4)	8 (16.3)
21.	It is possible for nurses to help patients prepare for death	12 (24.5)	15 (30.6)	6 (12.2)	5 (10.2)	11 (22.4)
22.	Death is not the worst thing that can happen to a person.	7 (14.3)	10 (20.4)	7 (14.3)	3 (6.1)	22 (44.9)
23.	I would feel like running away when the person died.	9 (18.4)	5 (10.2)	2 (4.1)	7 (14.3)	26 (53.1)
24.	I would not be assigned to care for a dying person	6 (12.2)	7 (14.3)	5 (10.2)	12 (24.5)	19 (38.8)

### Self-reported palliative care practices

In the self-reported palliative care practice section of the survey, 33 (67%) participants scored lower than 75%. While 32 (65%) of participants indicated that they assessed the symptom of pain ('application of assessment tools - pain'), the other listed symptoms were addressed less often. In particular, participants indicated that they did not assess symptoms such as 'spiritual needs' and 'diarrhoea' and 'constipation' (29, 59%); 'fatigue' (28, 57%). The highest self-reported practice scored in the medication administration theme, 'administer tramadol' was 37 (76%) followed by morphine 24 (49%) (see Table 6.4).

**Table 6.4**  
**Self-reported palliative care practices of nurses**

Items		Yes f (%)	No f (%)
<b>Caring for people with a life-limiting illness practice</b>			
1	Counselling service	35 (71.4)	14 (28.6)
2	Hygiene	35 (71.4)	14 (28.6)
3	Family education	31 (63.3)	18 (36.7)
4	Comfort care	28 (57.1)	21 (42.9)
5	Patient education	23 (46.9)	26 (53.1)
6	Family meeting	21 (42.9)	28 (57.1)
7	Multidisciplinary team meetings	21 (42.9)	28 (57.1)
8	Working with community and religious leaders	21 (42.9)	28 (57.1)
<b>Application of assessment tools</b>			
9	Pain	32 (65.3)	17 (34.7)
10	Emotional/psychological state	27 (55.1)	22 (44.9)
11	Nausea and vomiting	24 (49.0)	25 (51.0)
12	Fatigue	21 (42.9)	28 (57.1)
13	Diarrhoea and constipation	20 (40.8)	29 (59.2)
14	Spiritual needs	20 (40.8)	29 (59.2)
<b>Administering medication for pain relief</b>			
15	Tramadol	37 (75.5)	12 (24.4)
16	Morphine	24 (49.0)	25 (51.0)
17	Paracetamol	23 (46.9)	26 (53.1)
<b>Using non-pharmacological management of pain</b>			
18	Distraction	33 (67.3)	16 (32.7)
19	Hot or cold compress	29 (59.2)	20 (40.8)
20	Massage	29 (59.2)	20 (40.8)
<b>Administering medication to treat symptoms</b>			
21	Nausea and Vomiting	29 (59.2)	20 (40.8)
22	Anxiety and Depression	28 (57.1)	21 (42.9)
23	Diarrhoea and Constipation	24 (49.0)	25 (51.0)

#### Correlation among outcome variables

In this case, a Spearman's rho correlation coefficient was used to identify the relationships among the outcome variables (Pallant, 2016). Similarly, to the Context result, there was a medium positive correlation between attitude and self-reported practice,  $\rho = .39$ ,  $n = 49$ ,  $p < .01$ , indicating a more favourable attitude was associated with a high level of self-reported



practice. However, like Case 1, there was a medium, negative correlation between knowledge and self-reported practice,  $\rho = -.39$ ,  $n = 49$ ,  $p < .01$ , indicating a high level of knowledge was associated with a low level of self-reported practice (see Table 6.5).

**Table 6.5**  
**Correlation between the outcome variables in Case 2.**

		Correlations			
Spearman's rho	knowledge	Correlation	knowledge	Attitude	Practice
		Coefficient	1.000	-.309*	-.396**
		Sig. (2-tailed)	.	.031	.005
		N	49	49	49
	Attitude	Correlation	-.309*	1.000	.394**
		Coefficient			
		Sig. (2-tailed)	.031	.	.005
		N	49	49	49
	Practice	Correlation	-.396**	.394**	1.000
		Coefficient			
		Sig. (2-tailed)	.005	.005	.
		N	49	49	49

\*. Correlation is significant at the 0.05 level (2-tailed).  
\*\*. Correlation is significant at the 0.01 level (2-tailed).

#### The association between the demographic and outcome variables in Case 2

Variables such as gender, working area, in-service palliative care training, and duration of the palliative care training had a significant association with the outcome variables.

There was a significant difference in self-reported practice levels concerning gender. A Mann-Whitney U test revealed that there was a significant difference in the level of practice of males ( $Md = 19.5$ ,  $n = 12$ ) compared to females ( $Md = 9$ ,  $n = 37$ ),  $U = 131$ ,  $z = -2.12$ ,  $p = .03$ ,  $r = -0.3$ . This rank indicates that males ( $Md = 19.5$ ) had a higher level of self-reported practice than females ( $Md = 9$ ). However, the difference between these two groups is very small.

Gender had a significant difference on attitude between males and females. A Mann-Whitney U test revealed that there was a significant difference in the level of positive attitude of females

(Md = 87, n = 37) males (Md = 79.5, n= 12) and  $U = 331.5$ ,  $z = 2.55$ ,  $p=.01$ ,  $r = 0.4$ . This rank indicates that females (Md=87) had the highest level of positive attitude, with males (Md = 79.5) the lowest. Again, the significant difference is very small.

There was also a significant difference in self-reported practice levels across different working areas. A Kruskal-Wallis Test (Pallant, 2016) revealed a statistically significant difference in level of self-reported practice across four different working areas (Gp1,  $n = 21$ : Medical ward, Gp2,  $n = 18$ : Surgical ward, Gp3,  $n = 5$ : ART, and Gp4,  $n = 5$ : OPD and emergency),  $X^2 (5, n=49) = 22.74$ ,  $p = .000$ . Nurses working in a surgical ward recorded a higher median score (Md=21) than the other three groups, which recorded a median value of 17 for nurses in ART; 12 for nurses in OPD and emergency; and 5 for medical ward nurses.

The attitude levels of nurses had a significant association with different working areas. A Kruskal-Wallis Test (Pallant, 2016) revealed a statistically significant difference in level of attitude across four different working areas (Gp1,  $n = 21$ : Medical ward, Gp2,  $n = 18$ : Surgical ward, Gp4,  $n = 5$ : ART, and Gp5,  $n = 5$ : OPD and emergency),  $X^2 (5, n=49) = 11.16$ ,  $p = .049$ . Nurses working in ART recorded a higher median score (Md=95) than the other three groups, which recorded a median value 86.5 for nurses in the surgical ward; 88 for nurses in OPD and emergency; and 79 for medical ward nurses.

There was a significant difference in self-reported practice levels, comparing in-service palliative care training. A Mann-Whitney U test (Pallant, 2016) revealed that there was a significant difference in the level of self-reported practice of those who had not taken palliative care training (Md = 7,  $n = 27$ ), compared with those who had taken such training (Md = 18,  $n = 22$ ),  $U = 459.5$ ,  $z = 3.28$ ,  $p=.001$ ,  $r = 0.5$ . Nurses who had undertaken palliative care training had the highest level of self-reported practice (Md=18) of those who had not taken palliative care training (Md=7).

The duration of in-service palliative care training. had a significant difference on attitude. A Mann-Whitney U test (Pallant, 2016) revealed that there was a significant difference between the level of positive attitude and the duration of in-service palliative care training. Nurses who had undertaken palliative care training for two weeks or more had the most positive attitudes (Md = 95,  $n = 7$ ), compared with those who had taken less than two weeks training (Md = 83,  $n = 15$ ),  $U = 88$ ,  $z = 2.5$ ,  $p=.01$ ,  $r = 0.4$ .

In the Case 2 survey results, the majority of participants held Bachelor's degrees and had learned about palliative care in their undergraduate courses. However, more than half had not received in-service palliative care training. In total, most of the participants scored lower levels of knowledge and poorer self-reported practice. All of the Case 2 survey participants had positive attitudes towards palliative care. There was a medium inverse correlation between knowledge and self-reported practice, indicating that higher levels of knowledge were associated with lower levels of self-reported practice. There was also a medium positive correlation between attitude and self-reported practice, indicating that participants who had a more favourable attitude were associated with a higher level of self-reported practice. In Case 2, the demographic variables such as gender, clinical area, in-service palliative care training and its duration were significantly associated with the outcome variables of attitude and self-reported practice.

### Qualitative results of Case 2

Like Case 1, in Case 2, the interviews were conducted at the General Hospital; Primary Hospital; Health Centre; and Health Post with the leadership teams of Nursing, Medicine, and Pharmacy working in General and Primary Hospitals; the medical leader and pharmacy head from the Health Centre; and a Health Extension Worker at the Health Post. One focus group discussion was held with four male and four female rural community members. A total of 14 interviewees, 10 males and four females were questioned in Case 2. The interviewees reflected their views of the status of palliative care policy, education, availability of medication and implementation in their settings. They also highlighted the challenges and opportunities related to the implementation of palliative care in their settings.

From the interviews, three major themes of Case 2 emerged: *palliative care policy and guidelines*; *palliative care education and training*; and *palliative care implementation*. Each theme is elaborated by sub-themes (see Table 6.6).

**Table 6.6**  
**Case 2 themes and sub-themes**

Themes	Sub-themes
Palliative care policy and guidelines	<ul style="list-style-type: none"> <li>• Policy status of palliative care and palliative care guidelines and related documents</li> </ul>
Palliative care education and training	<ul style="list-style-type: none"> <li>• Palliative care training</li> <li>• Professional and community awareness of palliative care</li> </ul>
Palliative care implementation	<ul style="list-style-type: none"> <li>• Pain management</li> <li>• Providing care</li> <li>• Resources related to opportunities and challenges</li> </ul>

### Palliative care policy and guidelines

As already described in the first chapter and the previous results chapters, there is a National Palliative Care Guideline and national health care plans that include palliative care. In this theme, participants described how the palliative care policy and plans translated in this second sub-region (Case 2). The interviewees were asked to clarify what they understood about the availability of palliative care policy and guidelines and for whom palliative care documents were available. Participants highlighted their perception about the priority given to palliative care and the regional government's focus on policy. One sub-theme was included: *policy status of palliative care and palliative care guidelines and related documents* in their health settings.

#### *Policy status of palliative care and palliative care guidelines and related documents*

Participants in Case 2 described their views about the presence of palliative care at the national health care policy level and the availability of these policies and guidelines in their settings. They also clarified their perceptions of the priority and focus on palliative care by the government policymakers as well as health professionals working in their settings.

Participants in Case 2 suggested that because a palliative care policy was not evident there was little ability to implement palliative care in their settings:

*... if we are going to talk about the status, it [palliative care policy] should be in place first ... palliative care is not [implemented] as a protocol or policy*

(Participant 2GHD)

This participant further clarified that the consequence of a low priority on palliative care by policymakers meant that health professionals in the Case 2 were reluctant to support the development of it in their settings, given competing needs:

*... the government may not consider palliative care as a priority at this moment ... we did not consider ... palliative care as an important part of the medicine ... There are a lot of things that need priority ... everything is now focused in maternal and child health ... So, palliative care is a sort of luxury ...*

(Participant 2GHD)

Similarly, other participants further described consequences results from palliative care being a low priority for policymakers; both health professionals and community members following this lack of direction:

*... the government did not give priority to it [palliative care] ... the focus is on communicable disease. The non-communicable diseases ... did not get priority from the top leaders ... the professionals are motivated to implement the government directions ... Even the community are following the [footsteps] of top leaders' direction ...*

(Participant 2PHND)

Professionals working in the health care settings and the focus group participants again described policy priorities are to the exclusion of palliative care:

*... we have a good health professional service in pregnant mothers ... and communicable diseases, but the chronic non-communicable disease did not get focus.*

(Participant 2RCFG)

In Case 2, participants perceived that palliative care was not included in the national health policies and guidelines and the government had a low focus on palliative care because of the priority given to treatable and preventable diseases. Professionals and community members followed this lead, meaning that palliative care was not prominent among a range of competing needs.

Palliative care is included in the National Cancer Control Plan (NCCP) and Health Sector Transformation Plan (HSTP); a National Palliative Care Guideline is also developed as

mentioned in the previous result Chapters and Chapter one. To determine if these documents or other related documents were available, participants were asked to clarify which palliative care documents were available in their settings. They also described where and with whom the documents were located in their settings.

Participants in Case 2 said that there were no National Palliative Care Guideline available in the ‘Zone’, with the exemption of a few documents that included reference to palliative care. They said that the pain management guideline, Ethiopia Hospital Service Transformation Guideline (EHSTG), and a WHO Module in a PowerPoint were only available for the leadership participants of the General and Primary Hospitals (see Table 6.7). The participants indicated that these documents were unavailable in either the Health Centre or the Health Post.

**Table 6.7****Available palliative care and related documents in Case 2**

<b>List of palliative care and related documents</b>	<b>Awareness and Availability</b>	<b>Neither Aware nor Available</b>
Pain management guideline	Nurses working in medical ward	<ul style="list-style-type: none"> <li>• Pharmacy leader of the General Hospital</li> <li>• Primary Health Care Unit (Primary Hospital, Health Centre and Health Post) participants</li> <li>• and surgical ward, and Medical and nurse directors of the General Hospital</li> </ul>
EHSTG (Ethiopia hospital service transformation guideline).	Nurse and medical leader of the Primary Hospital	<ul style="list-style-type: none"> <li>• General Hospital</li> <li>• Health Centre and Health Post participants</li> </ul>
WHO palliative care training ppt	Medical doctor of the General Hospital	<ul style="list-style-type: none"> <li>• Nurse leader; clinical nurses' leader; and pharmacy leader from the General Hospital</li> <li>• Primary Health Care Unit (Primary Hospital, Health Centre and Health Post) participants</li> </ul>

Despite the leaders in General and Primary Hospitals having access to some palliative care guidelines and related documents, they were not distributed to the professionals working directly with patients, or to Health Centres and Health Posts of the ‘Zone’.

### Palliative care education and training

This theme describes how the participants in Case 2 experienced education and training related to palliative care. Participants also described their views on how professionals and the community understood palliative care. They further clarified where and to whom the palliative care training was provided and, the presence of palliative care in the health care curricula. This theme consists of two sub-themes: *palliative care training*; and *professional and community awareness of palliative care*.

#### *Palliative care training*

In this sub-theme, participants reflected on the focus of training they had received and how they practiced after their training. They also clarified where the training was provided, and which professions were trained. The opportunities and challenges related to palliative care training were also described.

Some participants indicated that palliative care training was given to health care staff in general. For example, the medical doctor working in the General Hospital provided training to the nurses and doctors working in the medical, and surgical wards, and the Anti-Retroviral Therapy (ART) staff in the General Hospital and Health Centre:

*... there was palliative care training for health care workers ... I used to provide training for ... the [selected] nurses, general practitioners ... working in medical ward, OPD [Outpatient Department], surgical wards and ART ... but not to all [professionals] ... It [the training] is not only [given for] nurses and GPs ... but [also] ... For the professionals working in Health Centre ...*

(Participant 2GHD1)

One of the trainees working in the ART clinic reflected that in-service training was pain management rather than palliative care education:



*... there was a training ... we got an invitation letter which indicated palliative care training, unfortunately, the training was pain management.*

(Participant 2PHWNH1)

Other participants claimed that palliative care training was only given to nurses working in ART because NGOs provided financial support for palliative care training only to ART staff:

*When we see palliative care, it connects with ART training ... Most of the time, the CDC projects ... providing support to the training in ART ... we do not have professionals trained in palliative care other than ART nurses ... Even there is no plan to have palliative care training ...*

(Participant 2GHND)

The General Hospital doctors also explained that palliative care was not included in the medical student curriculum. However, they mentioned that ART training was given to the graduate medical students:

*... in the university level ... palliative care is not incorporated in the curriculum. But ... comprehensive HIV care training ... or ART training is given for every graduate medical student ...*

(Participant 2GHD1)

This participant also highlighted the issue of high turnover of staff, suggesting the need for regular consistent training to all new staff:

*... there is a lot of turnover of health care workers. So, we have to give training every time when you have recruited health care workers ...*

(Participant 2GHD1)

However, despite the training available at the General Hospital, participants working in the Health Centre said they had received no training for either palliative care or pain management:

*... no palliative care training at all ... if the health professional is not trained how can we translate the knowledge to the community.*

(Participant 2HCHO)

In Case 2, despite palliative care or pain management training being provided to a few health care professionals and graduate medical students, there was little training available in primary health care, particularly in the Health Centre and Health Posts, and it was difficult to discern either a planned training program or the content of training.

### *Professionals and community awareness of palliative care*

Participants were asked to elaborate on how professionals and community understood palliative care. They also discussed the challenges related to increasing palliative care awareness in health care professionals and community members.

As in Case 1, participants in Case 2 said there were professionals who did not understand the term ‘palliative care’. However, this medical doctor highlighted that palliative care was not only focused on medical treatment, but also physical, psychosocial, and spiritual care:

*... we usually do not have the idea on the concepts of palliative care. It is not only a medical care, I think it [palliative care] includes psychological, social and spiritual components and so on ...*

(Participant 2GHD1)

Other participants said that despite ART nurses having information on palliative care, those working in the General Hospital and in Primary Health Care Units lacked awareness:

*... Except for ART nurses, we have nurses who did not know the term palliative care ... and to whom [which patients] we [should] give palliative care ...*

(Participant 2GHND)

Some participants perceived that community members, as well as professionals, had little awareness of palliative care. For example, a medical doctor explained how the community reacted and understood palliative care when someone was diagnosed with incurable disease. This participant said that the community members turning to spiritual healing methods if they knew they had an incurable disease.

*... when the patients and family are aware their disease is incurable, they do not usually come to hospital ... they prefer to go to the holy water or spiritual healers ... they don't*

*prefer to follow on with the palliative care issue, because they [community] do not know palliative care ...*

(Participant 2GHD1)

Some participants justified why the community had low palliative care awareness, suggesting that patients and families misunderstood chronic diseases like cancer:

*... palliative care awareness of the community is low ... the community understand cancer as a killer disease but how to manage, what to do is not known ... they search their own alternatives ...*

(Participant 2PHND)

In addition, the focus group community participant, and some other health professional participants in Case 2 described how the family members lacked information about how to provide care for their chronically ill relatives at home. The focus group participants also made suggestions to enhance community palliative care awareness:

*... the community have a lack of awareness ... the family member of chronic patient, did not know how to look after the chronic patient ... at home ... the family should be trained ... Although the patient did not get the sustainable curative management [curative treatment], he/she can be satisfied and happy until the end of their life.*

(Participant 2RCFG)

However, participants described how they provide health education for patients with some incurable diseases; provided by Health Extension Workers (HEWs) and other clinical staff on care of the patient diagnosed with HIV. They also suggested it was possible to enhance palliative care awareness in the community by educating all professionals and administrative bodies:

*... we provide health education to the family members, how to provide care for HIV patients ... and how to look after themselves ... at home ... palliative care ... awareness should be given starting from the top policymakers to the professionals in every level and administrative bodies ...*

(Participant 2HEWHP)

Despite the possibility of the media enhancing community understanding of palliative care, other participants suggested the media were focused on preventable diseases rather than palliative care:

*... there are directions ... from the top levels, the media are working in prevention health activity, but it [media] did not focus on palliative care from the top to the bottom levels. The focus is for the acute and epidemic not the non-communicable diseases.*

(Participant 2PHND)

The General Hospital doctors suggested that enhancing palliative care knowledge and attitudes started with education of policymakers and administrators:

*Sustainability started first with changing the knowledge and attitude ... palliative care training should be given to policy makers, staff, administrators, Regional Health Bureau, federal ministry of health care workers ...*

(Participant 2GHD1)

In contrast, the medical director said that, while professionals already had palliative care knowledge, the challenge was the attitudes of professionals and administrative bodies which impacted on the practice of palliative care:

*... it is more an attitude ... problem ... it is not only the physicians ... but the political leaders ... clinical health bureaus and others ... So, the big gap is in the attitude is not in knowledge, we know we have the knowledge ... Our attitude should change first.*

(Participant 2GHD)

Despite the ART staff and HIV patients and family members having palliative care information, generally, health care professionals and community members lacked awareness about palliative care, with health professionals describing the main issue as attitudinal in implementing palliative care education. Suggestions were given to enhance professionals', community members', and administrators' palliative care knowledge and attitudes through consistent training.

### [Palliative care implementation](#)

Participants in Case 2 described how health professionals provided care for the patients diagnosed with incurable diseases. These participants reflected how and where the family looked after the patients and when the doctor informed the patients and family that the disease was not

curable. The opportunities and challenges related to palliative care were also described. In this theme there are three sub-themes: *pain management*, *providing care*, and *resource related to opportunities and challenges*.

### *Pain management*

Like the previous two results Chapters, participants said that pain management is an essential part of palliative care implementation in health care settings. In this sub-theme, participants described how severe pain was managed, the availability, accessibility, affordability, prescription, and administration of opioids particularly morphine.

Like in the Context, despite pain medications being available in the General and Primary Hospitals, participants in Case 2 claimed that morphine was not consistently accessible:

*... in palliative care medical wing ... we focus on pain ... we usually follow WHO pain management ladder ... we have pain medications up to a level of morphine ... But ... morphine ... is not consistently available ...*

(Participant 2GHD1)

Another participant also described the available forms of morphine, suggesting that morphine syrup was not accessible, but the doctors were prescribing it:

*... we have morphine in the form of tablet and IV. We do not have a syrup form ... Morphine was prescribed by general practitioners and above ...*

(Participant 2PHHO)

However, there was reticence from some doctors, particularly general practitioners, to prescribe morphine because they feared the side effects, resulting in morphine only being prescribed by specialists in the General Hospital:

*... Most of the time, morphine prescribed by the internist, surgeon, orthopaedics ... for inpatients who have a severe pain such as femoral bone fracture [because] the general practitioners fear the side effects to prescribe morphine ...*

(Participant 2GHD1)

Other participants argued that, despite morphine being available in hospital, some doctors were unaware of it. However, in the General Hospital, the clinical nurse of the medical ward said that morphine was neither available nor prescribed by the doctors in his ward:

*... they [doctors] did not prescribe morphine still now ... morphine is not available in our hospital ...*

(Participant 2GHWNH1)

And the General Hospital clinical nurse leader of the surgical ward clarified that morphine was not often prescribed in their ward either:

*... the doctor starts from the mild pain medication to severe, they start from paracetamol, diclofenac, tramadol, ibuprofen, pethidine, if it is not managed ... morphine is a rarely prescribed medication.*

(Participant 2GHWNH2)

Morphine was available in hospitals, but not all doctors prescribed it, because there were doctors without information on its availability, inconsistent availability in addition to fear of side effects.

In addition, the director of the Health Centre reflected that morphine was unavailable in the Health Centres and Health Posts, because country regulations prohibited the availability of morphine in these settings due to the lack of qualified medical staff to prescribe it:

*... we have a standard coming from the Regional Health Bureau, what medications should be available in Health Centre, primary, General Hospital. So, we do not have morphine ...*

(Participant 2HCHO)

Country regulations, additionally, did not permit nurses to prescribe opioids including morphine:

*... opioids [such as] pethidine, codeine, morphine is not allowed to prescribe by the nurses. But they can prescribe NSAIDs [such as] paracetamol, diclofenac, tramadol tablet and injection ...*

(Participant 2GHD1)

As in Case 1, participants said that tramadol was the strongest level of pain medication in the Health Centre. If the patient's pain was not responding to tramadol, then they were referred to the hospital:

*... we are treating mild and moderate pain ... we call mild, starting from paracetamol, diclofenac, ibuprofen and indomethacin ... tramadol is our maximum anti-pain drugs ... for those who not treated [whose pain is not relieved] with tramadol, we refer to the hospital.*

(Participant 2HCHO)

As in Case 1, at the Health Post, the HEW claimed that paracetamol was the only pain medication available in their setting:

*... we do not have any other medication except for paracetamol that we give for the patient in our clinic ... but this is not working for the cancer patients ...*

(Participant 2HEWHP).

The patient participant in the focus group said that the prescribed pain medication in Health Centre did not relieve his pain:

*... when I feel suffering, I got anti-pain from the Health Centre, but it is not working. I am just taking it simply instead of keeping silent, I took the medication though not working for me ...*

(Participant 2RCFG).

Participants in Case 2 believed that the challenges were not because of budgetary constraints, but a lack of medications from the Pharmaceutical Fund and Supply Agency (PFSA). For example, the General Hospital pharmacy leader described morphine as one of the cheapest medications, but when the pharmacy made a purchase list of medications from the PFSA, they may only receive a small amount:

*... in this hospital, we don't have a budget problem ... morphine is not expensive ... the challenge we have is lack of medications from PFSA. When we list the medicines to buy in PFSA, from a list of 300 medicines only 50 or 60% were available ...*

(Participant 2GHP)

Morphine was unavailable in Health Centres and Health Posts because the country standard prohibited it. So, tramadol was the strongest pain medication prescribed in the Health Centre and paracetamol in the Health Post. There were issues with the limited supply of morphine in the pharmacy store of the hospital, resulting from issues with the central supply at the PFSA.

### *Providing care*

In this sub-theme, participants of Case 2 reflected on their perception of the status of palliative care implementation in their setting. They acknowledged how professionals provided care to patients diagnosed with incurable disease in the health care settings and at the patients' homes. Participants described palliative care as being implemented for HIV patients. They recognised that physical care, pain-management, and psychosocial supports were also provided in General and Primary Hospitals of Case 2. Some participants also described the family role in providing care at home, and taking their sick relatives to hospitals and alternative care sites. They also elaborated on the challenges and opportunities related to the care given at home and in the health care settings.

As in Case 1 and the Context, some participants recognised that palliative care was only implemented for HIV patients in the hospital. For example, the General Hospital's nurse leader said that there was no thought of providing palliative care for patients with other incurable disease:

*... the main thing is focus and thinking about palliative care ... so, we do not think about ... palliative care and rehabilitation ... nothing is available ... palliative care [for] those with non-communicable disease is not started yet except for HIV patients.*

(Participant 2GHND)

Participants confirmed that palliative care was available for people with HIV because there was financial support from NGOs and a high incidence of HIV:

*... as a country, ... palliative care is implemented as part of comprehensive ART [Anti-Retroviral Therapy] care for HIV patients ... you cannot only manage HIV with drugs, it needs psychological, spiritual, social support and so on ... HIV is a public health problem ... the HIV medication, the care, and treatment are supported by international NGOs ... Every HIV medication is for free ...*



(Participant 2GHD1).

This participant further described that palliative care for HIV patients was not only implemented in the hospital, but it was also given at the patients' home because HIV patients needed to have continuous follow-up:

*... those [HIV] patients who required rehydration, treatment of vomiting and diarrhoea and so on, it can be easily managed in the hospital. But the problem is ... the treatment should be consistent ... so, they [HIV] patients can be treated with IV medications ... at home ... home palliative care was provided for ART patients ...*

(Participant 2GHD1)

In addition, some participants suggested that there were case managers who provided psychosocial support for HIV patients at home, being trained by the NGOs to provide palliative care:

*All ART patients are receiving palliative care ... such as psychological support and managing pain in their home ... case manager is recruited by NGOs ... to provide palliative care and psychological supports ... and social care by going to the patients' home ... They are not professionals, but HIV patients who get some training in palliative care ...*

(Participant 2PHWNH1).

Another participant also highlighted the case manager's role and how they communicate with the HIV patients using mobile phones. Despite this practice, this participant believed that it was impossible to provide home-based palliative care for other chronic disease patients:

*there are case managers trained to communicate with the patients or home care via telephone ... home palliative care for those out of ART patients is unthinkable because the government cannot afford it.*

(Participant 2GHD1)

In addition, the focus group participants described that HIV patients were supported by both governmental and non-governmental organisations with non-HIV patients not receiving such assistance from these stakeholders:

*... we consider a chronic disease patient in our rural area is HIV AIDs, get follow-up already ... I think in HIV may have a good service ... our Tabiya [district] administration, when some benefits come from NGO or the government, they support them ... But in our district the main challenge is chronic patients other than HIV ...no one looks after them*

(Participant 2RCFG).

However, despite palliative care being implemented for patients with HIV at home, some participants commented that the HIV patients did not want to receive home-based care because they feared stigma and discrimination in their communities:

*... the HIV patients fear stigma and discrimination ... so they do not want us [professionals or case managers] to go to their house to provide care ...*

(Participant 2PHWNH1).

Palliative care was implemented in health care settings as well as at the patient's home for those with HIV in some settings. There were case managers who provided psychosocial support and links with the doctors. Palliative care for HIV patients was not consistently delivered because it was dependent on the NGO support.

Despite participants highlighting that palliative care was implemented for HIV patients, some participants working in Primary Health Care Units and General Hospital argued that palliative care service had not been implemented in any settings across the country:

*... we are not yet start to implement palliative care ... it is difficult to say available, I prefer to say it [palliative care] is not applicable ... not only here [Primary Hospital], even in our country, we don't have palliative care.*

(Participant 2PHND)

However, other participants perceived that despite palliative care not being implemented as a whole service, there were aspects of physical care, pain management, and psychosocial support provided to chronically ill patients in the hospitals. For example, the nurse leader suggested that psychologists and sociologists need to be in the hospital to provide holistic palliative care service because it needs a multi-disciplinary team:

*... they [nurses] are providing physical care and some advice ... this is not to the standard of palliative care ... because palliative care is not only physical care ... It includes psychological, social and all types of care ... palliative care needs a person graduated in psychology, sociology to provide psychological and social care, it is teamwork ...*

(Participant 2PHND).

A medical doctor suggested that the nurses provided psychosocial support and the doctors focused on treatment in the ward. However, the participant was concerned that this care and support was provided without a conscious understanding of palliative care:

*... palliative care usually focuses on main medical treatment ... by the physician ... and the psychological and social support in the ward is given by the nurses ... for example, in hospital, we provide ... treatment, pain management, oxygen support and so on for cancer patients ... but I am afraid not up to the standard. Because there is no up to date follow-up ...*

(Participant 2GHD1).

The General Hospital clinical nurse leader described many aspects of patient care starting from admission to discharge, the participant highlighting the lack of bereavement care:

*... we provide care ... to the patient diagnosed with incurable disease ... since admission until peaceful death ... such as positioning, prevention of bedsore, bed bath ... changing bed lines and blankets ... measuring vital sign ... administering medication ... managing their chronic pain ... and we provide psychological support for the patients ... even if the death happens ... based on the culture of the community, we are providing [post-mortem] care ... but we do not have a bereavement care ...*

(Participant 2GHWNH1).

In addition, participants working in Primary Hospital described how they provided care for patients in need of palliative care, with the medical director detailed the nursing care provided in their hospital using this example:

*... we are providing medical support ... for example, a few days before, we had a child who sleep for five months in here [Primary Hospital] ... he was discharged from the big*

*hospital because he was not cured but, here for around six months ... He gets supportive care and manages his pain, positioning, to prevent bed sore ... so we have such type of care ... in our hospital ...*

(Participant 2PHHO).

Therefore, as in Case 1 and the Context, despite a lack of understanding of the holistic philosophy of palliative care, participants articulated aspects of physical care, pain management and psychosocial support that was provided for patients admitted in General and Primary Hospitals.

In addition to care of the patients, some participants described how they provided emotional support for the family members. For example, the clinical nurse leader recalled that some families prefer to take the chronically patient home to die while others prefer to receive care at the hospital. They said that some family members were unable to pay for transport of the body to their home for burial:

*... we provide care though the patient case is not cured ... we provide advice to family on the hospital care ... Some of the family accept our advice so we provide care until the patient's death. Some of them did not accept our advice because they did not want to pay for the transport ... because it is expensive to pay for the transport of the dead body, so they prefer to discharge earlier and the patient to die at home.*

(Participant 2GHWNH1).

In addition, when the patients and family knew their diagnosis was incurable, they were unable to pay for hospital care, except for pain management, if the pain was severe; thus, there is a preference for dying at home:

*... they [the community] do not want to afford and pay for incurable disease. Just keep being treated for pain that is very demanding [severe], so they [the family and the patient] will leave the hospital, the patient prefers to die at home.*

(Participant 2GHD1).

Some doctors recommended patients to die at home considering the benefit and risks of referral:

*... there is only a single hospital providing radiation [treatment for some cancers] in the country ... Even the patients may die before getting care [waiting for their appointment for treatment] ... they may add an economic crisis to the rest of their family ... so we consider all things but what usual practice is sending patients to their home to die in peace ...*

(Participant 2GHD).

Participants justified why the doctors preferred to send the chronically ill patients' home, especially if there was late presentation to the hospital. However, this participant described that the hospital was the best place for pain management:

*... they [the patient and family] prefer to get the possible end of life care when they have severe pain and other symptoms ... they prefer the health facility to get the appropriate anti-pain, the patient and family become stressed, so they prefer to go to the hospitals ...*

(Participant 2HEWHP).

Therefore, while the patient and family prefer the hospital for pain management, financial costs of hospital care meant they preferred to die at home.

Some participants described that the patient and families preferred alternative care when they knew the case was not curable, seeking treatment from holy water. For example:

*... when the patients went to the hospitals ... They [doctors] said your disease is impossible to treat by our capacity, you will not be cured ... by understanding these words, the patient thinks I will not be cured in the hospitals and they become hopeless and search a curative treatment from different holy waters ...*

(Participant 2RCFG).

In addition, the patient in the focus group said that after losing confidence in hospital care and traditional treatment, he sought to visit the holy water sites:

*... it has been four years since I was sick, I face a lot of difficulties and challenges ... with the hospitals; and the surgery of harmful traditional practice. I gave up I am trying everything ... I am not going to health institutes. I was frustrated ... I was crying ... I am going to different holy water sites ...*

(Participant 2RCFG).

Some participants also clarified the care family provided at home by preparing the patient food, giving psychological support, and checking prescribed medication:

*... they [the patients] have family in their home, wife, children, all this is giving the patients care ... And other kinds of care given by the children then the patients died peacefully ... one thing in the feeding process, the family provide emotional support ... and follow-up in the prescribed medication ...*

(Participant 2HEWHP).

Despite the willingness of families to provide care at home, some participants highlighted the challenges for family members who look after dying patients, such as feeling upset, not being able to leave the patient alone and thus being unable to work, resulting in financial difficulties:

*... when the family saw always, he/ she is sick, they are frustrated, so the patient did not get the appropriate care [from the family] ... there are different challenges such as transport and financial problem, even the family caregiver, if I [the family] have patient ... I have to look after him/her. So, I am not going anywhere, I have to give care. Not only with the patient in bed, I could not also leave him/her alone at home ...*

(Participant 2RCFG).

Other focus group participants also elaborated the difficulties of chronically ill patients with no family, waiting alone at home to die. They suggested that the government needed to provide services to care for them:

*... there are a lot of chronic patients who died due to ... lack of someone or family to look after them and to take them to the health facility ... the only alternative they have is waiting for the time of death at home ... those who have no family to look after them, the government should give attention just like aged care service ...*

(Participant 2RCFG).

Some other participants from the focus group suggested that chronically ill patients need professional support for patients as well as the family:

*... the patient needs psychological and other kind of support from health professionals ... but in the ground, it is not like that ... there should be a health professional in our home who provides care for chronic patients and looks after us until the end of our life ...*

(Participant 2RCFG).

Therefore, despite many families seeking the best care for their family member at home, they face significant issues and require professional support. Other patients had no family support and either lacked health professionals to care for them at home or faced their death alone.

### *Resources related to opportunities and challenges*

This sub-theme reflected the participants' perceptions about the opportunities and challenges related to resources available for the delivery of palliative care. They described their views about financial and human resources, palliative care clinics and mobile phone technology to implement palliative care.

Some participants described the opportunities related to having general practitioners and specialists in the General and Primary Hospitals:

*... we have a top-level specialist and general practitioners, and we also have nurses who are providing care together with the doctors ...*

(Participant 2GHWNH1)

However, this participant also claimed that the nurse-to-patient ratio was not to the standard required to provide the holistic palliative care:

*... for the 50 patients totally, we have 17 nurses ... then based on the standard, one nurse provide care for six patients. but here, we could not do that. Even 12 to one is difficult. So, there is a problem to implement palliative care.*

(Participant 2GHWNH1)

Some participants also described a lack of palliative care-trained professionals. For example, the medical doctor of the General Hospital suggested that palliative needed skilled health care professionals in all health care settings, such as hospitals and Health Centre:

*... in [our region], there are a lot of hospitals, but you cannot find a lot of health care professionals in cancer management ... having the hospital is not enough to start the*

*palliative care integration to the existing health system ... the most important thing is professionals should be trained in palliative care...*

(Participant 2GHD1)

Differently to Case 1, some participants suggested to include palliative care in the activity of HEWs, thus integrating palliative care into the care, including the patient's preference to die at home:

*... when HEWs move to the patient house, they can find chronically ill patient who sleep and suffering in their home ... they can provide palliative care service ... So, with these 16 components, ... there is an issue to include the chronic diseases with these components, so palliative care is part of chronic disease care. If it is integrated in these components ... the patients can get the better service ... Even if they may prefer to die in their home ...*

(Participant 2HCHO)

While doctors and specialists were available in General and Primary Hospitals, participants suggested training for health care professionals and to integrate palliative care into the existing health system including the HEWs' activities.

Further resources, challenges and suggestions were that palliative care should have a separate clinic and palliative care should start in one hospital as exemplary for the remaining hospitals:

*... the hospitals should have a specific ... palliative care ... room ... and we have to start palliative care at one big hospital [name of the hospital], as a pilot project ... that the patient can refer to it, for palliative care ... then we can continue to other hospitals.*

(Participant 2GHD1)

In addition, some participants from the General Hospital stated that the hospital evaluation guideline indicated that palliative care needed a separate clinic and physiotherapist, and these were unavailable in the hospital:

*... it [EHSTG] shows ... to have physiotherapy ... focal person and a separate [palliative care] class ... to implement the service because we have no physiotherapy, and we have*



*no separate classes. we neglect that Chapter... zero report ... Our infrastructure could not be able to implement palliative care*

(Participant 2PHHO)

Palliative care not only requires a separate clinic, but palliative care needs separate financial resources. Participants highlighted that palliative care should not be a predominantly professional and hospital responsibility, but a concern of the national and regional government:

*... palliative care is not implemented by a single physician, hospital or Health Centre, it should be in the federal ministry of health, Regional Health Bureau ... So, the budget should be assigned ...*

(Participant 2GHD)

However, as in Case 1, this participant also clarified that being a poor country and an economically constrained community added to the challenge in providing palliative care for patients diagnosed with chronic diseases. He suggested that the government should have a leadership commitment to enhance and motivate funding organisations to provide financial support for palliative care:

*... we have to take poverty into consideration, not only the society even the government had no money ... let alone ... palliative care for every ... disease ... even for the HIV patients ... it is [difficult] ... [in addition] the community did not want to afford and pay for incurable disease ... So, ... the core is poverty ... the government can give a political commitment, but the funding should come from another, so the political commitment will help the other funders to come and operate in this hospital. That is what has been done in HIV*

(Participant 2GHD1)

In addition, some participants elaborated that patients were suffering with incurable diseases due to lack of financial support. For example, the focus group participants described how financial challenges delayed treatment for acute disease, resulting in its further progression:

*... the challenge is the financial problem of the community. The family lack capacity to support as the patient need it... For example, if the caregiver does not have enough money, he/she will leave the patient at home and went to work ... If you cannot get money*

*to treat it [the acute problem] changes to chronic disease ... now, when you go to the health facilities, you spend a lot of money ...*

(Participant 2RCFG)

Despite the health insurance initiative in the community, designed to support the funding of health care, focus group participants reflected that the service was not yet started because all the members had not paid the insurance premium:

*... the health insurance is a solution for getting early treatment ... with the health insurance you can easily get treated, if it was started with those who paid ..., however. all the community was not paid ... those who paid could not get the service until all the community paid ... so the health insurance is not starting yet ...*

(Participant 2RCFG)

Some other participants described the opportunity of financial support from local and international NGOs. The HEWs described that there was some financial support to fund those patients who had economic problems, provided by NGOs and community members in the region:

*For those, who have economic problems ... we facilitate to get support ... from the community and the SafetyNet ... For example, HIV-infected patient, they lost their life in the earlier times. So, we consider the main reason for this is ... economic problem.*

(Participant 2HEWHP)

Other participants questioned the sustainability of palliative care for patients with HIV, without consistent support from NGOs:

*... when the NGOs are holding the project, we implement a standard palliative care for HIV patients ... for example, we had established a local NGO [such as] mom-to- mom. The HIV patients were sharing their experience ... We also had a cultural coffee ceremony time ... because, there was a small incentive [money]... from the NGOs such as I-TECH [International Training and Education Centre for Health] ... and others ... When the NGOs handover to the government to phase out, the care completely stops ... we are dependent on the NGOs.*

(Participant 2HCHO).

In addition to recommending financial support, some participants also suggested that the community network might help to provide social support and a link between the patient and the health professionals or NGOs, in particular, connecting by using mobile phones:

*We already have case managers who facilitate the HIV care by using mobile phones to connect with the doctors and NGOs ... we assigned one to facilitate a support activity for those patients who have a problem, those who need economical support ...*

(Participant 2PHHO)

The medical doctor working in the General Hospital also described how they provided HIV care at home with the aid of mobile phones:

*... we reach out to HIV patients with phone, particularly, when they have an appointment ... We have to call to attendant or brother, sister or a family with phone*

(Participant 2GHD1)

Some participants described that every household of the district had the phone number of HEWs that assisted with communication about the health care services:

*... every farmer has Health Extension Worker's mobile phone number ... If some of them have no phone, they use their neighbour's if there is emergency and for mothers, they called us especially in relation to pregnant mothers ... we have a good communication ...*

(Participant 2HEWHP)

However, despite chronically ill patients calling ambulance services for support, focus group participants described the challenge of transportation in rural communities, because of the priority given to pregnant mothers:

*... I have been calling for the ambulance many times, they told me it is for pregnant mothers not for you ... from my home to Health Post takes two and half hours ... There are a lot of emergency deaths because of these problems. This and other things make the chronic patients suffer a lot ... we lack the transportation and other problems ... so, we suffer at home ...*

(Participant 2RCFG)

The HEWs confirmed that there were insufficient ambulances to serve all the patients, so they were not used for chronically ill patients:

*... we have a lack of ambulances, so we give priority for those who can live longer or for those who need emergency care to save their life quickly ... So, we inform the chronic patients the ambulance is not for you ... people carry them to come to the hospital which is a traditional way of transport.*

(Participant 2HEWHP)

Although mobile phones were used to communicate between community members and the HEWs and other stakeholders, other infrastructure such as patient transport and emergency services were under resourced for chronically ill patients.

In Case 2, participants believed that palliative care was not available in health care setting of this sub-region, reflecting its lack of inclusion in the national health policies and guidelines. They believed that palliative care had a low focus in policy, meaning that health professionals and community members were reluctant to provide focus on palliative care. In addition, the national palliative care guidelines were not available in health care settings, except for a few palliative care related documents than resided with the leaders of the General and Primary Hospitals.

Palliative care training was given to a few health care professionals working in different health settings. However, some participants claimed that the training was only given to ART staff and the training was focused on pain management, rather than palliative care. Patients with HIV and family members also had information about palliative care because the ART staff and other professionals provided education. In addition, participants indicated that palliative care was not integrated into the medical students' curriculum, except in HIV training for graduate medical students: so, most health professionals and community members lacked palliative care awareness. Participants suggested training to enhance palliative care knowledge and attitudes of professionals, communities and policymakers.

Pain was managed in Case 2 using different pain medications including morphine. Morphine was available in both General and Primary Hospitals, but not consistently available in the pharmacy store because there was a lack of morphine centrally at the PFSA. Despite this, when morphine was available in the hospital, all the doctors were not prescribing it because they feared the side

effects and lacked information about its availability. Morphine was unavailable in the Health Centre and Health Post because the country's medication standard did not permit it to be there and the nurses and assistant doctors could not prescribe it. Tramadol was used to manage pain in the Health Centre and paracetamol in the Health Post.

Palliative care was described as being implemented for HIV patients in hospitals and at a patient's home because NGOs provided financial support for HIV care and treatment. However, when the NGOs handed over the project to the government, the palliative care service was no longer delivered. In hospitals, despite the holistic palliative care service not being understood, participants reported that physical care, pain management and psychosocial support was provided by health care professionals. In addition, health professionals provided emotional support to patients' families in the hospital. However, although some preferred the hospital for pain management, others preferred to look after the patient at home or at alternative care sites because of financial difficulties. There were also patients who had no one to look after them at home.

There were a number of resource related opportunities and challenges in palliative care implementation. In the General and Primary Hospital, doctors trained to prescribe morphine were needed. There was also a health care initiative that could help the community members to solve their health care related financial challenges. However, there was a gap in the implementation of health insurance in Case 2, because not all community members could pay a premium. There was also the opportunity of using mobile phone technology for future palliative care. However, staff indicated that the patient-to-nurse ratio would not allow the provision of palliative care: lack of budget, lack of a palliative care clinic and lack of palliative care-trained professionals in the region were issues impacting on capacity to provide palliative care.

## Chapter summary

In Case 2, the survey and qualitative results have been reported. In the survey results, nurses' demographic variables; the level of palliative care knowledge, attitudes and self-reported practice are described. The correlation among the outcome variables; and the demographic variables that had a significant association are also identified. In the qualitative results, participants in Case 2 described the availability of palliative care policy and guidelines; palliative care education and

training; availability of morphine and palliative care implementation in General Hospital and Primary Health Care Unit.

The survey results showed that nurses had inadequate knowledge and self-reported practice towards palliative care. Some of the survey results supported the qualitative results in Case 2. For example, the survey results indicated that most nurses supported palliative care as only appropriate in situations where there is evidence of patient deterioration. Some participants described that there were nurses who lacked awareness of palliative care because the professionals had no information about palliative care policy, and they were not motivated to provide focus and implement palliative care.

In the qualitative results, in-service palliative care or pain management training was provided to a few professionals working in ART clinics and other wards of the health care settings. Survey results also indicated that more than half of the nurses had not received in-service palliative care training. In addition, the qualitative results showed that palliative care was not included in the curricula of medical students except in ART training for the final year students.

In Case 2, participants described that morphine was available and prescribed by some of the doctors working in General and Primary Hospitals. However, there were challenges relating to the inconsistent availability and doctors who feared prescribing it.

The survey results described that all nurses had positive attitudes towards palliative care. In the qualitative results of Case 2, some participants confirmed that the nurses had positive attitudes to looking after dying patients who were admitted to the hospital. They also provided emotional support to the patient's family. However, bereavement care was not provided.

In the qualitative results, palliative care was implemented for HIV patients in the health care settings and at the patients' home. However, for other patients with chronic illness, participants described that physical care, pain-management and psychosocial support was delivered to the admitted patients in hospitals, without considering the concept of palliative care. In the survey results, nurses reported that they assessed pain and administered pain medications. Majority of nurses administered tramadol followed by morphine. They also managed other symptoms through counselling, looking after the patient's hygiene and administering medication to relieve nausea and vomiting.

There were challenges and opportunities relating to resources for palliative care. In Case 2, there were some initiatives related to health insurance and palliative care for HIV patients. However, both training in and the administration of morphine were not consistently available in the hospitals. Despite the nurses having positive attitudes towards palliative care, there was lack of palliative care awareness, and participants interviewed believed there was a lack of health care resources; inadequate budget; and lack of palliative care clinics to implement the service. The integrative discussion of results will continue in Chapter Seven.

## Chapter Seven: Integrative Discussion

### Introduction

The aim of this thesis was to describe the current status of palliative care and the strategies and challenges for a sustainable public health approach for the provision of palliative care in rural and regional Ethiopia. This discussion focuses on answering the two broad research questions:

1. What is the current palliative care status in rural and regional Ethiopia?
2. How could a sustainable public health approach be implemented in rural and regional Ethiopia?

The detailed results have been presented in Chapters four, five, and six. Qualitative data were analysed and interpreted to describe the status of palliative care, and the strategies and challenges related to the delivery of palliative care in the region. The Result chapters addressed a number of issues which were highlighted by the nurses, leaders of nurses, doctors, pharmacists, assistant doctors, educational leaders, HEWs, and rural community members in the region.

The aim of this chapter is to integrate the previous result chapters by providing a discussion of the key findings. A discussion of the integrative findings from the Context, Case 1 and 2, is presented by identifying the key themes from both survey and qualitative results.

The WHO Public Health Strategy was used to frame this thesis (Callaway et al., 2018). This framework provides a structure for describing the status of palliative care in developing countries at the policy level, in educational institutes and in health care settings. This framework was also used to identify and organise the strategies and challenges related to resources for palliative care delivery in the region. The findings reported in Chapters 4, 5, and 6 have been merged into four common (key) themes. These themes are:

1. Awareness of palliative care policy and guidelines
2. Palliative care education and training
3. Availability and accessibility of opioid medications
4. Palliative care implementation

Each theme is described by several key findings derived from the case study and survey data. These findings will be discussed and compared to published evidence focused on the status of palliative care and strategies to develop palliative care in rural and regional areas of Ethiopia.



## Awareness of palliative care policy and guidelines

Following the WHO Public Health Strategy (Callaway et al., 2018), improved access to palliative care is dependent on its integration into the national health policies. The qualitative findings revealed that despite a few individuals having access to palliative care service in the region, this service was primarily related to the Human Immunodeficiency Virus Infection and Acquired Immunodeficiency Syndrome (HIV/AIDS), rather than palliative care service for patients with other life limiting illnesses such as cancer. Currently, palliative care is included in the Ethiopian Health Sector Transformation Plan as a fifth health pillar, alongside primary health promotion, prevention, curative and rehabilitation (FMOH, 2015). Palliative care is also included into the National Cancer Control Plan (Federal Ministry Of Health, 2015); Ethiopian primary health care clinical guidelines (Federal Ministry of Health, 2017); and integrated in Ethiopia Hospital Transformation Guidelines (MOH, 2016) as well as the National Strategic Action Plan For Prevention & Control of Non-Communicable Diseases (MOH, 2014-2016). A National Palliative Care Guideline has also been developed (Federal Ministry of Health, 2016). The Ethiopian policy approach is consistent with the 2014 resolution of the World Health Assembly that palliative care should be included in all national health policies (World Health Assembly 67, 2014). However, despite palliative care being included in the national health policies and guidelines in Ethiopia, study participants were critical that palliative care was not included in the national health care budget.

## Policy status of palliative care

According to Rhee et al. (2018), Ethiopia was ranked the second highest among African countries, in palliative care policy development. As already described above, palliative care is included in the national health policies and guidelines. In this section, the participants' awareness of the palliative care plans and guidelines and the availability of palliative care documents are discussed. The Context findings indicated that a few leaders from the Regional Health Bureau and tertiary hospital were familiar with the National Palliative Care Guideline and the presence of palliative care in the National Cancer Control Plan and Health Sector Transformation Plan. However, the ward professionals in the tertiary hospital and the educational leaders had no information about either policy or guideline. Similarly, the qualitative findings of Case 1 and Case 2 indicated that despite a few leaders having access to palliative care-related documents,

they had no access to the National Palliative Care Guideline, and participants were unaware of the presence of palliative care in the national policy. This might be because these palliative care documents had not been distributed to the hospitals and primary health units, they were not known about, or had not been viewed.

### Palliative care budget

Participants discussed the budgetary issues of establishing and managing palliative care in health care settings. The qualitative findings revealed that palliative care initiatives were not included in the national health care budget. Because of this, there was argument among professionals about the focus and priority of palliative care in the health care system, especially when participants indicated that, in the region, there was no allocation of public funding, or institutional resources, and no reimbursement for palliative care services. This might be because the palliative care initiatives commenced with a project supported by third-party donors and grants (WHO, 2004; Wube et al., 2010). For example, Ethiopia has participated in the palliative care project titled *Community Health Approach to Palliative Care for HIV/AIDS and Cancer project* (WHO, 2004). This project was limited to the mobilisation of resources in the capital city of the country; and the ability to seek funds raised by WHO and other Non-Governmental Organisations (NGOs)). Similarly, the published paper presented in Chapter Two and the updated literature showed that funding of palliative care in other developing countries is dependent on NGOs (Aregay, O'Connor, Stow, Ayers, & Lee, 2020; Poyhia et al., 2020). The findings of previous studies supported the current qualitative findings; that despite palliative care being implemented for HIV patients, it was only possible with NGO financial support. A Case 2 participant expressed concern that once the project was completed and handed back to the participant, the service would discontinue, highlighting sustainability as a major service delivery issue.

### Palliative care education and training

The 67th World Health Assembly resolution (2014) mentioned earlier, called on governments to include palliative care as an integral component of ongoing education and training offered to care providers. The current findings discussed the issue of cultural attitudes to palliative care, and palliative care integration into the health professionals' curricula and in-service training.

## Cultural attitudes to palliative care

Cultural attitudes and behaviours determined by customs, habits, languages, and geography have been identified as the biggest barrier to the delivery of palliative care, because cultural norms have a significant role in the communication and nature of care (Fraser et al., 2017; Hannon et al., 2016). In low- and middle-income countries (LMICs), models of palliative and end-of life care should be tailored to the specific clinical settings and health care systems and to the societal and cultural norms, as well as reflecting local preferences about death and dying (Hannon et al., 2016). In Ethiopia, a Home-and Community-Based Care program relied on traditional burial societies ('Iddir') to provide sustainable support for community-based interventions, closely linked to local health care facilities and HIV/AIDS patients (Wube et al., 2010). Similarly, the current study findings of both Cases revealed that case managers (HIV patient volunteers) who provided palliative care were the only network between professionals and HIV patients. In addition, some participants described a Health Development Army (Community Volunteers) who facilitate financial support for patients with HIV from local community members, government, and NGOs. Despite the service being limited to those with HIV, these cultural or local based strategies represent key learnings and future opportunities for delivering rural palliative care for patients in need.

In addition, the survey results indicated improvement in the attitude score of nurses towards palliative care, compared to the study conducted by Kassa et al. (2014) and Zeru, Berihsu, et al. (2020) in the Comprehensive Specialized Hospital and General Hospital settings in Ethiopia. The variation of results with Kassa et al. (2014) may be due to the different study setting; the current study focused on nurses working in rural and regional health care settings, where there may be more time to provide respectful and compassionate care. Additionally, the time difference in the study period (2-5 years) may demonstrate the uptake of palliative care initiatives like training. The survey findings were supported by the participating nurses of the tertiary setting in the Context, who said that some professionals assisted in changing community attitudes towards chemotherapy.

Despite there being attitudinal changes to chemotherapy treatment for cancer, some participants argued that the community and health professional attitudes all demotivated patients from expressing their feelings of pain to their families or health professionals. Similarly, Mamo et al.

(2020) reported that in the highly-valued Ethiopian culture, the expression of pain is equated with weakness and a lack of courage. Indeed in many African countries, cultural attitudes discouraged complaints or expressions of pain, as this was considered to be a sign of weakness, so most adults denied or failed to report their pain symptoms (Nchako, Bussell, Nesbeth, & Odoh, 2018). In general, then, the culture of the community, as well as the attitudes of health professionals, inhibited patients from talking about their illness and pain, making good pain relief, a key component of palliative care, extremely difficult.

In the qualitative findings there was discussion about cultural taboos in speaking about death among patients, families, and health care providers. The current qualitative findings of the Context reported that despite telling of diagnosis improving over time, talking about death and dying with patients depended on the doctor's decision. Some participants in both Cases revealed that they are prohibited from speaking about incurable disease; rather, health professionals provided counselling and psychological support. In contrast though, other participants described how some doctors openly communicated about incurable illness with the family. Similarly, Ayers (2015) reported that health care staff openly communicated with family members about the news of a terminal illness, rather than to the patient, in order to avoid upset. This showed that concern about talking about death and dying, and incurable disease with the patient, was related to affecting the patient emotions such as being upset, feeling hopeless, and other related psychological problems. In Ethiopia, most patients are dependent on the support of family members because family live together as a unit and this family unit has a major role in providing support and care; the Ethiopian Diaspora living in Western countries also supported their families by sending money back home (Ayers, 2015).

#### [Integrating palliative care into under-graduate and post graduate curricula](#)

As already noted, the World Health Assembly 67 (2014) resolution and Callaway et al. (2018) both recommend that palliative care education be integrated in all undergraduate and postgraduate courses. The current findings discussed the status of palliative care integration in health care curricula (Nursing, Pharmacy, and Medicine). The findings reported that despite palliative care being integrated into the nursing diploma curriculum, and some postgraduate medicine and nursing specialisations, it is not currently integrated into all undergraduate

medicine, nursing, and pharmacy curricula. Further, there was a suggestion from the University participants, that integration into the medical curriculum was a national core curriculum issue.

In contrast, palliative care is integrated into the undergraduate medical curriculum at the University of Zambia; in both the School of Medicine and Faculty of Health Sciences at Moi University in Kenya (Grant et al., 2017); and in the undergraduate and postgraduate curriculum in Uganda and South Africa (Rawlinson et al., 2014). Furthermore, in Kerala, India, there are several ongoing palliative training programs for physicians, including postgraduate courses; a one-year residential fellowship; a one-year distance education fellowship; an eight week certificate course in essentials of palliative care and four to six weeks residential training programs (Kumar, 2013). Certificate courses in palliative care have been offered in many African countries including Uganda (Hannon et al., 2016), South Africa, Kenya, Zambia, Swaziland, and Botswana (Rawlinson et al., 2014). The integration of palliative care into the health care curricula may make a difference across countries, perhaps related to the university's readiness and the aim of funding organisations. For example, the Diana Princess of Wales Memorial Fund provided guidance and funding to include palliative care training into medical and nursing schools in Kenya, Malawi, Tanzania and South Africa (Rawlinson et al., 2014). So, the lack of palliative care integration into undergraduate health curricula has a potential impact on the professional's knowledge about palliative care. But there are numerous opportunities to learn from the experiences of other countries, in seeking ways to develop a palliative care curriculum across health science courses.

### [Inadequate palliative care knowledge](#)

The survey results indicated that health professionals working directly with patients had low levels of palliative care knowledge, with less than 50% of nurses working at all levels of the health care system scoring 75% or greater in the knowledge test. This study reported slightly higher knowledge scores, compared with the report of nurses' knowledge in an earlier study conducted in Addis Ababa, Ethiopia by Kassa et al. (2014), where fewer than 40% of nurses scored 75% or greater. The difference between these findings might be due to the differences in the study period and the study setting. In Ethiopia, at the time of the earlier study, there were no government programs for palliative care, except a small number of non-governmental hospice care centres which provided palliative care for patients with chronic illness at home (Reid et al.,

2018). Improvement in knowledge scores may indicate that palliative care initiatives in the Northern region, has had some effect throughout the system.

However, the nurses' level of palliative care knowledge in the present study is lower than the study conducted in Tigray secondary and tertiary hospitals, where more than 60% nurses had scored 75% or greater for palliative care knowledge (Zeru, Berihu, et al., 2020). Despite this study being conducted in the same study period and region, there is a difference in the study settings and the hospital units, with Zeru, Berihu, et al. (2020) focusing only on nurses working in secondary and tertiary hospitals, while the current study recruited nurses working in all levels of health care settings, including primary health care units. The differences in knowledge might be a result of hospital staff having access to palliative care and pain management training, whereas primary health care staff did not (Abdi & Dmitrovsky, 2020; O'Brien, Schwartz, & Plattner, 2018). The qualitative findings of this study also supported that palliative care and pain management training was provided to Anti-Retroviral Therapy (ART) staff and a few professionals working in different units of the hospitals. However, participants from both Cases reported that professionals working in primary health care units had not received any palliative care training, with the exception of a few ART staff.

Despite palliative care and pain management training being delivered to a few professionals, participants described health professional staff and the community as having had low palliative care awareness. Although some health education was provided to the community, the focus of health education was on illness prevention and communicable diseases rather than palliative care and that contributed to the low awareness of palliative care in the community. In contrast, a study conducted among cancer patients in the Addis Ababa specialist hospital revealed that more than 60% patients had previous knowledge about palliative care services for cancer patients (Lakew, Musema, Shimeles, & Challinor, 2015). The study, reported in 2015, assessed palliative care knowledge among cancer patients from the only oncology centre in the country (Reid et al., 2018). In addition, the study was conducted in the capital city of the country where the early palliative care projects and research were conducted (Reid et al., 2020; WHO, 2004), and hospice/palliative care were reported as only found in this city (Reid et al., 2018).

However, the World Health Assembly 67 (2014) and Callaway et al. (2018) aimed to include palliative care as part of in-service training of primary care caregivers; intermediate training for

secondary health care professionals; and specialist palliative care training for tertiary health professionals. One Ethiopian paper also described the program that developed a training module on how to provide holistic palliative care and integrate palliative care into the existing home-based training package (Wube et al., 2010). Wube et al. (2010) presented a train-the-trainer program, training community workers and volunteer care givers. Similarly, another palliative care project in four African countries reported that the palliative care program builds the staff capacity through training, and train-the-trainer program and mentoring by clinical experts at clinical placement sites (Grant et al., 2017). Grant et al. (2017) reported that the palliative care program in Kenya, Rwanda, Uganda, and Zambia was developed using clinical placement sites and centres of excellence to model best practice. Despite these opportunities, participants in the current study described the challenges of providing training: high turnover staff, inconsistent training, a lack of clinical placement-based training, insufficient health care resources, and a lack of follow-up after the training. These challenges might result in trained professionals not practising their theoretical knowledge in the health care settings.

#### Using mass media to promote palliative care awareness

The qualitative findings showed that regional mass media were not used to promote palliative care awareness to the community; rather, the media promoted preventable and communicable diseases. In contrast, the media, including television and radio broadcasts and monthly newsletters, have been used in Uganda to raise awareness of palliative care and encourage openness about death and dying, as well as to sensitise the public to issues about palliative and end-of-life care (Fraser et al., 2017). Similar to Uganda, the Kenyan Hospice and Palliative Care Association was promoted using local television, radio, print paper, and public events to communicate and enhance awareness of palliative care (Ali, 2016). The findings of this study indicated that the use of mass media to promote palliative care is feasible, given its use in other countries and its previous use in Ethiopia to promote other health issues.

#### Availability and accessibility of opioid medications

Pain is one the most common symptoms in life-limiting ill patients (De Lima & Pastrana, 2016). Pain medicines (non-opioids and opioid analgesics) are incorporated in the WHO model list of essential medicines (World Health Organization, 2017). Similarly, in Ethiopia and other African



countries opioid medications were included into the essential medicine lists (Ethiopian Food And Drug Authority, 2020; Fraser et al., 2017).

The qualitative findings of the Context and participants from the General and Primary Hospitals in Case 2 demonstrated that morphine was included in their essential list of medications; however, this was not so in Case 1 hospitals. But despite being included in some hospital lists of essential medicines, morphine was not consistently available in the Context and Case 2 settings, which influenced morphine prescribing by the physicians. As already noted, participants were also concerned that there was inconsistent pain management and palliative care training for physicians and other health care staff. So, making opioids available without trained prescribers might result in expiration and wastage of opioids before they can be prescribed, and a trained physician without availability of opioids might lead to unrelieved pain (Callaway et al., 2018). Therefore, the availability and accessibility of opioids and training of physicians need to occur simultaneously in order to manage pain and deliver sustainable palliative care.

#### [Availability, Accessibility and Affordability of opioids](#)

In Ethiopia, “a government owned company formulates and distributes oral morphine solution in various concentrations, and a National Pain Management guideline has been developed” (Hannon et al., 2016, p. 64). However, some participants from the Context said that, despite the Ethiopian pharmaceutical industry being capable of manufacturing morphine syrup, during the study period, the industry was not producing it. For this reason, despite morphine tablets being available in the Context and Case 2 (General and Primary Hospitals), participants said it was not consistently available in their health care settings. Other jurisdictions in Africa reported that a shortage of opioids was the major challenge for the delivery of palliative care in health care settings (Bond & Knopp, 2018). The participants of Case 1 claimed that morphine was totally unavailable in the hospitals and primary health care units, also reporting issues of limited and inconsistent supply from the Pharmaceuticals Fund and Supply Agency, as well as lack of financial capacity to import sufficient raw materials for the manufacture of morphine syrup.

In addition, the findings of both Cases indicated that morphine was inaccessible at the community level (Health Centres and Health Posts) in the rural health care settings of the region, in contrast to a review paper indicating that in Uganda, morphine was accessible in rural and remote areas (Hannon et al., 2016). This variation might be due to the difference in the country's



regulations about morphine prescriptions. In Uganda, the government allows nurses and clinical officers who have completed specialised training (a 9-month course) to prescribe oral morphine; and this has enhanced the accessibility of morphine to more than 85% patients who live in rural or remote areas (Fraser et al., 2017; Hannon et al., 2016). However, in Ethiopia, participants reported that morphine prescription is a role only permitted by doctors, and the rural health settings are staffed primarily by nurses and health officers (clinical officers). In addition, despite the fact that there were doctors in the hospitals of Case 1, participants revealed that morphine was not included in their medications policy. In addition to improving prescriber access in Uganda, opioid access was improved because the Ugandan government allocated a specific budget to the purchase of morphine (Fraser et al., 2017), in contrast to the current Ethiopian study, participants argued that there was no specific morphine budget allocation. Some participants of the Context also reported a lack of budget to purchase essential medications in their hospital, which may affect other important medications used in palliative care.

Participants of the Context said that when morphine was unavailable in the pharmacy, the nurses discussed with the doctors' alternative available pain medications such as tramadol before they administered any medication. Participants described that tramadol was the strongest medication prescribed in Case 1 and in Case 2 primary health care units. In the self-reported practice part of the survey, nurses of the Context and both Cases scored higher in the frequency of administration of tramadol than morphine. Similarly, the study conducted by Yorke et al. (2019) reported that morphine was inaccessible in some African rural areas, so tramadol was the essential alternative medication to provide pain management in the absence of access to strong opioids.

The participants reported that morphine was the cheapest and safest medication in their settings. For other patients, some participants from the Context argued that morphine is expensive in comparison with the daily income of patients. Similarly, in Kenya, morphine is unaffordable (Fraser, 2017). Some participants of Case 2 reported that medications including morphine were provided free of charge for HIV patients only. In the Ugandan palliative care program, morphine was available at no cost for patients in need (Fraser, 2017). Fraser et al. (2017, p. 4) reported that "Uganda has secured financing for opioids ... and relaxed restrictive opioid regulations, and placed safe, accessible, and affordable pain relief at the forefront of palliative care". Thus, there are numerous examples of how comparable countries address the issues of access to strong opioids, morphine in particular.

## Training for physicians prescribing opioids such as Morphine

The Pain-Free Hospital Initiative was a one-year hospital-based health worker training initiative to improve the quality of pain assessment and treatment in Sub-Saharan Africa, including Ethiopia (O'Brien et al., 2018). Participants of the Context reported that the tertiary hospital of the region had adopted this initiative. Some participants of the Context said that pain management training was delivered to health care professionals working in different health care settings. In addition, the qualitative findings of Case 1 and Case 2 demonstrated that pain management training was provided to some professionals working in different hospital units and ART staff.

In Ethiopia, palliative care education is neither part of basic medical training nor specialist training (Reid et al., 2018). Some participants claimed that palliative care training was only given to ART staff including graduate medical students. In support of their claim, a paper conducted in Ethiopia by Onyeka et al. (2013) reported that palliative care and pain management training was included in the basic ART program; and the training was provided only for physicians. Abdi and Dmitrovsky (2020) also reported that seven physicians from several medical disciplines from the tertiary hospital in this current study were trained in all types of pain management. Similarly, the qualitative findings of the Context showed that seven specialists from the tertiary hospital had been in fellowships for pain management. This fellowship was planned to produce proficient physicians in pain medicine and palliative care because prior to the training, many physicians in Ethiopia were reluctant to prescribe opioids and this resulted in the expiration of unused morphine.

The participants of the Context identified that the Pain-Free Hospital Initiative had improved morphine prescription among the doctors; and, since the training, morphine was used and no longer expired on shelves. However, the limitation with supply remains a major obstacle. Similarly, a 3.5- year program was implemented in 12 governmental hospitals, three each in Kenya, Rwanda, Uganda, and Zambia reported that morphine orders no longer expired (Grant et al., 2017). Grant et al. (2017) reported that morphine was prescribed by health care staff, who were no longer fearful of it.

Despite the positive outcomes of the Pain Free Hospital Initiative reported by some participants in the Context, others in the Context and Case 2 argued that there were physicians who still fear

prescribing morphine because they believed it depressed respiration. This was supported by the survey results, where nurses were concerned about drug addiction in the use of morphine. Similarly, physicians working in a number of African countries had negative attitudes and fear of prescribing opioids, (Bond & Knopp, 2018; Fraser et al., 2017; Nchako et al., 2018). indicating that more evidence-based training might be needed to improve the prescribers' attitudes. However, a study conducted in Zambia indicated that while most physicians were comfortable prescribing morphine for patients, they used it more judiciously in the suspected addicted patients (Robertson et al., 2020). The survey results in the current study also indicated that despite the nurses in the Context and two cases having insufficient knowledge about the drug addiction and long-term morphine used for pain management, they had positive attitudes about the administration of pain-relieving medication for dying patients.

In addition, the qualitative findings of the Context revealed that although doctors working in some units of the tertiary hospital prescribed morphine for patients for when they were at home, doctors in other units of the hospital did not. While Reid et al. (2018) suggested morphine is available in outpatient settings, their study is set in the capital city of Ethiopia, where existing palliative care institutions are found. This indicates that the training of physicians, availability and access to morphine, may be influenced by the development and implementation of specialist palliative care services; and there are numerous examples of such effective training from which to draw (Fraser et al., 2017; Grant et al., 2017).

## Palliative care implementation

As already described, Callaway et al. (2018), Batiste and Connor (2017), and the World Health Assembly 67 (2014) recommended palliative care integration into the existing national health system. In this section, the status of palliative care integration; the implementation of palliative care for patients with HIV; the care provided to the patients suffering with life-limiting illnesses in health care settings; the home-based care and the role of family in providing care are discussed. The opportunity of mobile phones for future palliative care service, and the status of palliative care research in implementing evidence-based palliative care, are also discussed.

As previously argued in the background chapter, access to palliative care is an international human right (Gwyther et al., 2009). The World Health Assembly 67 (2014) recognised that inadequate integration of palliative care into health systems is a major contributing factor to the

lack of equitable palliative care access in health care settings. In Ethiopia, despite more than 85% of the population living in rural area (Ayers, 2015), millions of people have limited access to palliative care (Reid et al., 2018). As already described, the National Cancer Control Plan document in Ethiopia had a plan to integrate palliative care for at least 50% of health care facilities in 2020 (Federal Ministry Of Health, 2015): the current qualitative findings reported that palliative care was still not integrated into the existing health system of the region. In Uganda and Kenya, palliative care is integrated into the mainstream health care because palliative care is included in the national health care budgeting process (Fraser et al., 2017).

### [Palliative care service in health care settings](#)

The WHA resolution of 2014 realised the urgent need to integrate evidence-based, cost-effective and equitable palliative care service in the continuum of care, across all levels of health care of care, particularly at primary care levels (World Health Assembly 67, 2014). In Rwanda, a stand-alone national palliative care policy was developed; the policy committed to providing high-quality and affordable palliative care to meet the physical, psychological, social and spiritual need of patients suffering with life-limiting illnesses (Rosa et al., 2018). Rosa et al. (2018) also reported that the national policy supported palliative care advocacy; improved confidence in palliative care providers; enhanced training and awareness of opioid requirements. Rosa et al. (2018) reported that the above mentioned strategies were used in Rwanda to integrate palliative care service into the primary, secondary and tertiary levels of the health care system (Rosa et al., 2018). The study conducted by O'Brien et al. (2019) also showed that palliative care was provided by a multi-disciplinary team in the hospital as well as in the sub-districts health care settings of Western Cape, South Africa. However, in the current study, the qualitative findings of the Context and both Cases revealed that a holistic palliative care service was not implemented in the hospitals and primary health care units, except the care provided for patients with HIV. Despite a palliative care team initiative in the tertiary hospital of the Context, one participant said that the service had not yet commenced. In contrast, in Rwanda, the multidisciplinary palliative care team were organised at a district teaching referral hospital (similar to the Ethiopian tertiary referral hospital context), and provide palliative care training to the Community Health Workers to establish continuity of care and identify chronic illness in the community (Rosa et al., 2018). In addition, in the Western Cape region of South Africa, the multi-professional team provided continuity of care and communication in the regional hospital, district hospital, clinics, NGO,

emergency medical services and the patients' homes (O'Brien et al., 2019). The participants in the Context thought that the hospital was overcrowded, so had no separate palliative care unit to provide the service. The palliative care team were waiting for a new building in order to start palliative care implementation in the tertiary hospital. In addition, despite a few hospital staff being trained in palliative care, participants perceived that the hospital lacked health care resources to implement theoretical knowledge into practice.

The current study showed that health professionals were mainly focused on pain management and treatment and not on the psychosocial and spiritual aspects of palliative care. Similarly, one study conducted in Ethiopia by Mamo et al. (2020, p. 312), revealed that “palliative care services mainly focus on pain management, while the other components – such as social, economic, and spiritual support – remain patchy, underdeveloped, and uncoordinated.” This might be because the palliative care initiative, and the training introduced in the tertiary hospital setting, was focused on pain management rather than palliative care. In addition, the participants saw government directions as emphasising preventable and communicable disease, rather than palliative care.

#### [Palliative care service in a patient's home](#)

In Ethiopia, the modern hospice and palliative care initiative started more as a response to the health care system inadequacy to respond to the HIV/AIDs epidemic (Mamo et al., 2020). Mamo et al. (2020) reported that home-based care was the only alternative in the absence of ART, and Hospice Ethiopia advocated a home-based care service.

There have been only two small not-for-profit palliative care institutions in Ethiopia (Hospice Ethiopia and Strong Hearts) that provided home-based hospice care to 20-30 patients in their homes (Reid et al., 2018). In these organisations, the service included home-visits by a nurse, pain and symptom management, including oral morphine and psychosocial support. Similarly, in Tanzania, a multi-disciplinary team provided weekly or monthly home visits in order to offer comprehensive, free of charge palliative care service to patients (Bond & Knopp, 2018).

However, the current study findings of the Context pointed out that there was only one private home-based care service which was unaffordable and inaccessible to the rural patients, because it is located in the capital city, potentially more than 500 kilometres from the capital city of the region. Participants in both Cases reported that despite there being home visits by Health

Extension Workers (HEWs) in rural areas, their focus was health education in preventable diseases. So, in relation to care and psychosocial support for chronically ill community members at home, the family or neighbours provided this, or took them to health care facilities and traditional or spiritual healing sites. This finding indicated that the people in the rural region had limited access to home-based services and palliative care. The implication of this is that perhaps other rural people also have limited access to palliative care (Reid et al., 2018) because 85% of the population live in rural areas (Ayers, 2015). Similarly, Gwyther et al. (2018), reported that palliative care is inaccessible in rural areas of South Africa.

As noted, access to palliative care was limited to patients with HIV because of the support of several NGO projects and programs. In Ethiopia, one Home-and Community- Based Care program was designed to address the palliative care needs of poor, chronically ill, and bedridden patients in their homes (Wube et al., 2010). As described earlier, the program relied on traditional burial societies ('Iddir') and was designed to assist only HIV/AIDs patients. Wube et al. (2010) reported that the 'Iddir' were actively involved in supporting patients and engaged in mobilising resources (food, clothes, and money) for patients in need and vulnerable children. In Hospice Care Ethiopia, the community self-help association or 'Iddir' was also developed to provide services for the dead, and support to patients and families (Mamo et al., 2020). In addition, a review of studies conducted in LMICs indicated that community-based volunteer programs were the main components of palliative care in the rural and remote areas (Hannon et al., 2016). Similarly, participants in the Context reported that there were a few charity and religious organisations that provided volunteer care, rather than palliative care, in the capital city of the region. This suggests that there is an opportunity to use the volunteer care givers and HEWs in order to increase palliative care access in rural areas.

In the current study, the qualitative findings of the Context and Cases indicated that palliative care implementation commenced in the region for HIV patients and family members at the hospitals, as well as in the patient's home. The participants from both Cases described trained HIV patients (case managers) who provided psychosocial support to HIV patients at home. These case managers also provided a network between the patient and the health care providers and fund organisations, with a number of NGO funded projects supporting these developments. Therefore, there is funding from the donors to facilitate palliative care for HIV patients and family members in the study settings and in Ethiopia. Similarly, the study conducted by Poyhia

et al. (2020), revealed that palliative care service in Tanzania is dependent on NGOs, and this common dependence of palliative care services, remains a challenge for sustainable palliative care in all health care settings.

### Mobile phone in palliative care service

Mobile phone use in healthcare delivery is available across palliative care services in Africa (Allsop, Namisango, & Powell, 2019). The current findings of the Context showed that health care professionals used mobile phones to provide palliative care for HIV patients for follow-up and consultancy services. In addition, some participants recounted that mobile phones were used to communicate with patients who have life-limiting illness requiring follow-up for chemotherapy. In both Cases, participants described that the rural community members had the mobile phone number of HEWs who helped them to request Red Cross, ambulance service and advice on other health-related issues. Similarly, in Ethiopia there was a palliative care project that aimed to create a remote monitoring system using mobile phone technology for patients and key stakeholders (Carey et al., 2019). The Phase 1 findings of that project indicated that the use of mobile phones was used to treat a number of patients at a time, assisting health professionals to manage their time travelling to patients. Similarly, an African review paper conducted by Allsop et al. (2019) revealed that mobile phones were used in providing palliative care at home, for online learning, consultation services, follow-up appointments, and related health care activities. In addition, the study conducted by Shabnam et al. (2018) reported that in Bangladesh, telephone consultation was used for the rural patients discharged from the hospital to provide a consultation service, to access information on the availability of beds in the hospital, and to get medication. Despite mobile phone technology for palliative care initiatives having commenced in Ethiopia, the current findings indicated that mobile phones use, particularly for palliative care, is underdeveloped. The mobile phones used for other health care issues might be a future opportunity for disseminating palliative care access and education using mobile phones in rural and regional settings.

### Palliative care research

Evidence-based medicine underpins high-quality palliative care, and research has been proposed as a fifth pillar in the WHO Public Health Strategy (Fraser et al., 2017; Hannon et al., 2016). Developing research in palliative care in low- and middle-income countries (LMICs) can be used



to build evidence-based palliative care in health care settings as well as in the patient's home, and there has been a significant increase in the number of peer-reviewed palliative care research publications in Ethiopia, with most palliative care research being conducted in the capital city of the country, or the main city in a region. Despite some palliative care research being conducted in different regions of the country, the associated research papers were published in non-peer reviewed journals and the first author of the papers was not from Ethiopia. Similarly, Hannon et al. (2016) reported that “a bibliometric analysis of the contribution of LMICs to the published palliative care literature demonstrated that they accounted for only 1.3% of all palliative care publications and (that) their publications were more likely to appear in journals with low or no reported impact factors” (Hannon et al., 2016, p. 65). Hannon et al. (2016) also reported that 25% of the published papers had the first authors from high income countries and less than half were published papers by authors from upper-middle-income countries, such as India and Brazil, and only 11% came from low-income countries.

Uganda and Kenya are recognised as the leaders of Africa in palliative care research (Fraser et al., 2017), mainly because they have been supported by the establishment of international collaborations such as African Palliative Care Research Network to develop African palliative care research and to provide an African network with international researchers. Fraser et al. (2017) also reported that Uganda has its own national research network, and Kenya have developed a partnership between international research groups and local researchers at the University of Nairobi. The lack of published research at the level of primary care made it difficult to compare the current findings, or for participants to draw ideas for the implementation of palliative care. So, including palliative care research in the WHO Public Health Strategy would help to increase the evidence base for a way to develop palliative care, as well as produce published papers in rural and regional areas.

## Chapter summary

The findings have led to a detailed discussion on the status of palliative care and strategies for sustainable palliative care in the rural and regional health care settings. The unification of thoughts from participants in the Context, Case 1 and Case 2 have merged into an overall understanding to the current status of palliative care; and investigate and make recommendations for sustainable public health approach to the provision of palliative care in the region.



A number of conclusions from the previous discussion could be drawn. Firstly, there is evidence to suggest inclusion of palliative care in the national policies and developed palliative care guidelines is insufficient without dissemination and follow-through to clinically implement these policies. The availability of palliative care documents might assist as a reference for professionals to use in implementation. However, having palliative care documents without understanding the term ‘palliative care’ is also another challenge identified in this study. To support this development, palliative care needs to be included in the national health care budget, including the funding for its implementation across the country.

Secondly, findings revealed that despite palliative care being integrated into the diploma curricula, and some medical and nursing specialities, palliative care is not part of the undergraduate health care curricula, with a consequential impact on professionals’ levels of palliative care awareness. The survey findings also indicated that there was insufficient palliative care knowledge among participants, and this meant that the community members lacked palliative care awareness. Despite some palliative care training provided to a few health care professionals, training was not supported by clinical application and follow-up. For this reason, the trained professionals were not practising their theoretical knowledge. So, a national curriculum, developed for inclusion in health professionals’ education, would assist in consistent palliative care training. Close follow-up in relation to clinical placements and mentoring would be likely to cement the theoretical learnings in clinical environments. There are opportunities for academics responsible for developing curricula, to explore successful education programs in other African countries.

Thirdly, understanding the term palliative care without the availability of palliative care medication is challenging to manage the severe pain of patients suffering with life-limiting illness. The findings indicated that morphine was inconsistently available in all settings of the study, with tramadol used as an alternative in the Context and Case 2. There were additional limitations in relation to prescribing and administration. There are opportunities to explore how comparable countries manage the availability of morphine and apply these learnings to the Ethiopian environments of this study.

To support the dissemination of cohesive structures in developing palliative care across the country, there are unexplored opportunities to use communication strategies like mobile phones.

Finally, the findings indicated that despite palliative care being implemented in some inpatient settings and at home for patients with HIV, the holistic palliative care philosophy was not implemented for other patients diagnosed with incurable diseases. This important finding highlights that palliative care was not integrated into the existing health care system.

## Chapter Eight: Conclusion, Limitations and Recommendations

This chapter provides the summary of key findings; considers limitations of the study; and describes the thesis implications, including recommendations for future research.

### Study Overview

This study is novel in using case study to understand, investigate and make recommendations for a sustainable public health approach in the provision of palliative care across all levels of health care settings in rural and regional Ethiopia. The research questions driving the study were: what was the current palliative care status in rural and regional Ethiopia and, how could a sustainable public health approach be implemented in rural and regional Ethiopia? To accomplish the aims of these research questions, the study used the four components of the WHO Public Health Strategy as a theoretical framework for the qualitative data interviews, analysis, and the discussion of the key findings. In this research, a multiple embedded mixed method case study design was used to compare two rural cases in a regional context. The triangulation of data source of survey, interviews, and focus groups enabled a comprehensive analysis of the status of palliative care and the strategies for the development of sustainable palliative care rural and regional health care settings. The combination of interviews, surveys and focus groups revealed that differences in the status of palliative care, considering the policymakers and the documents, compared to the status of clinical palliative care being delivered to patients.

The Context represented the policy institution, educational institutes (tertiary education and regional health college) and the major Comprehensive Specialised Hospital (tertiary hospital referral system), informing the two cases of the study. Case 1 and Case 2 represented two ‘Zones’ and the rural areas of the ‘Zones’ in the region, and included the General and Primary Hospitals, Health Centres, Health Post and the communities. A survey was conducted among nurses working in adult health care unit of the Context major Comprehensive Specialised Hospital; and Case 1 and 2 of the General Hospitals, Primary Hospitals, and Health Centres. The survey used the standard questionnaire tool (PCQN and FACTOD) to describe the nurses’ level of palliative care knowledge, and attitudes. The self-reported practice tool was developed for this study and prepared from the literature. In the Context, representatives of the Regional Health Bureau; the educational institute (School of Nursing, Medicine, and Pharmacy) representatives

from the university and regional college; and doctors, pharmacy and nurses in leadership roles at the Comprehensive Specialised Hospital were interviewed. In Case 1 and 2, interviews were conducted with, pharmacy representatives, doctors, health officers (clinical officers), nurses in leadership roles and Health Extension Workers (HEWs). Lastly, in both Case 1 and 2, community focus group discussions were facilitated.

The overall survey results indicated that despite all nurses having positive attitudes towards palliative care, they had an inadequate level of palliative care knowledge, and poorer self-reported practices; and some qualitative findings supported these survey results.

The qualitative findings described that there was limited palliative care access in health care settings except for patients with HIV. In addition, morphine was not consistently available in the Context and Case 2, and totally unavailable in Case 1 and palliative care was not integrated to the undergraduate curricula of Nursing, Medicine, and Pharmacy.

### The key findings

Several key findings have emerged from the current study. The key findings are:

1. As previously mentioned, palliative care is included in national health policies and guidelines. However, despite a few leaders having awareness of these inclusions, professionals at the bedside had no access to these documents and were unaware of their existence.
2. Palliative care was not integrated into the under-graduate health care curricula. Despite in-service palliative care and pain management training being provided in health care settings, all professionals were not trained in palliative care. For this reason, professionals lacked awareness of palliative care and this had a flow-on impact on the awareness of palliative care in the community.
3. Pain medications were included in the essential list of medications at the regional policy level, in the Comprehensive Specialised Hospital (Context) and in one of the Case hospitals. Despite morphine being included in the list of essential medications in these health settings, it was inconsistently available in the pharmacy stores. Morphine was totally unavailable in one of the Case hospitals and the primary health care units of both Cases. Tramadol was prescribed as an alternative pain medication in the absence of morphine. However, paracetamol was the only pain

medication available at the Health Posts, implying that morphine is inaccessible to rural community members unless they travel to hospitals.

4.. Despite aspects of palliative care being implemented for patients with HIV, there was a lack of holistic palliative care for other incurable diseases in health care settings of the region.

However, an integrated health care and referral system was evident in such aspects as: the role of HEWs in communities; the Health Development Army; case managers; family; neighbours and different associations. These could be considered as opportunities for future culture-based and context-based palliative care in the rural areas of the region. Professionals and communities also used mobile phones for contact regarding health care issues in the rural and regional health settings, suggesting a further opportunity for strengthening the development and integration of palliative care service.

In the following section of the chapter, detailed conclusions on the two broad research questions are described.

### The current status of palliative care

As noted above, palliative care is included in the national health policies and guidelines. Because professionals working in all health care settings lacked awareness and so lacked access to national health policies and guidelines, there was a view that the priority and focus of policy makers was towards preventable and curable diseases rather than palliative care.

During the study period, there was no evidence of allocation of a budget or health care resources particularly for developing palliative care service and no line item for the funding of morphine. The health care professionals who had initiated aspects of palliative care, were not supported by additional funding or resources. Palliative care implementation that was identified commenced in the region only for HIV patients and was funded by Non-Governmental Organisations (NGOs). So, the Anti-Retroviral Therapy (ART) staff were motivated to provide palliative care in the health care settings as well as at the patient's home. However, it was noted that the service discontinued when the NGOs handed over the palliative care program to the government, implying dependence on the NGOs for continuity. So, the lack of palliative care integration into the existing health care systems and the national health care budget was the main challenge for sustainable palliative care in the region. Integration of palliative care into the national health care budget on its own was insufficient for implementation of palliative care, and the literature

indicated that it was essential to integrate palliative care into pre-service and in-service training of health professionals.

Despite the presence of palliative care in nursing and medical speciality studies, the qualitative findings indicated that palliative care was not integrated into undergraduate curricula of Medicine, Nursing or Pharmacy. It is possible that this might influence professionals' level of knowledge and self-reported practice in regard to palliative care. Overall, the survey results indicated that most participants scored lower levels of knowledge and poorer self-reported practice, with the qualitative findings also reflecting this. The Pain-Free Hospital Initiative was commenced in the Comprehensive Specialised Hospital. This initiative was planned to provide palliative care and pain management training for health care staff. Despite training to assist physicians to improve their attitude to the prescription of morphine, not all staff working at primary, secondary and tertiary levels received training. It was only provided for a few health care professionals and ART staff; it was not consistently part of in-service activities; and it was focused on pain management rather than palliative care. This resulted in continued lack of palliative care awareness among professionals working in rural and regional health care settings.

In addition, despite the survey results indicating that all participants had positive attitudes towards palliative care, those professionals who did receive training were unable to practice their theoretical palliative care knowledge, because the training was not supported by clinical activity and opportunity. Despite positive attitudes and some knowledge about palliative care, it was not translated into practice, with the focus of the training described as theoretical with no opportunities for clinical practice. The lack of self-reported practice among health professionals who had received training may be due to a lack of insight into how their practice related to people with life limiting illness should or could change, within their current resources.

Morphine was included in the list of essential medications and was the cheapest and safest medication in the hospital. However, despite morphine tablets or parenteral injection being available in the Comprehensive Specialised Hospital pharmacy and Case 2 pharmacy, it was inconsistently available in health settings and there was no morphine syrup in the hospitals. Despite morphine syrup being produced industrially in Ethiopia and doctors' ability to prescribe it, neither morphine tablets nor syrup was available in some General and Primary Hospitals. However, morphine syrup was not being produced during the data collection period because of

financial issues regarding the importation of ingredients into the country, thus limiting availability of morphine in the region. Morphine was totally unavailable and not accessible in the rural health care settings.

Sometimes, doctors prescribed tramadol as an alternative for severe pain management in the absence of morphine. The self-reported practice results of Case 1 indicated that almost all nurses had administered tramadol, perhaps because morphine was unavailable in the hospitals, the Health Centre and Health Post, and neither the nurses nor the health officers (clinical officers) could prescribe morphine. So, tramadol was used to manage pain in the Health Centre, and paracetamol in the Health Post, but these medications were also inconsistently available in the health care settings, with limited availability in the rural health care settings. So, a lack of morphine and other pain medications in health care settings had a major impact on prescribing the right pain medication to patients in pain.

In the regional health care settings, health care professionals provided physical care, pain management and psychosocial support to the patients admitted into their settings without a conscious understanding of palliative care. Despite palliative care being included as a chapter in the Ethiopian Hospital Transformation Guideline, supervisors were reluctant to enquire about or report on the status of palliative care implementation in hospitals especially the Primary Hospitals. The government's direction was mostly focused on preventable and curable diseases, so health care professionals also reflected these directions. Therefore, palliative care was regarded as additional work because they were not accountable for its delivery. In addition to a lack of palliative care trained professionals in every level of health care, the health care professional to patient ratio was not sufficient to provide quality palliative care.

HEWs provided health education in churches, community meetings, and during home visits. However, they did not provide any direct care, as their focus was on health promotion through health education. This education emphasised the prevention and treatment of communicable diseases. In general, health care professionals and HEWs viewed palliative care as not part of their responsibilities and thus considered it not part of health care activities.

The HEWs also facilitated the Human Development Army to raise funds from community members, the government and NGOs for financial support of patients with HIV; they and case managers organised community networks to provide psychosocial support to patients with HIV.

Family of sick relatives also played a major role in providing care at home and with the support of neighbours, they took their sick relatives to health care facilities as well as to other traditional and spiritual healing sites. So, through providing palliative care training for these support groups, palliative care could be more established in rural health care settings as well as in the patient's home.

### Strategies and challenges for a sustainable public health approach to the provision of palliative care

A number of strategies and challenges have been proposed for sustainable palliative care implementation in the region. These are human resources, communication using mobile phone technology, access to palliative care medications, and the establishment of palliative care clinics.

A charity and religious organisation provided volunteer care and a private home-based care service in the capital city of the region and universities and colleges also helped to train professionals in the region. Building on the expertise of a few palliative care and pain management trained professionals, there may be an opportunity to provide palliative care training for nurses, doctors, specialists, and sub-specialists in the hospitals. The networked health care system and the referral system in the region may also provide the basis for strengthening future integration of palliative care into the existing health care system.

A number of opportunities were also described to develop palliative care in the rural communities. The HEWs play a major role in generating community trust, through close contact with households and providing health education about the prevention of communicable diseases and health promotion activities. Palliative care could be part of their responsibilities.

In addition, building on the experiences of other teams use of mobile phones, a palliative care consultation service could be supported in rural and regional health care settings.

Even with the above-mentioned opportunities, there were several challenges that affected palliative care development in rural and regional health care settings. Health care professionals were motivated to provide care, but hospitals were overcrowded and there was no space to establish a palliative care service; there were challenges relating to staffing levels, awareness, and training; and limited availability of morphine. Rural community members faced transport



challenges due to the limited ambulance service and the priority given to pregnant mothers and emergencies.

Despite a health insurance initiative in the region, it had only been partially implemented in rural areas because of the cost, meaning some paid the premium and others did not. The consequence of this was that, although families and neighbours preferred to take the patient to health settings, because of the financial cost they stayed at home or took the patient to holy water sites which were viewed as an alternative to health care.

Finally, the lack of evidence to support the development of palliative care strategies in rural and regional areas was noted in this study. The absence of research as a component of the WHO Public Health Strategy meant that research and the publication of research in the development of palliative care is less likely to be funded and makes the replication of successful strategies difficult. Future research needs to be done on the application of WHO Public Health Strategy in different regions of the country.

### Strength and limitations

The data collected from different health care institutes across the health sector, and a range of informants from those in leadership in the regional health bureau to rural patients; this breadth is a strength of the study. A number of limitations were recognised, particularly in the survey method, but also with data collection and analysis. Due to language and distance, one researcher (the student researcher) collected and analysed the data. To address this limitation, data were collected from multiple sources using self-administered survey questionnaires, interviews and focus group discussions. Additionally, the survey data were analysed with consulting statistical experts.

The sample size of nurses undertaking the survey was relatively small and limited to the nurses working in adult health care settings, with data collected using a self-administered questionnaire; thus, there may be bias in the response to the items. However, the response rate was strong. The self-reported practice questions developed from the literature; had not been validated and needs to be re-tested in the Ethiopian context. The survey was not pre-tested, and this had an impact on Item 10 of the Palliative Care Quiz for nursing (PCQN). Some participants knew about pethidine and, but they may not have understood the use of ‘Demerol’ in the PCQN questionnaire.

The data were translated from English to local language and back-translated into English, but some words might not have had an exact English translation. The data were translated and transcribed by the student researcher and this could have been impacted by researcher bias. In an attempt to reduce this bias, the research team reviewed and questioned the researcher regarding concepts as the results developed, until the results resonated with the data. In addition, the case study report draft was not reviewed by key informants to ensure construct validity due to the limitations on travel created by COVID-19 and civil unrest in the region which blocked communication.

The case study site was one region located in the Northern Ethiopia, and included a Regional Health Bureau, universities and colleges, all levels of health care system (tertiary, secondary and primary health care) and rural communities. As already described in Chapter Three, utilising case study research was not intended to provide statistical generalisation but rather, analytical generalisation (generalised theories). The case study site was not representative of all regions of the country; rather this study aimed to facilitate the generalisation of theoretical propositions relating to the application of the WHO Public Health Strategy.

## Recommendations

This study offers a local and culturally based WHO Public Health Strategy for the provision of sustainable palliative care in the region. It offers recommendations to the Regional Health Bureau and Federal Ministry of Health; to educational institutes; and to the case study sites; and serves as a guide to the future palliative care research in the region, as well as the country.

### Recommendations – Policy/Education/Clinical Practice

First, this study offers the following recommendations to enhance awareness of palliative care plans and guidelines to the professionals working at the patient level and educational institutes. It is recommended that:

1. While palliative care features in national health policies and guidelines, health care professionals working at every level of the health care system need to be aware of them. It is recommended that policymakers take responsibility for distributing relevant palliative care documents and provide follow-up in all health care settings, particularly in primary health care units in rural areas, since this is where more than 85% of the population lives. Tying the

palliative care policy to budget line items at every level of the health care system, would provide visible accountability for reporting palliative care activity and ensure that administrators at each level are encouraged to consider the implications for their budgets.

2. It is recommended that universities and colleges are engaged in the development of a palliative care education strategy. All health care professionals need to receive core education in palliative care, integrated into the curricula of Nursing, Medicine, Pharmacy and allied health students, as well as in-service training in health settings, including primary health care. Extending theoretical education and training to include clinically-based palliative care practice, will ensure the translation of theory to practice and encourage further development of palliative care.

3. In Ethiopia, despite morphine being included in the essential list of medications, its supply is inconsistent. Essential medicines for palliative care, including morphine, need to be prescribed and available to rural patients from the Health Centres or at least the General Hospital. It is recommended that further research needs to investigate both the difficulties of Ethiopian manufacturing, as well as the demand and supply shortfalls in order to determine a how supply can be guaranteed to rural areas.

4. Given the staff limits affecting morphine prescription in Ethiopia, government regulations need to be reviewed, and training developed, to licence nurses and health officers (clinical officers) to safely prescribe morphine in order to increase its accessibility.

5. Developing strategies for implementing palliative care seems dependent on NGOs, health department priorities and a developing health insurance initiative for some financial support. There is no public funding from the government for the delivery of palliative care. It is recommended that government policymakers be committed to seeking ongoing partnerships with local and international NGOs for financial and other palliative care resources. Emphasis needs to be on the integration of palliative care into the available local opportunities such as the networked health system; family and other community supports; the referral system; and HEW health care activities.

6. There is a networked health care and referral system in the region and health providers and the community are familiar with this system. It is recommended that a sustainable palliative care program be integrated as an identifiable stream within the existing networked system rather than as a private or additional service.

7. The use of television and social media provide an opportunity for positive public health education about death, dying and palliative care. It is recommended that palliative care trained specialists develop ongoing partnerships with public and private media of the region, to promote and enhance palliative care awareness among professionals and community members; and a panel discussion about death and dying on television and radio in local language would engender more positive community attitudes to palliative care.

8. Pain-Free Hospital Initiatives have commenced in the Comprehensive Specialised Hospital with the support of Federal Ministry of Health, to provide palliative care and pain-management training and a palliative care team. For sustainable palliative care in the region, it is recommended that the team act as a referral point and regional resource for further training as well as clinical role-modelling of palliative care practice.

9. Mobile phones were used by patients to communicate with professionals about the patient's and other health care issues. Mobile phone consultations may be used to provide palliative care service where this support is required in rural areas, and to support HEWs in communities to provide palliative care. It is recommended that mobile phone communication be utilised as part of a sustainable palliative care implementation plan in regional areas of Ethiopia.

10. It is recommended to the Federal Ministry of Health and Regional Health Bureau consider including palliative care in the HEWs components of care. To support this addition to the HEW role, the regional health college could provide the palliative care training.

11. There are resource volunteer groups in communities that will enhance the development of sustainable palliative care, particularly in rural areas. It is recommended that a palliative care volunteer training and support program be developed, with a training organisation in each region, such as the regional health college, to run such a program.

#### [Recommendations for future research](#)

This case study research is the first detailed study of describing the status of palliative care and strategies for sustainable public health approach to the provision of palliative care, using WHO Public Health Strategy in a rural LMIC region, and has potential to integrate research as a fifth component of WHO Public Health Strategy. The opportunities identified in this study might offer a direction to assist development of sustainable cultural and locally-based palliative care in

the region and potentially in other regions. As a result of this study findings, a number of research directions are recommended:

- Exploring strategies to generate availability of morphine ingredients within the country. Preparation of oral Morphine solution in Ethiopian hospitals will make the drug more accessible to rural patients.
- Examining strategies and challenges in the use of mobile phones for palliative care in rural health care settings.
- Evaluating effective theoretical and clinical education on the implementation of palliative care practice. Integration of palliative care in the theoretical and practical examination of the national Certificate of Competency (COC) of health sciences (Nursing, Medicine, Pharmacy, and allied health), will ensure uniform inclusion of palliative care in the curriculum and thus raise the level of knowledge and skill regarding palliative care.

## Conclusion

Palliative care is increasingly recognised as an international human right. Despite the need for palliative care increasing in Ethiopia due to the incidence of non-communicable diseases and ageing, the current study found that there was limited access to palliative care in the rural and regional communities of the region studied. The study indicated that the reasons might be that palliative care documents were not widely distributed; there was a lack of palliative care awareness; and a lack of consistent availability of morphine and other palliative care medications in the rural and regional health care settings.

Palliative care was not integrated into undergraduate curricula, and the in-service palliative care and pain management training was not consistently available to all health professionals.

Although palliative care was implemented for patients with HIV, it was not available to other patients in the hospitals. In the community, it is traditionally accepted that families provide a major role in providing care for their sick relatives at home and taking their sick relatives to hospitals and spiritual and traditional healing sites.

In addition, HEWs play a major role in providing health education on the preventable diseases and generating community trust, as well as providing home visits in the rural areas. With sufficient education and support, HEWs are well placed to integrate palliative care into their

professional role. Several associations and voluntary groups were also identified in rural communities to organise community networks in the rural area and are potential resources for supporting palliative care. Networking to integrate palliative care into these and other resources would be assisted by the use of contemporary technology. The recommendations can further enhance the development of palliative care in regional and rural Ethiopia.

## Postscript

In hindsight, my PhD journey has been both interesting and challenging. I came across the world to Australia, full of enthusiasm for the adventure of my studies, but my PhD journey became severely impacted by personal tragedy.

Having travelled from Ethiopia with my husband and two beautiful girls and settling into a new life, in the first year my mom, mother in-law and two grandmothers died. I did not get the chance to say goodbye to any of them or participate in my family's grieving.

In the second year, the house we were living in burned down. The family needed to find alternate accommodation and replace all that was lost.

COVID-19 has also affected the study's progress, particularly the qualitative data analysis. In the early stages of COVID-19, I was stressed about the transmission of the virus to my family, even though I had no symptoms or close contact with the disease, which affected my ability to focus on the PhD activities. Melbourne experienced almost six months of restricted lockdown in 2020 and we were living in a small apartment with two young children; the space for uninterrupted study was limited. My husband, also a student, and I took turns looking after our children in shifts. Online supervision became the norm, which also affected the quality and timelines of the qualitative analysis. As lockdown went on, one of the supervision team became involved in the COVID response work, significantly impacting the ability to submit a manuscript to a journal within a required timeline.

Also, in 2020, war broke out in Tigray region, where the study was conducted and where my family lives. Not only was there no ability to communicate with family members to learn if they were alive, but the health infrastructure described in this study was looted and remains out of use.

But even with all these challenges, I am grateful for the opportunity to have undertaken this study and I was fortunate to have very supportive supervisors who always encouraged me. This study remains relevant for rural areas across Ethiopia and hopefully when Tigray region emerges from the conflict, it will be applicable there too.



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## Appendix 1A: The explanatory statement for leaders



**MONASH University**

### English Version: Explanatory Statement

Leaders (representatives of Regional Health Bureau; medical, nurses, and pharmacy leaders of Primary, General and Comprehensive Specialised Hospitals; Health Centre leaders and pharmacy leaders; and educational leaders of school of Nursing, Medicine and Pharmacy)

13402: Investigation of a sustainable public health approach to the provision of palliative care service in North Ethiopia.

Name of the chief investigator: A/Prof. Susan Lee      Student researcher: Atsede Fantahun Aregay

School of Nursing and Midwifery	School of Nursing and Midwifery
Phone Number: +61 3 9904 4204	Phone Number: +251-940975593
E-mail : <a href="mailto:susan.lee@monash.edu">susan.lee@monash.edu</a>	E-mail : <a href="mailto:atsede.aregay@monash.edu">atsede.aregay@monash.edu</a>

My name is Atsede Aregay, and I am a PhD candidate at the School of Nursing and Midwifery, Monash University. My Supervisors are Associate Professor Susan Lee, Emeritus Professor Margaret O'Connor AM, Dr Jill Stow and Dr Nicola Ayers.

You have been invited to join in this study. I am providing this explanatory statement to inform you and assist you in deciding whether you wish to participate or not in this study. If you would like further information regarding any aspect of this study project, please contact the researchers via the above-listed phone number or e-mail address.

**What does the study involve?**

This study aims to investigate how to care for people with a chronic life-limiting illness may be addressed in the rural communities of Ethiopia. We are using a case approach to find out what is currently being provided and what barriers and opportunities might exist to new services. We are hoping, as a leader in your organisation; you will participate in an in-depth audiotaped interview about care for people with life-limiting illness and their families. You will be invited either through personal contact, poster or your peers who work in your institution. This interview will take 30-45 min.

**Why were you chosen to involve in this study?**

You are invited to contribute to this study because you are a leader in your organisation who may be able to inform us how you view the implementation of palliative care policy.

**The sponsor of this study?**

This study is funded by a Monash International Postgraduate Research Scholarship.

**Consenting to participate in this study and withdraw from this study**

You can indicate your willingness to accept involvement in this project by signing the consent form before the interview commencing. You have the right to withdraw from participating in this study at any time, including during the interview and up until the interview is de-identified. Participating in this study is voluntary, no payment will be made, and you are not obligated to consent or participate.

**Potential benefits and risks of the participant**

Participating in this study will have a low risk of harm for leaders working in the regional health bureau, educational institute and hospitals. This letter constitutes a full explanatory statement, and should you be interested; I can answer any questions you have before you consent to the interview. You are not required to disclose personal cases that might be upsetting. For this small number of participants, the researcher, an experienced nurse, will stop the interview if this happens, and provide emotional support.

The interview will only recommence once the participants are comfortable or stopped. The

benefits of being involved in this study include the opportunity to shape future services for caring people with life-limiting illness in your region.

### **Confidentiality**

All aspects of the study including the results will be strictly confidential, and only the researcher and supervisors will have access to information on participants. Participants de-identified by name and the information collected will not be personal. The organisations will be de-identified, but in some larger organisations (ministry, University, regional hospital) your position title may make your contribution identifiable. However, every effort will be made to condense this. To maintain confidentiality, codes will be used in the results and publications. The region and organisations will not be named.

### **Storage data**

The collected data will adhere to the university regulations and kept in a password secured electronic platform (LabArchives) at Monash University permanently.

### **Use data for another purpose**

If published, individual participants will not be identifiable in such a report, and de-identified data used for further research projects.

### **Results**

The result of this study will be published in peer-reviewed journals and presented at relevant conferences. Results will also be made available to study participants and organisations on request.

### **Complaints.**

Should you have any concerns about how this study is being conducted (project number 13402), please contact the School of Nursing Ethical Committee member at Mekelle University, Health Research-Ethical Review Committee (MU-HRERC).

Mr. Desta Hailu

**Tel : +251-934-722071**

**E-mail: [destahailu19@gmail.com](mailto:destahailu19@gmail.com)**

**Fax +251344 416681**

**Thank you,**

A handwritten signature in black ink, appearing to read "Susan Lee". The signature is fluid and cursive, with the first name "Susan" and the last name "Lee" clearly distinguishable.

Associate Professor Susan Lee

### ሐበሬታ መውሃቢ ቅጥዒ

ንሓለፍቲ (ተወካሊ ክልል ቢሮ ሓለዋ ጥዕና ፣ ሆስፒታል ሚዲካል ዳይሬክተር፣ ሚትሮን፣ ጣብያ ጥዕና ሓላፊ፣ ሐልፍቲ ትምህርቲ ክፍሊን ሄድ ነርስን )

13402፡ ኣብ ሰሚን ኢትዮጵያ ዘላቂ ኣቀራርባ ጥዕና ሕብረተሰብ ንኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ዝካየዱ ዳህሳስ ፡

ሹም ዋና ተመራማሪ፡ ተሐባባሪ ፕሮፌሰር ሱዛን ተመሃሪት ተመራማሪ፡ አፀደ ፋንታሁን አረጋይ ሊ

ክፍሊ ትምህርቲ ነርስንግን ሚዲካል ዳይሬክተር	ክፍሊ ትምህርቲ ነርስንግን ሚዲካል ዳይሬክተር
ቁፅሪ ስልኪ ፡ +61 3 9904 4204	ቁፅሪ ስልኪ ፡ +251-940975593
ኢ-መይል፡ <a href="mailto:susan.lee@monash.edu">susan.lee@monash.edu</a>	ኢ-መይል፡ <a href="mailto:atsede.aregay@monash.edu">atsede.aregay@monash.edu</a>

ሽመይ አፀደ ፋንታሁን አረጋይ ይበሃል፡፡ ኣብ ሞናሽ ዩኒቨርሲቲ ክፍሊ ትምህርቲ ነርስንግን ሚዲካል ዳይሬክተር ተመሃሪት ዶክተሬት ዲግሪ እየ፡፡ መማኸርተይ ወይ መምህራነይ ድማ ፤ ተሐባባሪት ፕሮፌሰር ሱዛን ሊ, ፕሮፌሰር ማርጋሪት ኦ ኮነር፣ ዶክተር ጂል ስቶው ከምኡውን ዶክተር ኒኮላ አየርስ ይበሃሉ፡፡

ኣብዚ መፅናዕቲ እዚ ንክትሳተፉ ተዓዲምኩም አለኩም፡፡ ኣብዚ መፅናዕቲ ንምስታፍ ወይ ንዘይምስታፍ ንምውሳኑ ንክሕግዘኩም እዚ ሐበሬታ መውሃቢ ቅጥዒ ብመሉኡ ክንበበልኩም እየ፡፡ ተወሳኺ ሐበሬታ እንተደሊኹም፣ኣብ ላዕሊ ብዝተገለፀ አድራሻ (ቁፅሪ ስልኪ፣ ኢ-መይል) ነታ ተመራማሪት ክትረከብዋ ትኽእሉ ኢኹም፡፡

### እቲ መፅናዕቲ እንታይ የካትት?

ዕላማ እዚ መፅናዕቲ ኣብ ሕብረተሰብ ገጠር ኢትዮጵያ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ሕብረተሰብ ብኸመይ ይርአይ ብዝብል ንምድህሳስ እንትኸውን ኣብዚ ሕጂ እዋን እንታይ ይግበር ከም ዘለዎን ንሓዱሽ ኣገልግሎት እንታይ ፀጋታትን ዕንቅፋታትን ክህሉ ከም ዝኽእል ንምድህሳስ ናይ ኬዝ ኣፕሮች ተጠቂምና አለና፡፡ ከም መራሒ/ት ናይዚ ትካል፣ ኣብ ሕብረተሰብ ገጠር ኢትዮጵያ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ (ዝሓመመን ቤተሰቡን) ብኸመይ ይርአይ ብዝብል ርእሲ ንዝካየዱ መፅናዕቲ ብምቕረቢ ድምዒ ተሓጊዙ ኣብ ዝግበር ዓሚቕ ቃለ-መጠይቕ ከም እትሳተፉ ተስፋ ንገብር፡፡ ብኣካል ወይ ድማ ብ ፖስተር ወይ ምሳኩም ኣብ ትካልኩም ዝሰርሑ ሰባት ናብዚ መፅናዕቲ ክዕድሙኩም እዮም፡፡ እዚ ቃለ-መሕትት ካብ 30-45 ደቂቃ ክወስድ ይከእል እየ ፡፡

### **ንምንታይ ኣብዚ መፅናዕቲ ንክትሳተፉ ተሓሪኹም/ኸን?**

ኣብዚ መፅናዕቲ እዚ ንክትሳተፉ ዝተዓዲምኩምሉ ምኽንያት ንሰኹም ናይዚ ትካልኩም ሃላፊ ብምዃንኩም/ ክን ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ (ዝሓመመን ቤተሰቡን) ፖሊሲ ብኸመይ ከም ዝትግበር ሓሳብኩም ክትነግሩና ስለ ትክእሉ እዩ ።

### **ናይዚ መፅናዕቲ ስፖንሰር**

እዚ ጽንዓት ብ ሞናሽ ዓለም ለኽ ድሕረ ምረቃ ምርምር ዝተሓገዘ እዩ።

### **ፈቃደኝነት ን ምስታፍ ኣብዚ መፅናዕቲን ካብዚ መፅናዕቲ ንምቁራፅን**

ቅድሚ እቲ ቃለ-ማሕተት ምጅማሩ ፣ ኣብዚ መፅናዕቲ ናይ ምስታፍ ድሌት ምህላውካ ኣብቲ ናይ ፈቃደኛ መውሃቢ ቅጥዒ ብፌርማካ ክተርኢ ትክእል ኢካ። ፣ኣብ ዝኾነ ግዜ ካብቲ መፅናዕቲ ምስታፍ ናይ ምቁራፅ መሰልኩም ዝተሓለወ እዩ።ዋላ ኣብ እዋን ቃለ-ማሕተትን ክሳብ እቲ ቃለ-ማሕተትን ዝውዳእን ማንነት ኣይገልፅን። ኣብዚ መፅናዕቲ ምስታፍ ግዴታ የብሉን፣ ከምኡውን ምንም ዓይነት ክፍሊት የብሉን፣ ብፈቃደኝነት ዝተመሰረተ ምኽኑ ንገልፅ።

### **ክርክብ ዝክእል ጥቅምን ፅልዋ ንተሳተፍቲ**

ኣብዚ መፅናዕቲ ምስታፍ ኣብ ክልል ቢሮ ሓለዋ ጥዕና ፣ ላዕለዎት ትካላት ትምህርትን ሆስፒታላትን ንዝርከቡ ተሳተፍቲ ብጣዕሚ ትሑት ፅልዋ ክህልዎ ይኽእል እዩ። እዚ ፅሑፍ ንምስታፍ ዘድልየኩም ሙሉእ ሓበሬታ ዝሓዘ እዩ። ካብዚ ብተወሳኺ ቅድሚ እቲ ቃለ-መሕተት ንክትሳተፉ ምውሳኔኩም ዝኾነ ጥያቄ እንተሃለዩኩም ክምልሰልኩም ይክእል እዩ። ርእሰኹም ዝርብሽ ግላዊ ምስጢር ዘይምግላፅ ትኽእሉ ኢኹም ። ኣብ ዝተወሰኑ ተሳተፍቲ ከምዚ እንተጋጢሙ ፣ እታ ተመሃሪት ተመራማሪት ልምዲ ዘለዋ ነርስ ስለዝኾነት ክተረጋገእኩም ስነ ኣእምሮኣዊ ድጋፍ ክትህበኩም ትኽእል እያ። እንድሕር ተሳተፍቲ ተረጋጊእኦምን ተመቓዎምን፣ እቲ ቃለ-መሕተት ዝቅፅል ። ኣብዚ መፅናዕቲ ምስታፍ ዘለዎ ጥቅሚ ንቐፃሊ ኣብ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ግልጋሎት ኣብ ምምሕያሽ ክሕግዝ ይኽእል እዩ።

### **ምስጢራውነት**

ኩለመዳያዊ ኣካይዳ ናይዚ መፅናዕቲ ኮነ ሓፈሻዊ ውፅኢት ብጥብቂ ብምስጢር ዝተዓቀበ እዩ። እታ ተመሃሪት ተመራማሪትን መማኸርቲ መምህራንን ጥራሕ እየን ነቲ ሓበሬታ ተሳተፍቲ ክረክቡኦ ዝክእሉ። ተሳተፍቲ ብምንም መልክዑ መንነቶም ኮነ ሽሞም ኣይግለፅን ከምኡውን እቲ ዝእኩብ መረዳእታ ብስሩ ግላዊ ኣይኮነን። ምስጢር ንምዕቃብ ኣብ ምግላፅ ውፅኢትን ሕትመትን መፍለይ ቁፅሪ እንተዘይኮይኑ ብሽም ዝግልፅ ተሳታፊ ኣይህሉን። ትካልኩም እውን መንነቱ ኣይግለፅን። ይኹን እምበር ኣብ ዓበይቲ ትካላት (ሚኒስቴር፣ ዩኒቨርሲቲ፣ ክልላዊ ሆስፒታል) እቲ ማእርግኩምን ኣበርክቶኹምን ክገልፅ ይክእል እዩ። እዚ ንምቅናስ ግን ዝከኣል ፃዕሪ ክግበር እዩ።

### **ምዕቃብ መረዳእታ**

እቲ ዝተኣከበ መረዳእታ ብመምርሒ እቲ ዩኒቨርሲቲ መሰረት ብምስጢር ቁፅሪ ኣብ ዝተዓፀወ መርበብ ሓበሬታ ሞናሽ ዩኒቨርሲቲ (ኣብኣርካይብ ዝባሃል) ተዓቂቡ ንሓዋሩ ይቅመጥ።

## መረዳኢታ ንካሊእ ምጥቃም

እንድሕር ደኣ ተሐቲሙ፣ መንነት ተሳተፍቲ አይግለፅን ሓፈሻዊ መረዳኢታ ኣብ ቐፃሊ ንካሊእ ምርምር ከንጥቀመሉ ንክእል ኢና።

## ውፅኢት

ውፅኢት እዚ መፅናዕቲ ኣብ ደረጃኡም ዝሓለዉ ዓለም-ለኻዊ መፅሔታት ከሕተም ከምኡውን ኣብ ትዛመድቲ መድረኻት ከቀርብን እዩ። እቲ ውፅኢት ንቶም ተሳተፍትን ትካላትን ብዝሕትዎ መሰረት ንክወሃቦም ፃዕሪ ክግበር እዩ።

## ጥርፃን

ኣብዚ መፅናዕቲ (መለለይ ቁፅሪ፡13402)፣ ዝኮነ ርኢቶ ኮነ ሓሳብ እንተሃልይኩም ነዚ ኣብ ታሕቲ ትገሊፁ ዘሎ ኣባል ኮሚቴ ስነ ምግባር መፅናዕቲ ኮሌጅ ጥዕና ሳይንስ ዩኒቨርሲቲ መቐለ ከትረክብዎ ትክእሉ ኢኩም።


## አቶ ደስታ ሃይሉ

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ንተሳተፎኹም ካብ ልቢ የመስግን,



ተሓባባሪት ፕሮፌሰር ሱዛን ሊ

## Appendix 1B: Interview questions framework for leaders

### English Version



### List of leaders' frameworks

Adapted from (Callaway et al., 2018)

1. Current status of palliative care policy implementation (regional health bureau representative, Medical Director, Chef nursing officer and head nurses)

#### Advocacy plan to implement palliative care

- 1.1. All national plans and policies include palliative care guideline, are implemented and monitored
- 1.2. Palliative care services and health care professionals are entirely financed
  - 1.2.1. Available of financial and human resources resource to implement palliative care
  - 1.2.2. Adequate funding for health professionals working in palliative care including reimbursement
- 1.3. Opportunities and barriers
2. Essential medicine policy
  - 2.1. Palliative care medicines such as morphine included in the country's essential medicine list (pharmacy head)
  - 2.2. All doctors have received training on opioid prescribing and are authorised to prescribe (medical directors, regional health bureau representative)
  - 2.3. Availability and affordability of opioids and other Palliative care medicines throughout the country (pharmacy head)
  - 2.4. Pain relieving medications in all forms and doses are available in the country (pharmacy head)
  - 2.5. Distribution, dispensing, and accountability system (pharmacy head)
  - 2.6. Opportunities and barriers
3. Palliative care education in health care professionals
  - 3.1. The policy encouraged palliative care education in curricula and examinations of undergraduate and postgraduate health care students (school heads, regional health bureau representative)
  - 3.2. Palliative care education through in-service training for health care professionals working in each level (regional health bureau representative, medical directors, chief nursing officers, head nurses, school heads)



- 3.3. Palliative care education for the public such as media and public awareness (regional health bureau representative)
- 3.4. Opportunities and barriers
- 4. Integration and implementation of palliative care
  - 4.1. Current palliative care services including home care and inpatient beds in all hospitals, nursing, and elderly homes
  - 4.2. Current status in supporting family caregivers (regional health bureau representative, health extension workers)
  - 4.3. Technology related service such as a mobile phone
  - 4.4. Sustainability of care for people diagnosed with life-limiting illnesses
  - 4.5. Opportunities and barriers



**ምስ መራሕቲ ንዝካየድ ምይይጥ መልዓሊ ነጥብታት**

1. ኣብዚ ሕዚ እዋን ፖሊሲ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ኣተገባብራ ዘለዎ ኩነታት (ተወካሊ ክልል ቢሮ ሓለዋ ጥዕና ፣ ሆስፒታል ሚዲካል ዳይሬክተር፣ ሚትሮን፣ ጣብያ ጥዕና ሓላፊ፣ ሓልፍቲ ትምህርቲ ክፍሊን ሄድ ነርስን)
  - 1.1. ናይ ውክልና/ሓገዝ ትልሚ ን ምትግባር ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ
  - 1.2. ኩሎም ናይ ሃገራዊ ትልሚን ፖሊሲን ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ መምርሒ፣ ምትግባርን ምቁፅፃርን
  - 1.3. ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ኣገልግሎትን ጥዕና ባዓል ሞያን ሙሉእ ወፃኢ ምሽፋን።
    - 1.3.1. ንኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ንምትግባር ዘድሊ ሓይሊ ሰብን ገንዘብን ምህላው።
    - 1.3.2. ኣብ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ንዘገልግሉ ሰብ ሞያ ጥዕና እኹል ገንዘባዊ ሓገዝ ከምኡውን መካሓሲ ምህላው
    - 1.3.3. ፀጋታትን ዕንቅፋታትን
2. ፖሊሲ ጠቀምቲ መድሓኒታት
  - 2.3. ንኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ከም ሞርፊን ዝኣመሰሉ መድሓኒታት ኣብ ሃገራዊ ዝርዝር ጠቀምቲ መድሃኒታት ተጠቓሊሉ ይርከብ። (ናይ ፋርማሲ ሓላፊ)
  - 2.4. ኩሎም ዶካትር “ኦፖይድ” ናይ ምእዛዝ ስልጠና ወሲዶም፡ ንክእዝዙ ፍቕድ እዩ (ተወካሊ ክልል ቢሮ ሓለዋ ጥዕና ፣ ናይ ሆስፒታል ሚዲካል ዳይሬክተር) ።
  - 2.5. ተበዓላትን ዓቕሚ መግዝኢ ኦፖይድን ካልኣት ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ መድሓኒታት ኣብ ኩሉ ቦታታት እታ ሃገር ይርከብ (ናይ ፋርማሲ ሓላፊ)
  - 2.6. ፀረ ቃንዛ መድሓኒታት ብኩሉ መልክዕ ከምኡውን ኣብ ምእኦ ክፋል እታ ሃገር ይርከብ (ናይ ፋርማሲ ሓላፊ)
  - 2.7. ዝርግሐ፣ ቀረብን ተሓታትነትን እዞም መድሓኒታት ከመይ ይመስል። (ናይ ፋርማሲ ሓላፊ)
  - 2.8. ፀጋታትን ዕንቅፋታትን
3. ንኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ዝወሃብ ትምህርቲ ን ሰብ ሞያ ጥዕና
  - 3.1. ሃገራዊ ፖሊሲ ትምህርቲ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ኣብ ስርዓተ ትምህርትን ፈተናታትን ቀዳማይን ካልኣይን ዲግሪ ሰብ ሞያ ጥዕና ተማሃሮ ንክካተት የተባብዕ። (ተወካሊ ክልል ቢሮ ሓለዋ ጥዕና ፣ ሓልፍቲ ክፍሊ ትምህርቲ)
  - 3.2. ኣብ ዝተፈላለዩ ብርኪ ዘለዎ ትካላት ጥዕና ንዝሰርሑ ሰብ ሞያ ጥዕና ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ዝምልከት ኣብ ኣገልግሎት ዝወሃብ ስልጠና ምሃብ ዝምልከት (ተወካሊ ክልል ቢሮ ሓለዋ ጥዕና ፣ ናይ ሆስፒታል ሚዲካል ዳይሬክተር፣ ሚትሮን፣ ጣብያ ጥዕና ሓላፊ፣ ሓልፍቲ ክፍሊ ትምህርቲን ሄድ፣ ነርስ፣ ፋርማሲ ሓላፊ)
  - 3.3. ብዛዕባ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ን ሕብረተሰብ ብመልክዕ ሚድያ ን ኣፍልጦ ሕብረተሰብ ትምህርቲ ኣብ ምሃብ (ተወካሊ ክልል ቢሮ ሓለዋ ጥዕና ፣ ናይ ሆስፒታል ሚዲካል ዳይሬክተር፣ ሚትሮን)
  - 3.4. ፀጋታትን ዕንቅፋታትን
4. ኣተገባብራ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ከማኡውን ምስቲ ዘሎ ግልጋሎት ጥዕና ኣተኣሳሰርካ ምሃብ
  - 4.1. ኣብዚ ሕጂ እዋን ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ኣብ ዝሓም፡ ሆስፒታላት ዝድቅሱ ሕሙማት ዝወሃብ ክንክን ብኣፈሻ ብከመይ ይግለፅ
  - 4.2. ኣብዚ ሕዚ እዋን ን ቤተሰብ እቲ ሕሙም ኣብ ምድጋፍ ዘለዎ ኣበርክቶ (ተወካሊ ክልል ቢሮ ሓለዋ ጥዕና ፣ ናይ ሆስፒታል ሚዲካል ዳይሬክተር፣ ሚትሮን፣ ባዓል ሞያ ጥሙር ጥዕና)
  - 4.3. ምስ ቴክኖሎጂ ዝተተሓዘ ግልጋሎት፡ ንኣብነት ሞባይል

## Appendix 1C: Consent form for leaders

English Version



**MONASH** University

### CONSENT FORM

For leaders (representatives of Regional Health Bureau; medical, nurses, and pharmacy leaders of Primary, General and Comprehensive Specialised Hospitals; Health Centre leaders and pharmacy leaders; and educational leaders of school of Nursing, Medicine and Pharmacy)

13402: Investigation of a sustainable public health approach to the provision of palliative care in North Ethiopia: A case study

Chief Investigator: Associate Professor Susan Lee

Student Investigator: Atsedie Aregay

I have been asked to take part in the Monash University research project specified above. I have read and understood the Explanatory Statement, and I at this moment consent to participate in this project.

I consent to the following:	Yes	No
I agree for audio recording during the interview	<input type="checkbox"/>	<input type="checkbox"/>
I agree that the data samples that I provide during this research may be used by the researcher in future research projects	<input type="checkbox"/>	<input type="checkbox"/>
I agree in the event of any distress the researcher will stop the interview and provide emotional support.	<input type="checkbox"/>	<input type="checkbox"/>

Name of Participant \_\_\_\_\_

Participant Signature Date \_\_\_\_\_

## Tigrigna Version



### ናይ ፈቃደኝነት መረገዝ ቅጥዒ

ንሓለፍቲ (ተወካሊ ክልል ቢሮ ሓለዋ ጥዕና ፣ ሆስፒታል ሚዲካል ዳይሬክተር፣ ሚትሮን፣ ጣብያ ጥዕና ሓላፊ፣ ሐልፍቲ ትምህርቲ ክፍሊን ሄድ ነርስን)

13402፡ ኣብ ሰሚን ኢትዮጵያ ዘላጅ ኣቀራርባ ጥዕና ሕብረተሰብ ንኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ደማ ሕዳር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ዝካየዱ ዳህሳስ ፡

ዋና ተመራማሪት፡ ተ/ፕሮፌሰር ሱዛን ሊ

ተመሃሪት ተመራማሪት፡ አፀደ ፋንታሁን አረጋይ

ኣብዚ ልዕል ክብል ዝተገለፀ ዝተገለጸ ናይ ሞናሽ ዩኒቨርሲቲ መጽናዕቲ ንክትሳተፉ ጠይቀ ነይረ፡ እቲ ዝተገለጸ መብርሂ ኣንቢቦሉ ከምኡውን ተረዲአሉ፡፡ ኣብዚ መጽናዕቲ ን ምስታፍ ፈቃደኛ እየ፡፡

ኣብዘም ዝስዕቡ ፍቃደኛ እየ፡	እወ	አይፋሉን
ኣብቲ ቃል-መሕትት ድምጺይ ን ክቅረጽ ይስማዕማዕ ኣለኩ፡፡	<input type="checkbox"/>	<input type="checkbox"/>
እቲ ዝህቦ መረዳእታ እዚ መጽናዕቲ ምናልባት እታ ተመራማሪት ን ንቐፃሊ መጽናዕቲታት ንክትጥቀመሉ ይስማዕማዕ ኣለኩ፡፡	<input type="checkbox"/>	<input type="checkbox"/>
ኣብዚ ቃል-መሕትት ዝኮነ ዘይምርግጋዕ እንተጋጠሙ፣ እታ ተመራማሪት እቲ ቃል-ምሕትት ኣጃሪፃ ደገፍ ስነ ኣእምሮ ከትገብረለይ ይስማዕማዕ ኣለኩ፡፡	<input type="checkbox"/>	<input type="checkbox"/>

ሹም ናይ ተሳታፊ

ፊርማ \_\_\_\_\_ ዕለት \_\_\_\_\_

## Appendix 2A : Survey questionnaire

**English version**



**MONASH University**

**Code: \_\_\_\_**

**The following questionnaire has four-part including**

**Socio-Demographic questions,**

**Knowledge, Attitudes, and self-reported practice towards palliative care.**

**This questionnaire will take you 25-30 minute.**

This study aims to understand, investigate and make a recommendation for a sustainable public health approach to the provision of palliative care in rural and regional Ethiopia

Please answer all the questions if you have any unclear question do not hesitate to flash on my phone number:

+251-913-30-8555

Atsede

**Part I. Instructions: Please place a circle or write a short answer, where appropriate, to indicate your response to the following questions:**

**1. Gender**

- a. Male
- b. Female

**2. Age, years \_\_\_\_\_**

**3. Clinical area**

- a. Medical Ward
- b. Surgical Ward
- c. Oncology/chemotherapy Unit

**4. Duration of nursing experience**

- a. <1 year
- b. 1-4 years
- c. 5-9 years
- d. 10-14 years
- e.  $\geq 15$  years

**5. Experience in caring for patients with life-limiting illness and their families  
(Palliative care)**

- a. <1 year
- b. 1-4 year
- c. 5-9 year
- d. 10-14 years
- e.  $\geq 15$  years
- f. None

**6. Educational qualification**

- a. Diploma nursing
- b. BSc Nurse
- c. Master

**7. Palliative care education as an undergraduate/post-graduate level**

- a. yes

b. no

**8. In-service training in caring for life-limiting ill patients and their families  
(Palliative care)**

a. Yes

b. No

**9. If your answer is yes for Q no.8, for how long you train?**

a. 1-2 weeks

b. 2weeks - 1 month

c. Six- month

d. Others Specify\_\_\_\_\_

**Part II. The questionnaire consists of several statements about palliative care if you think the statement is true, please tick in the true part, and if you think the statement is false, please tick in the false section. If you do not know the answer put a tick in the do not know section. Please answer all the questions.**

Questions	Yes	No	Do not know
1. Do you know about palliative care?			
2. Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration			
3. The extent of the disease determines the method of pain treatment			
4. Adjuvant therapies (antidepressant, anticonvulsant and anti-emetics) are essential in managing pain.			
5. Drug addiction is the major problem when morphine is used on a long-term basis for the management of pain			
6. The provision of palliative care requires emotional detachment			



- 
7. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnoea
  8. The philosophy of palliative care is compatible with that of aggressive treatment
  9. The use of placebos is appropriate in the treatment of some types of pain
  10. Meperidine (Demerol) is not an effective analgesic in the control of chronic pain
  11. The accumulation of losses renders burnout Inevitable for those who work in palliative care
  12. The manifestation of chronic pain is different from those of acute pain
  13. Terminal ill patients have the right to choose 'Do not resuscitate'.
  14. Terminal ill patients should be encouraged to have a hope against all odds
- 

**Source:** The palliative care quiz for nursing (PCQN). The development of an instrument to measure nurses' knowledge of palliative care (Ross et al., 1996).

**Part III. The following questions ask you about your thoughts on palliative care. This section has five alternatives to choose from which range from Strongly Agree (SA), Agree (A), Unsure (U) Disagree (D) and Strongly Disagree (SD)). Please answer all the questions.**

Items	SA	A	U	D	SD
1. Palliative care is given only for a dying patient.					
2. As a patient nears death; the nurse should withdraw from his/her involvement with the patient.					
3. Giving nursing care to the chronically sick patient is a worthwhile learning experience.					
4. It is beneficial for the chronically sick person to verbalise his/her feelings.					
5. Family members who stay close to a dying person often interfere with a professionals' job with the patient.					
6. The length of time required to give nursing care to a dying person would frustrate me.					
7. Families should be concerned about helping their dying member make the best of his/her end of life.					
8. The family should maintain an as healthy environment as possible for their dying member.					
9. The nurse should not be the one to talk about death with the dying person					
10. The family should be involved in the physical care of the dying person					
11. It is difficult to form a close relationship with the dying person.					
12. There are times when death is welcomed by the dying person					
13. Nursing care for the patient's family should continue throughout grief and bereavement					
14. The dying person should <u>not</u> be allowed to make decisions about his/her physical care					
15. Addiction to pain relieving medication should not be a concern when dealing with a dying person					
16. Nursing care should extend to the family of the dying person					

- 
17. When a patient asks, “Am I dying?” I think it is best to change the subject to something cheerful
  18. I am afraid to become friends with chronically sick and dying patients.
  19. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.
  20. I would be uncomfortable talking about impending death with the dying person
  21. It is possible for nurses to help patients prepare for death
  22. Death is not the worst thing that can happen to a person.
  23. I would feel like running away when the person died.
  24. I would not be assigned to care for a dying person
- 

Source: Adapted from (Mastroianni et al., 2015)

**Part IV. The following questions relate to the delivery of palliative care., Please choose from the following options, you may circle more than one.**

1. Which of the following care practices do you use in your setting in caring for people with a life-limiting illness?
    - 1.1. Counselling
    - 1.2. Hygiene
    - 1.3. Comfort care
    - 1.4. Patient education
    - 1.5. Family education
    - 1.6. Family meetings
    - 1.7. Multidisciplinary team meetings
    - 1.8. Working with community and religious leaders
  2. Application of assessment tools
    - 2.1. Pain
    - 2.2. Nausea and Vomiting
    - 2.3. Diarrhoea and Constipation
    - 2.4. Fatigue
    - 2.5. Emotional/Psychological state
    - 2.6. Spiritual needs
  3. Administering medication for pain relief
    - 3.1. Morphine
    - 3.2. Tramadol
    - 3.3. Paracetamol
  4. Using non-pharmacological management of pain
    - 4.1. Hot or cold compress
    - 4.2. Massage
    - 4.3. Distraction
  5. Administering medication to treat symptoms
    - 5.1. Nausea and Vomiting
    - 5.2. Diarrhoea and Constipation
    - 5.3. Anxiety and Depression

Others (please specify)
-

Thank you for completing this questionnaire

Tigrigna Version



ዳህሰሳ መጠይቅ

መፍለጫ ቁፅሪ ትካል: \_\_\_\_\_

እዞም ዝስዕቡ መጠይቃት ብዛዕባ ኩለንተናዊ ክንክን ብጽኑዕ ሕጻን ወይ ድማ ሕፃር ሕጻን ዝሓመሙ ክፋላት ሕብረተሰብ ወይ ድማ ፓሌቲቭ ኬር ዝምልከት እዩ። እዚ መጠይቕ ኣርባዕተ ክፍልታት ዝሓዘ እዩ። ንሳቶም እዚን

1. ማሕበራዊ ህይወት
2. ፍልጠት
3. ተግባርን
4. ኣረኣእያን

እዚ መጠይቅ ንምምላእ ካብ 25-30 ደቂቃ ክውድእ ይኽእል እዩ።

ናይዚ መፅናዕቲ ዓላማ እዚ ንምርዳእ፣ ንምምርማርን ምሕባርን ዘለቂታዊ ሕብረተሰብ ጥዕና መዳይ ን ኩለንተናዊ ክንክን ብጽኑዕ ሕጻን ወይ ድማ ብዘይድሕን ሕጻን ዝሓመሙ ሕብረተሰብ ኣብ ሰሜን ኢትዮጵያ

በይዛኩም ኩሎም ጥያቄ ንምምላስ ሞክሩ።

**ክፍሉ 1. በይዛኩም አብዞም ዝሰዕቡ ጥያቄታት መልሲ ዝበልኩምዎ ኣበተ ዝተወሃብ ቦታ ብምኽባብ ወይ ብምፅሓፍን መልስኩም ኣንብሩ።**

**1. ፆታ**

ሀ. ወዲ ተባዕታይ

ለ. ጓል ኣንስተይቲ

**2. ዕድሙ፡ \_\_\_\_\_ ዓመት**

**3. ትሰርሕሉ ክፍሊ**

ሀ. ሜዲካል ዋርድ

ለ. ሰርጂካል ዋርድ

ሐ. ካንሰር ክፍሊ

መ. ካልእ፣ይገለፅ \_\_\_\_\_

**4. ናይ ነርሲ ልምዲ ግዜ**

ሀ. ትሕቲ 1 ዓመት

ለ. 1-4 ዓመታት

ሐ. 5-9 ዓመታት

መ. 10-14 ዓመታት

ሠ. 15 ዓመትን ልዕሊኡን

**5. ኡብ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ብሕዳር ሕማም ዝሓመሙ ሕሙም ን ቤተሰብን ኣገልግሎት ልምዲ**

ሀ. <1 ዓመት

ለ. 1-4 ዓመት

ሐ. 5-9 ዓመት

መ. 10-14 ዓመት

ሠ. 15 ዓመት

ረ. የብለይን

**6. ደረጃ ትምህርቲ**

ሀ. ዲፕሎማ ብ ነርሲንግ

ለ. ቀዳማይ ዲግሪ ብ ነርሲንግ

ሐ. ካልኣይ ዲግሪ

**7. ብዛዕባ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ብሕዳር ሕማም ዝሓመሙ ክፋላት ሕሙም ን ቤተሰብን ኡብ መጀመርያ ዲግሪ ወይ ካልኣይ ዲግሪ ተማሂርኩም ዶ ትፈልጡ?**

ሀ. እወ

ለ. ኣይፋሉን

**8. ኡብ ትካላት ጥዕና እንዳሰራሕኩም ብዛዕባ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ብሕዳር ሕማም ዝሓመሙ ክፋላት ሕሙም ን ቤተሰብን ስልጠና ተሳቲፍኩም ዶ ትፈልጡ?**

ሀ. እወ

ለ. ኣይፋሉን

**9. ናይ ቁፅሪ eight መልሲ እወ እንተኾይኑ ፣ ንክንደይ ዝኣክል ግዜ ሰልጢኹም?**

ሀ. 1-2 ሰሙን

ለ. 2 ሰሙን - 1 ወርሒ

ሐ. 6 ወርሒ

መ. ካልእ, ግለጽ \_\_\_\_\_

**ክፍሊ 2. እዚ መጠይቅ ብዛዕባ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ብሕዱር ሕማም ዝሓመሙ ክፋላት ሕመምን ቤተሰብን ብርክት ዝበሉ ሕቶታት ዝሓዘ እዩ። እንድሕር እቲ ሕቶ ሓቂ ከይኑ ኣብቲ እወ ዝብል ምልክት ራይት ግበሩ፤ እንድሕር እቲ ሕቶ ጌጋ ኮይኑ ኣብቲ ኣይፋሉን ዝብል ምልክት ራይት ግበሩ፤ እንድሕር እቲ ጥያቄ ዝገልፅ ዘይትፈልጥዎ ከይንኩም ኣብቲ ኣይፈልጦን ዝብል ምልክት ራይት ግበሩ። ብዝከኣልኩም ኩሎም ሕቶታት ንምምላስ ሞክሩ።**

ሕቶታት	እወ	ኣይፋሉን	ኣይፈልጦን
1. ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ብሕዱር ሕማም ዝሓመሙ ክፋላት ሕመምን ን ቤተሰብን ትፈልጡ ዶ?			
2. ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ብሕዱር ሕማም ዝሓመሙ ክፋላት ሕመምን ን ቤተሰብን ኣድላይ ዝኸውን ኣብ ግዜ ብጣዕሚ ዝገደደ ብርኪ ሕማም እዩ።			
3. ዓይነት ፀረ ቻንዛ መድሐኒት ዝውሰን ብናይቲ ሕማም ብርኪ እዩ።			
4. ኣድጃቨንት መድሐኒታት (ፀረ-ዲፕሬሽን, ፀረ-ምንፍርፋርን ፀረ-ተምላስ) ስቃይ ንምቁፅፃር ይጠቅም።			
5. ቻንዛ ንምቁፅፃር ንነዊሕ ግዜ ሞርፊን ምጥቃም ናይ መድሐኒት ወልፊ ዓብይ ፀገም እዩ።			
6. ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ብሕዱር ሕማም ዝሓመሙ ክፋላት ሕመምን ን ቤተሰብን ንምሃብ ናይ ኣእምሮ ምብትታን ክህሉ ኣለዎ ።			
7. ኣብ ናይ መወዳእታ ብርኪ እቲ ሕማም፣ ናይ ምስትንፋስ ፀገም ከምፅኡ ዝክእሉ መድሐኒታት ብርቱዕ ናይ እስትንፋስ ሕፅረት ሕማም ንምሕካም ኣድላይ እዩ።			
8. ናይ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ብሕዱር ሕማም ዝሓመሙ ክፋላት ሕመምን ን ቤተሰብን ፍልስፍና ምስ ካብ ልሙድ ንላዕሊ ዝኾነ ሕክምና ይመሳሰል እዩ።			
9. ሓደ ሓደ ናይ ቻንዛ ዓይነት ንኣእምሮ መረጋግኢ ዝኾን መድሐኒት ኣልባ(መዓሸዊ) ምጥቃም ኣድላይ እዩ።			
10. ሜፐርዲን (ዲሜርል) ብርቱዕ ሕማም ን ምቁፅፃር ውፅኢታዊ ኣይኮነን።			
11. ተደጋጋሚ ሞት/ምስኣን ኣብ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ሕመምን ን ቤተሰብን ትካላት ዝሰርሑ ዘይቀሪ ምስልቻው/ፅዕንቶ የሓድር።			
12. ናይ ፅኑዕ ቻንዛ መግለፅታት ካብ ግዚያዊ ቻንዛ ይፍለ እዩ።			
13. ብፅኑዕ ሕማም ዝሓመመ ሰብ ከም ብሂወት/ሪሳስቴሽን ክነብር ኣይደልን ዝመሳሰሉን ጉዳያት ናይ ምምራፅ መሰል ኣለዎም			
14. ብፅኑዕ ሕማም ዝሓመመ ሰብ ተስፋ ንክገብር ብዛዕባ ዝሓመምዎ ነገራት ክበረታታዕ ኣለዎ			

**ምንጭ:** ዝተመሓየሸ ካብ:

ከፍሊ 3. እዞም ዝሰዕሱ ሕቶታት ብዛዕባ ኣብ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ብሕዳር ሕማም ዝሓመሙ ከፋላት ሕብረተሰብ ዘለኩም ኣመለካኪታ ዝምልከት እዩ።እዚ ከፍሊ ሓሙሽተ ኣማራጻታት ካብ ብጣዕሚ ይሰማማዕ (ብይ)፣ ይሰማማዕ (ይ)፣ ርግፀኛ ኣይኮንኩን(ርአ)፣ ኣይሰማማዕን(አ)፣ ብጣዕሚ ኣይሰማማዕን (ብአ)። እንተኾኢልኩም ኩሎም ጥያቄ ኣብቲ ዝግባእ ቦታ ራይት ብምግባረ ንምምላስ ሞክሩ።

ተ.ቁ	መግለጺታት	ብይ	ይ	ርአ	አ	ብአ
1.	ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዳር ሕማም ዝሓመሙ ን ከመቶ ዝበሉ ሰባት ጥራሕ እዩ ዝወገብ።					
2.	ብጽኑዕ ዝሓመመ ሰብ ንሞት ክቀርብ ከሎ፣እቲ ነርስ ነቲ ሕመም ካብ ምቕራብ ክርስቅ ኣለዎ።					
3.	ብፅኑዕ ንዝሓመመ ሰብ ግቡእ ናይ ነርስ ክንክን ምግባር ትርጉም ዘለዎ ናይ ትምህርቲ ልምዲ እዩ።					
4.	ብፅኑዕ ዝሓመመ ሰብ ሰሚዒቱ ንክገልፅ ምብርታዕ ጠቓሚ እዩ።					
5.	እብ ጥቓ ብፅኑዕ ዝሓመመ ሰብ ዘሎ ኣባል ቤተሰብ መብዛሕትኦ ግዜ ኣብ ናይ ባዓል ሞያ ስራሕ ጣልቃ ይኣትዉ እዮም።					
6.	ብፅኑዕ ዝሓመመ ሰብ /ሕዳር ሕማም ዝሓመመ ዘድልዮ ነዊሕ ናይ ነርስ ክንክን የሰላችዉኒ እዩ።					
7.	ንቤተሰብ ብፅኑዕ/ሕዳር ሕማም ዝሓመመ ሰብ እቲ ሕመም ከሰብ ናይ ሂወቱ መወዳእታ ብተዛማዲ ሕጉን ንክኸውን ብኸመይ ክሕግዝዎ ከም ዝግባእ ከተሓሳስቦም ይግባእ።					
8.	ብዝተካለለ መጠን ቤተሰብ ን ኣቲ ብፅኑዕ/ሕዳር ሕማም ዝሓመመ ሰብ ምቕዉን ጥጡሕ ቦታ ክዳለዉሉ ኣለዎ።					
9.	ነቲ ብፅኑዕ/ሕዳር ሕማም ዝሓመመ ሰብ ስለ ሞት እንታይነት ከዛረብ ዘለዎ ነርስ ክኸውን የብሉን።					
10.	እቲ ቤተሰብ ኣብቲ ብፅኑዕ/ሕዳር ሕማም ዝሓመመ ሰብ ኣካላዊ ክንክን ከሳተፍ ይግባእ።					
11.	ምስ ክመውት ዝቐረበ/ብፅኑዕ ዝሓመመ ሰብ ዝጠበቐ ዝምድና ምህላው ከቢድ እዩ።					
12.	ክመውት ዝቐረበ/ብፅኑዕ ዝሓመመ ሰብ ዝሓሸ መማረፂ ዝኾነሉ ግዜ ኣሎ እዩ።					
13.	ናይ ነርስ ክንክን ኣብ ግዜ ሓዘን እቲ ቤተሰብ እውን ክቅፅል ይግባእ					
14.	ክመውት ዝቐረበ/ብፅኑዕ ዝሓመመ ሰብ ብዛዕባ ናይ ባዕሉ ኣካላዊ ክንክን ንክውስን ክፍቀደሉ የብሉን።.					
15.	ምስ ክመውት ዝቐረበ/ብፅኑዕ ዝሓመመ ሰብ ክንዛተ ከለና ስለ ናይ ሲቃይ መድሐኒት ወልፊ መነጋገሪ ክኸውን የብሉን።					
16.	ንቤተሰብ ክመውት ዝቐረበ/ብፅኑዕ ዝሓመመ ሰብ ናይ ነርስ ክንክን ክቅፅል ኣለዎ።					
17.	እቲ ብፅኑዕ ዝሓመመ ሰብ “ይመውት ድዩ ዘለኹ?” ኣሉ እንድሕር ጠይቁ ከሕጉሶ ዝኸለል ካሊኦ ርእሲ ምቕያር ዝበለፀ እዩ።					
18.	ብፅኑዕ ዝሓመመ ሰብ ምቕርራብ/ማሓዛ ምጂን ብጣዕሚ እዩ ዝፈርሕ።					
19.	እንድሕር ናብ ብፅኑዕ ዝሓመመ ሰብ ዘለዎ ከፍሊ ኣትዮ እሞ እንዳበኸየ እንተ ረኺበዮ ኣይምቐወንን።					
20.	ምስ ዝመውት/ብፅኑዕ ዝሓመመ ሰብ ብዛዕባ መግኢ ሞት ምዝርራብ ኣይምቐወንን።					
21.	ንነርስታት ብፅኑዕ ዝሓመመ ሰብ ንሞት ክዳለዉ ምሕጋዝ ይካኣል እዩ።					
22.	ሞት ኣብ ሰባት ዚጋጥም ክፋእ ነገር ኣይኮነን።					
23.	እንድሕር እቲ ብፅኑዕ ዝሓመመ ሰብ ሞይቱ፣ እርሒቀ ክጎይይ ይደሊ					
24.	ኣብ ብፅኑዕ ዝሓመመ ሰብ ክንክን ከምድብ ኣይደልን።					

ምንጭ: ዝተመሓየሸ ካብ: (Mastroianni et al., 2015)



**ክፍሉ 4፡እዞም ዝስዕቡ ጥያቄታት ምስ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ካፋላት ሕብረተሰብ ዝወሃብ ግልጋሎት ዝተተሓሓዘ እዩ። ካብዞም ዝቐረቡ መማረፅታት ካብ ሓደ ን ላዕሊ ምምራፅ ይካኣል እዩ።**

1. ካብዞም ዝስዕቡ ተግባራት፡ኣብ ትካልኩም ንኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ካፋላት ሕብረተሰብ ዝወሃብ ኣገልጋሎት ኣየናይ/ኖት እዩ/ዮም?

- 1.1. ምኽሪ
- 1.2. ፅሬት
- 1.3. ጥጡሕ ክንክን
- 1.4. ንሕመማት ምምሃር
- 1.5. ንቤተሰብ ምምሃር
- 1.6. ምስ ቤተሰብ ምምዕያጥ
- 1.7. ናይ ዝተፈላለዩ ሰብ ሞያታት ምዕያጥ
- 1.8. ምስ ተወከልቲ ማሕበረሰብን ሃይማኖትን ምስራሕ
- 1.9. ምርምራ ምክያድ
- 1.10. ቃንዛ
  - 1.10.1. ዕውልውልን ተምላስን
  - 1.10.2. ዉፅኢትን ድርቀትን
  - 1.10.3. ድኻም
  - 1.10.4. ናይ ኣእምሮ ጭንቀት
  - 1.10.5. መንፈሳዊ ድሌት
- 1.11. ናይ ስቓይ መድሐኒት ምሃብ/ምውጋእ
  - 1.11.1. ሞርፊን
  - 1.11.2. ትራማዶል
  - 1.11.3. ፓራሲታሞል
- 1.12. ብዘይ-መድሀኒት ተጠቂምካ ስቓይ ምቅናስ
  - 1.12.1. ሙውቕ/ዝሓል ኮምፕረስ
  - 1.12.2. ምድራዝs
  - 1.12.3. ሓሳብም ብካሊ እ ምዝንጋዕ
- 1.13. ንቶም ሕማማት ንምሕካም መድሃኒት ምሃብ/ምውጋእ symptoms
  - 1.13.1. ቅልውልውን ተምላስን
  - 1.13.2. ዉፅኢትን ድርቀትን
  - 1.13.3. ጭንቐትን ፀቕጥን

ካልኣት (ግለፅ)

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**ንተሳትፎኹምን ካብ ልቢ የመስግን**

## Appendix 2B: Explanatory statement survey

### English Version



**MONASH University**

### EXPLANATORY STATEMENT

#### Nurses

13402: Investigation of a sustainable public health approach to the provision of palliative care in North Ethiopia: A case study

Chief Investigator's name: Susan Lee

Student's name: Atsedegay

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Email : [susan.lee@monash.edu](mailto:susan.lee@monash.edu)

Email : [atsede.aregay@monash.edu](mailto:atsede.aregay@monash.edu)

My name is Atsedegay, and I am a PhD candidate at the School of Nursing and Midwifery, Monash University. My Supervisors are Associate Professor Susan Lee, Professor Margaret O'Connor, Dr Jill Stow and Dr. Nicola Ayers.

You have been invited to contribute to this study. I am providing this explanatory statement to inform you and assist you in deciding whether you wish to participate or not in this study. If you would like further information regarding any aspect of this study project, please contact the researchers via the above-listed phone number or email address.

#### What does the research involve?

This study aims to investigate how to care for people with a chronic life-limiting illness may be addressed in the rural communities of Ethiopia. We are using a case approach to find out

what is currently being provided and what barriers and opportunities might exist to new services.

### **Why were you chosen for this research?**

You are invited to participate in this study which involves a structured survey questionnaire. We are interested in understanding nurses' knowledge, thoughts, and experience of providing care for people with a life-limiting illness. We are requesting you to complete this questionnaire which will take 25-30 min. You will be told about this project in a staff meeting by me, a poster or by your contact staff member.

### **Source of funding**

This study is funded by a Monash International Postgraduate Research Scholarship.

### **Consenting to participate in the project and withdrawing from the research**

Completing the anonymous survey, sealing it in the envelope provided in a box to deposit in, implies your willingness to be involved in the study. If you do not wish to be involved, seal the survey in the envelope without completing it and return it to the box provided. You will not be able to withdraw your survey once it has been put into the box. You may choose to answer some or all the questions, though completing all the questions is most useful to the study. Participating in this study is voluntary; there is no obligation to consent and no payment to participate.

### **Possible benefits and risks to participants**

This survey is about your knowledge and attitudes, and the risk of harm to you is low. You cannot be identified in any way in the survey. We do not need to know your name or personal information about you. This survey will assist in determining the education, and support nurses need in caring for people with a life-limiting illness. You may directly benefit from this education in the future.

### **Confidentiality**

All aspects of the study including the results will be strictly confidential, and only the researcher and supervisors will have access to information on participants. No identifying information about participants will be collected, and the information they provide is not personal. The organisations will be de-identified. To maintain confidentiality, codes will be used in the results and publications.

### **Storage of data**

The collected data will adhere to the university regulations and kept in a password secured electronic platform (LabArchives) at Monash University permanently.

### **Use of data for other purposes**

If published, individual participants will not be identifiable in such a report, and de-identified data may be used for further research projects.

### **Results**

The results of this study will be published in peer-reviewed journals and presented at relevant conferences. Results will also be made available to study participants and organisations on request.

### **Complaints**

Should you have any concerns about how this study is being conducted (project number 13402), please contact the School of Nursing Ethical Committee member at Mekelle University, Health Research-Ethical Review Committee (MU-HRERC).

### **Mr. Desta Hailu**

Tel : +251-934-722071

Email : [destahailu19@gmail.com](mailto:destahailu19@gmail.com)

Fax : +251344 416681

Thank you,



Associate Professor Susan Lee

**ሐበሬታ መውሃቢ ቅጥዒ ነርስታት**

13402፡ አብ ሰሚን ኢትዮጵያ ዘሎ ዘላቂ አቀራርባ ጥዕና ሕብረተሰብ ንኩለንተናዊ ክንክን ብጽኑዕ ሕጻን ወይ ደማ ሕጻን ሕጻን ዝሓመሙ ክፋላት ሕብረተሰብ ዝካየዱ ዳህሳስ ፡

ሹም ዋና ተመራማሪ፡ ተሐባባሪ ፕሮፌሰር ሱዛን ሊ	ተመሃሪት ተመራማሪ፡ አፀደ ፋንታሁን አረጋይ
<b>ክፍሊ ትምህርቲ ነርስንግን ሚድዋይሬሪን</b>	<b>ክፍሊ ትምህርቲ ነርስንግን ሚድዋይሬሪን</b>
ቁፅሪ ስልኪ ፡ +61 3 9904 4204	ቁፅሪ ስልኪ ፡ +251-940975593
ኢ-መይል፡ <a href="mailto:susan.lee@monash.edu">susan.lee@monash.edu</a>	ኢ-መይል፡ <a href="mailto:atsede.aregay@monash.edu">atsede.aregay@monash.edu</a>

ሹመይ አፀደ ፋንታሁን አረጋይ ይበሃል፡፡ አብ ሞናሽ ዩኒቨርሲቲ ክፍሊ ትምህርቲ ነርስንግን ሚድዋይሬሪን ዶክተሬት ዲግሪ ተመሃሪት እየ፡፡ መማኸርተይ ወይ መምህራንይ ደማ ፤ ተሐባባሪት ፕሮፌሰር ሱዛን ሊ, ፕሮፌሰር ማርጋሪት ኦ ኮነር፤ ዶክተር ጂል ስቶው ከምኡውን ዶክተር ኒኮላ አየርስ ይበሃሉ፡፡

አብዚ መፅናዕቲ እዚ ንክትሳተፉ ተዓዲምኩም አለኩም፡፡ አብዚ መፅናዕቲ ንምስታፍ ወይ ንዘይምስታፍ ምድላይኩም ንምውሳኔ ንክትግዘኩም እዚ ሐበሬታ መውሃቢ ቅጥዒ ክህበኩም እየ፡፡ ሐበሬታ እንተደለኹም፤አብ ላዕሊ ብዝተገለፀ አድራሻ (ቁፅሪ ስልኪ፤ ኢ-መይል) ነታ ተመራማሪት ክትረክብዎ ትኽእሉ ኢኹም፡፡

**እቲ መፅናዕቲ እንታይ የካትት?**

ዕላማ እዚ መፅናዕቲ አብ ሕብረተሰብ ገጠር ኢትዮጵያ ኩለንተናዊ ክንክን ብጽኑዕ ሕጻን ወይ ደማ ሕጻን ሕጻን ዝሓመሙ ክፋላት ሕብረተሰብ ብኸመይ ይርእይ ብዝብል ንምድህሳስ እንትኸውን አብዚ ሕዚ እዋን እንታይ ይግበር ከም ዘሎን ንሓዱሽ አገልግሎት እንታይ ፀጋታትን ዕንቅፋታትን ክህሉ ከም ዝኽእል ንምድህሳስ ናይ ኬዝ አፕሮች ተጠቂምና አለና፡፡

**ንምንታይ አብዚ መፅናዕቲ ንክትሳተፉ ተመሪፅኩም?**

አብዚ መፅናዕቲ ንክትሳተፉ ማለትውን ዝትዳለወ መጠይቕ ንክትምልሱ ተዓዲምኩም አለኩም፡፡ ንሕና ናትኩም ናይ ነርስታት ፍልጠት፤ተግባርን ኣረኣኢያን አብ ኩለንተናዊ ክንክን ብጽኑዕ ሕጻን ወይ ደማ ሕጻን ሕጻን ዝሓመሙ ክፋላት ሕብረተሰብ ዘሎኩም ግንዛቤ ክንርዳእ ስለዝደለናና እዚ ካብ 25-30 ደቂቃ ክውድእ ዘክእል መጠይቕ ንክትመልኡልና ብትሕትና ንሓትት፡፡አብ ናይ ነርስታት መኣከሊ ብባዕሊይ ብዘግበር ገለፃ ወይ ደማ ብፖስተር ወይ ብ መሳርሕትኩም ነርስ አብዚ መፅናዕቲ ንክትሳተፉ ክገብሩም እየ፡፡

**ናይዚ መፅናዕቲ ስፖንሰር**

እዚ ጽንዓት ብ ሞናሽ ዓለም ለኽ ድሕረ ምረቓ ምርምር ዝተሓገዘ እዩ ፡፡

**ፈቓደኝነት ን ምስታፍ አብዚ መፅናዕቲን ካብዚ መፅናዕቲ ንምቁራፅን**

እቲ ሹም አልባ መጠይቕ መሊእኩም ብፖስታ ኣሺግኩም ናብቲ ዝተዘጋጀዎ ካርቶን ክተቐምጥዎ ንላበወኩም፤እዚ ደማ አብዚ መፅናዕቲ ናይ ምስታፍኩም ድሌት ዝገልፅ እየ፡፡ ንክትሳተፉ እንድሕር ዘይደሊኩም ፤እቲ መጠይቕ መሊስኩም ብፖስታ ኣሺግኩም ናብቲ ዝተዘጋጀዎ ካርቶን ክትግበርዎ ትኽእሉ ኢኹም ፤ እንድሕር ናብቲ ዝተዳለወ ካርቶን ጌርኩምዎ፤እቲ መጠይቕ መሊስኩም ክተውፅእዎ ኣይትክእሉን፡፡ ዋላ ኩሎም ሕቶታት ምምላስ ጠቓሚ እንተኾነ፤ ዝመረፅኩምዎ መጠይቕ ክትምልሱ ትክእሉ ኢኹም ፡፡ አብዚ መፅናዕቲ ምስታፍ ግዴታ የብሉን፤ ከምኡውን ምንም ዓይነት ክፍሊት የብሉን፤ ብፈቓደኝነት ዝተመስረተ ምኻኑ ንገልፅ፡፡

## ክርክብ ዝክእል ጥቅምን ፅልዋ ንተሳተፍቲ

እዚ መጠይቕ እዚ ብዛዕባ ናትኩም ፍልጠት፣ተግባርን ኣረኣእያን ዘተኩር ስለዝኾነ ፣ኣብ ባዕልኩም ዝህልዎ ፅልዋ ብጣዕሚ ትሑት እዩ። ብዝኾነ መልከዑ ኣብዚ መጠይቕ ናይ ባዕልኩም ኩነታት ምግላፅ ኣየድልን። ሹምኩም ኮነ ናይ ግልኩም ሐበሬታ ምግላፅ ኣየድልን ። እዚ መጠይቕ ናይ ነርስታት ትምህርትን ደገፍን ኣብ *ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዱር ሕማም ዝሓመሙ ክፋላት* ሕብረተሰብ ዘሎ ግንዛብ ብምድህሳስ ንኸመሓየሽ ይሕግዝ። ካብዚ ትምህርቲ ንወደፊቱ ክትጥቀሙ ትክእሉ ኢኹም።

### ምስጢር ምዕቃብ

ኩለመዳያዊ ኣካይዳ ናይዚ መፅናዕቲ ኮነ ሓፈሻዊ ውፅኢት ብጥብቂ ብምስጢር ዝተዓቀበ እዩ። ኣታ ተመሃሪት ተመራማሪትን መማኸርቲ መምህራንን ጥራሕ እየን ነቲ ሐበሬታ ተሳተፍቲ ክረክቡኦ ዝክእሉ። ተሳተፍቲ ብምንም መልከዑ መንነቶም ኮነ ሽምም ኣይግለፅን ከምኡውን እቲ ዝእኩብ መረዳኢታ ብስሩ ግላዊ ኣይኮነን። ትካልኩም እውን መንነቱ ኣይግለፅን። ። ምስጢር ንምዕቃብ፣ ውፅኢትን ኣብምግላፅን ሕትመትን መፍለይ ቁፅሪ ኢና ክንጥቀም።

### መዐቀቢ መረዳኢታ

እቲ ዝተኣከበ መረዳኢታ ብመምርሒ እቲ ዩኒቨርሲቲ መሰረት ብምስጢር ቁፅሪ ኣብ ዝተዓፀወ መርበብ ሓበሬታ ሞናሽ ዩኒቨርሲቲ (ላብኦርካይብ ዝባሃል ) ተዓቂቡ ንሓዋሩ ይቅመጥ።

### እቲ መረዳኢታ ንካሊእ ምጥቃም

እንድሕር ደኣ ተሐቲሙ፣ መንነት ተሳተፍቲ ኣይግለፅን ሓፈሻዊ መረዳኢታ ኣብ ቐፃሊ ንካሊእ ምርምር ከንጥቀመሉ ንክእል ኢና።

### ውፅኢታት

ውፅኢት እዚ መፅናዕቲ ኣብ ደረጃኡም ዝሓለዉ ዓለም-ሰኻዊ መፅሔታት ክሕተም ከምኡውን ኣብ ትዛመድቲ መድረኻት ክቀርብን እዩ። እቲ ውፅኢት ንቶም ተሳተፍትን ትካላትን ብዝሕትዎ መሰረት ንክወሃቡም ፃዕሪ ክግበር እዩ።

### ጥርፃን

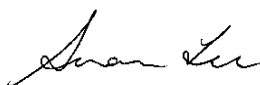
ኣብዚ መፅናዕቲ (መለለይ ቁፅሪ:13402)፣ ዝኮነ ርኢቶ ኮነ ሓሳብ እንተሃልይኩም ነዚ ኣብ ታሕቲ ትገሊፁ ዘሎ ኣባል ኮሚቴ ስነ ምግባር መፅናዕቲ ኮሌጅ ጥዕና ሳይንስ ዩኒቨርሲቲ መቐለ ክትረክብዎ ትክእሉ ኢኩም።

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ፋክስ: +251344 416681



ተሓባባሪት ፕሮፌሰር ሱዛን ሊ

የቅንዖለይ,

## Appendix 2C : Poster

**English Version**



**Would you like to improve the care of people with incurable illness?**

**You are invited to participate in a research project:**

***Title: Investigation of a sustainable public health approach to the provision of palliative care in North Ethiopia: A regional case study***



**source (ONA, 2015)**

**Please contact the PhD student researcher**

**Mrs Atsede F Aregay**

Phone. +251-940975593

OR

E-mail: [atsede.aregay@monash.edu](mailto:atsede.aregay@monash.edu)

**Thank you**

**Looking forward to your participation**



*ብጽኑዕ ሕማም ወይ ድማ ብዘይድሕን ሕማም ዝሓመሙ ሕብረተሰብ ኩለንተናዊ ክንክን ክተመሓይሹ ዶ ትደልዩ?*

**ኣብዚ መጽናዕቲ ንክትሳተፉ ይዕድመኩም**

**ርእሲ:** *ዘለቂታዊ ናይ ሕብረተሰብ ጥዕና መዳይ ንምህላው ብጽኑዕ ሕማም ወይ ድማ ብዘይድሕን ሕማም ዝሓመሙ ኩለንተናዊ ክንክን ዝካየዱ ምርምር ኣብ ሰሚን ኢትዮጵያ፡ ኪዠ መጽናዕቲ*



ዝተረከበ (ONA, 2015)

**በይዛኩም ናይ ሳልሳይ ዲግሪ ተመሃራይ ተምራማሪ ርክብዎ**

**ሲ/ር አጸደ ፋንታሁን አረጋይ፡**

**ቁፅሪ ስልኪ፡ +251-940975593**

**ወይድማ**

**ኢ መይል፡ [atsede.aregay@monash.edu](mailto:atsede.aregay@monash.edu)**

**የቅንየለይ**

**ንተሳተፎኩም ንቅድሚት ንጽበ።**



## Appendix 3A: Focus Group questions framework

### English Version



### **Community members ((local/national NGO, traditional healers, community and religious leaders))**

Adapted from (McIlfatrick et al., 2014)

Have you ever had people with incurable illness in this community? Tell me what it was like towards the end of their life?

1. If the patient discharged from the hospital with an incurable illness, what did they do in their home?
2. Who provides care for those patients in their home?
3. What was the role of the family in providing care from terminally ill patients
4. What was the personal preference place of care in the last days of life?
5. What is the source of strength and hope for patient and family on the last day of their lives and to cope with the disease?
6. Do you know any alternative options on how to care for these patients? Can you tell me what they are?
7. If you need information related to caring for life-limiting people, whom do you ask? Where would you look for it?
8. What do you expect from health professionals who care for life-limiting people?
9. Views and opinions of related caring for people who have an incurable illness?
10. If you dream some solutions, what do you think we should have in this community to help care for people with incurable illness?
11. What do you think will make it difficult to in this community to put in place some of these solutions?
12. Some countries have used mobile phone networks to support families in these circumstances. What kind of access do you have to mobile phones?

መልዓሊ ነጥብታት ምይይጥ ጉጅለ አባላት ሕብረተሰብን መራሕቲ ሃይማኖትን ተወካልቲ ሕ/ሰብን

ፍልፍል እዚ ፅሑፍ (McIlfatrick et al., 2014)

እቲ ሕማምኩም አይድሕንን ዘተባሃሉ ሰባት ኣብ ከባቢኩም ኣጋጢሙኩም ዶ ይፈልጥ? ናይ መጨረሻ ሂወቶም እንታይ ከም ዝመስል ዶ ክትነግሩና ትክእሉ?

1. ብሕዱር ሕማም ዝተተሓዘ ሰባት ካብ ሆስፒታል ወሂኦም፣ ኣብ ገዝኦም እንታይ ይገብሩ?
2. ንዘምነ ብከምዚ ዝሓመሙ፣ መን እዩ ኣብ ገዝኦም ዝከናኸኖም?
3. ኣብ ምክንኻን ብፅኑዕን ዘሓመመ ናይቲ ቤተሰብ ኣበርክቶ እንታይ ይመስል?
4. እቲ ሕሙም ኣብ ከባቢ መወዳእታ ሂወቱ ክንክን ክረክብ ዝመርፆ/ዝደልዮ ቦታ ኣበይ እዩ?
5. ነቲ ሕሙምን ቤተሰቡን ኣብ ናይ ሂወቶም መወዳእታ ከባቢ ነቲ ሕማም ኣሚኖም ንክነበሩ ፍልፍል ጥንካረኦምን ተስፎኦምን እንታይ እዩ?
6. ንከምዚ ዝበሉ ሕሙማት ክንክን ክረክቡ ዝክእሉሉ ካሊ እመማረፂ ዶ ትፈልጡ? እንታይ ዓይነት ሞማረፂ?
7. ብዛዕባ ክንክን ብሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ሓበሬታ/ኢንፎርሜሽን እንተ ደሊኩም ንመን ትጥይቅዎ? ኣበይከ ንኡኡ ትረኽብዎም?
8. ኣብ ክንክን ብሕዱር ሕማም ዝሓመሙ ሰባት ካብ ሰብ ሞያ ጥዕና እንታይ ትፅበዩ?
9. ብዛዕባ ክንክን ብሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ዘለኩም ርኢቶን ሓሳብን እንታይ ይመስል?
10. ብሕዱር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ንምሕጋዝን ምክንካንን መፍትሒ ይኸውን እትብልዎ ሓሳብ እንተ ሃሊዩኩም፣ ኣበዚ ሕብረተሰብ እንታይ ክህሉ የድሊ ኢልኩም ትሓስቡ?
11. ኣብዞም እተቐርብዎም ዘለኹም መፍትሒታት፣ነዚ ሕብረተሰብ ከቢድ ክኸውን እዩ ኢልኩም እተሓሰብዎ ዶ ክትነግሩና?
12. ኣብ ካላኣት ዓድታት ስልኪ/ሞባይል ብዝተፈላለዩ መንገድታት ጥዕና ንምሕጋዝ ይጥቀሙሉ እዮም ንስካትኩም ከ ካብ ሞባይል እንታይ ዓይነት ግልጋሎት ትረክቡ?

## Appendix 3B: Focus Group Explanatory statement

### English Version



### Explanatory statement

#### Focus group (community members)

13402: Investigation of a sustainable public health approach to the provision of palliative care service in North Ethiopia.

Name of the chief investigator:

A/Prof. Susan Lee

Student researcher: Atsede Fantahun Aregay

School of Nursing and Midwifery	School of Nursing and Midwifery
Phone Number: +61 3 9904 4204	Phone Number: +251-940975593
E-mail : <a href="mailto:susan.lee@monash.edu">susan.lee@monash.edu</a>	ኢ-መሪያ: <a href="mailto:atsede.aregay@monash.edu">atsede.aregay@monash.edu</a>

My name is Atsede Aregay, and I am a PhD candidate at the School of Nursing and Midwifery, Monash University. My Supervisors are Associate Professor Susan Lee, Professor Margaret O'Connor, Dr. Jill Stow, and Dr. Nicola Ayers.

You have been invited to participate in this study. I will read this explanatory statement for you in full if you need me to. I am providing this explanatory statement to inform you and assist you in deciding whether you wish to participate or not in this study. If you would like further information regarding any aspect of this study project, please contact the researchers via the above-listed phone number or email address.

**What does the study involve?**

This study aims to investigate how to care for people with a chronic life-limiting illness addressed in the rural communities of Ethiopia. We are using a case approach to find out what is currently provided and what barriers and opportunities might exist to new services. A group discussion of 45-60 minutes will be conducted at the community centre as a part of a coffee ceremony with community members and leaders.

**Why were you chosen to involve in this study?**

You are invited to participate in this study which involves audio-taped group interviews. We are hoping, as community members of this rural area, you will be able to share your experience in care for people with life-limiting illness in a group discussion. You will have heard about this study through a poster, advertisement in your community or from health extension workers in your area.

**The sponsor of this study?**

This study is funded by a Monash International Postgraduate Research Scholarship.

**Consent to participate in this study and withdraw from this study**

If you respond to the invitation by arriving at the community centre on the advertised date and time, I will be available to answer questions, and you can sign the consent form. If you chose not to stay for the interview, you might still be part of the coffee ceremony. You have the right to withdraw from participating in this study at any time up until the interview commences. You can choose which questions you wish to participate in and can leave the discussion at any time you wish. Participating in this study is voluntary, no payment will be made, and you are not obligated to consent or participate.

**Potential benefits and risks of the participant**

For the focus group discussion in your rural area, you will receive a full explanation and written consent. You may choose to discuss personal experiences, the recollection of which might be distressing. An experienced nurse will provide emotional support to members of the group who need it. Further, after the discussion, as an experienced nurse, I will provide some debriefing to members of the group who have been distressed. However, by being involved in this discussion, you have the opportunity to contribute your experience to a report which may inform the development of services in this region.

**Confidentiality**

All aspects of the study including the results will be strictly confidential, and only the researcher and supervisors will have access to information on participants. Participants in the group discussion will not be identified in any way; however, as you will be speaking in a group, confidentiality cannot be guaranteed. Members of the group will be asked to keep the discussion confidential, and the rural area will be de-identified. To maintain confidentiality, codes will be used in the results and publications. No participant will be identified by name.

**Storage data**

The collected data will adhere to the University regulations and kept in a password secured electronic platform (LabArchives) at Monash University permanently.

**Use data for another purpose**

If published, participants personality is not identified in such a report; the de-identified data may be used for other future research projects.

**Results**

The results of this study will be published in peer-reviewed journals and presented at relevant conferences. Results will also be made available to study participants and organisations on request.

**Complaints**

Should you have any concerns about how this study is being conducted (project number 13402), please contact the School of Nursing Ethical Committee member at Mekelle University, Health Research-Ethical Review Committee (MU-HRERC).

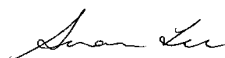
Mr. Desta Hailu

Tel : +251-934-722071

E-mail: [destahailu19@gmail.com](mailto:destahailu19@gmail.com)

Fax +251344 416681

Thank you,



Associate Professor Susan Lee

**ሐበሬታ መውሃቢ ቅጥዒ**  
**ጉጅለ ምይይጥ (ማሕበር ሕብረተሰብ)**

13402፡ አብ ሰሚን ኢትዮጵያ ዘላቂ አቀራርባ ጥዕና ሕብረተሰብ ንኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዳር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ዝካየዱ ዳህሳስ፡

ሹም ዋና ተመራማሪ፡ ተሐባባሪ ፕሮፌሰር  
ሱዛን ሊ

ተመሃሪት ተመራማሪ፡ አፀደ ፋንታሁን አረጋይ

ክፍሊ ትምህርቲ ነርሲንግን ሚድዋይፈሪን	ክፍሊ ትምህርቲ ነርሲንግን ሚድዋይፈሪን
ቁፅሪ ስልኪ፡ +61 3 9904 4204	ቁፅሪ ስልኪ ፡፡ +251-940975593
ኢ-መይል፡ <a href="mailto:susan.lee@monash.edu">susan.lee@monash.edu</a>	ኢ-መይል፡ <a href="mailto:atsede.aregay@monash.edu">atsede.aregay@monash.edu</a>

ሽመይ አፀደ ፋንታሁን አረጋይ ይበሃል፡፡ አብ ሞናሽ ዩኒቨርሲቲ ክፍሊ ትምህርቲ ነርሲንግን ሚድዋይፈሪን ተመሃሪት ዶክተሬት ዲግሪ እየ፡፡ መማኸርታይ ወይ መምህራንይ ድማ ፤ ተሐባባሪት ፕሮፌሰር ሱዛን ሊ፣ ፕሮፌሰር ማርጋሪት ኦኮነር፣ ዶክተር ጂል ስቶው ከምኡውን ዶክተር ኒኮላ አየርስ ይበሃሉ፡፡

አብዚ መፅናዕቲ እዚ ንክትሳተፉ ተዓዲምኩም አለኩም፡፡ አብዚ መፅናዕቲ ንምስታፍ ወይ ንዘይምስታፍ ንምውሳኔ ንክሕግዘኩም እዚ ሐበሬታ መውሃቢ ቅጥዒ ብመሉእ እንድሕር ከንብበልኩም ደሊኩም፣ ከንብበልኩም እየ፡፡ ተወሳኺ ሐበሬታ እንተደሊኹም፣አብ ላዕሊ ብዝተገለፀ አድራሻ (ቁፅሪ ስልኪ፣ ኢ-መይል) ነታ ተመራማሪት ክትረክብዎ ትኽእሉ ኢኹም፡፡

**እቲ መፅናዕቲ እንታይ የካትት?**

ዕላማ እዚ መፅናዕቲ አብ ሕብረተሰብ ገጠር ኢትዮጵያ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዳር ሕማም ዝሓመሙ ሕብረተሰብ ብሽመይ ይርአይ ብዝብል ንምድህሳስ እንትኸውን አብዚ ሕጂ እዋን እንታይ ይግበር ከም ዘሎን ንሓዱሽ አገልግሎት እንታይ ፀጋታትን ዕንቅፋታትን ክህሉ ከም ዝኸለል ንምድህሳስ ናይ ኬዝ አፕሮች ተጠቂምና አለና፡፡ ምስ አባላትን ተወከልቲ ሕብረተሰብን አብ ከባቢ ገዝእም ብምእካብ ቡን ኣፍሊሕና እናስተና ካብ 45-60 ደቂቃ ክውድእ ዝከእል ናይ ጉጅለ ምይይጥ ከንገብር ኢና ፡፡

**ንምንታይ አብዚ መፅናዕቲ ንክትሳተፉ ተመሪፅኩም?**

ከም ሓደ ናይዚ ከባቢ ገጠር ማሕበረተሰብ አብዚ ብምቕረፃ ድምፂ ተሓጊዙ አብ ዝግበር ቃለ-መጠይቅ ንክትሳተፉ ተዓዲምኩም አለኩም፡፡ ከም አባል ናይዚ ከባቢ ገጠር ማሕበረተሰብ ፣ አብቲ ናይ ጉጅለ ምይይጥ ፣ አብ ኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ድማ ሕዳር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ዘለኩም ልምዲ ከም ተካፍሉና ተስፋ ንገብር ፡፡ እዚ መፅናዕቲ ዝምልከት ትወሳኺ ሓበሬታ አብ ከባቢኹም ብዝልጠፍ ፅሑፍ ወይ ድማ አብ ከባቢኹም ካብ ዘለዎ ሰብ ሞያ ጥሙር ጥዕና ቤተሰብ ክትስምዕዎ ኢኩም ፡፡

## ናይዚ መፅናዕቲ ስፖንሰር

እዚ ጽንዓት ብ ሞናሽ ዓለም ለኸ ድሕረ ምረቃ ምርምር ዝተሓገዘ እዩ።

## ፈቃደኝነት ምስታፍ ኣብዚ መፅናዕቲን ካብዚ መፅናዕቲ ንምቁራፅን

እንድሕር ኣብቲ ዝተፋለጠ መዓልትን ሰዓትን ኣብቲ መራሽቢ ቦታ ብምብጻጽ ነቲ ዕድመ መልሲ ሂብኩም ፣ ኣነ ንዝለዓሉ ሕቶታት መልሲ ክህብ እየ፤ ንስኩም ድማ ናይ ስምምዕነት ክትፍርሙ ትክእሉ ኢኹም። እንድሕር ኣብቲ ክትሳተፉ ዘይደሊኩም ፣ ቡን ሰቲኹም ክትከዱ ትክእሉ ኢኹም። ቅድሚ እቲ ቃለ-መሕተት ምጅማሩ ኣብ ዝኾነ ግዜ ፣ ካብቲ መፅናዕቲ ምስታፍ ናይ ምቁራፅ መሰልኩም ዝተሓለወ እዩ። ክትምልስዎ ዝደለኹም ሕቶ ክትመርፁ ከምኡውን ኣብ ዝኾነ ግዜ እቲ ምይይጥ ክተጃርፅዎ ትክእሉ ኢኹም። ኣብዚ መፅናዕቲ ምስታፍ ግዴታ የብሉን፤ ከምኡውን ምንም ዓይነት ክፍሊት የብሉን፤ ብፈቃደኝነት ዝተመሰረተ ምኻኑ ንገልፅ።

## ክርክብ ዝክእል ጥቅምን ፅልዋን ተሳተፍቲ

ንጉጅለ ምይይጥ ንምስታፍ ክሕግዘኩም ኣብ ከባቢኩም ሙሉእ ሓበሬታን ናይ ፈቃደኝነት መረጋገጺ ፅሑፍን ክትቅበሉ ኢኹም ። ናይ ባዕልኩም ልምዲ ኣብ ኣተካፍሉሉ እዋን ፅቡቕ ዘይ ክስመዓኩም ይክእል እዩ። ልምዲ ዘለዎ ባዓል ሞያ/ነርስ ን ከምዙይ ዘጋጠሞም ኣባላት ሕብረተሰብን ክረጋጋኡኹም እዮም። ብተወሳኺ፣ ኣብቲ መወዳእታ ምይይጥ፣ ከምዚ ዘለዎ ባዓል ሞያ/ነርስ ምኻነይ ነቲ ዘይተረጋገአ ኣባል እቲ ጉጅለ ዝተወሰነ ገለፃ ክገብረሎም እዩ። ይኹን እምበር፣ ኣብዚ ምይይጥ ብምስታፍኩም፣ ልምድኹም ተካፍልሉ ኣጋጠሚ ኮይኑ እዚ ካዓ ነቲ ኣብቲ ክልል ዝወሃብ ግልግሎት ንምምሕያሽ ሓጋዚ ክኸውን ይኽእል እዩ።

## ምስጢር ምዕቃብ

ኩለመዳያዊ ኣካይዳ ናይዚ መፅናዕቲ ኮነ ሓፈሻዊ ውፅኢት ብጥብቂ ብምስጢር ዝተዓቀበ እዩ። ኣታ ተመሃሪት ተመራማሪትን መማኸርቲ መምህራንን ጥራሕ እየን ነቲ ሓበሬታ ተሳተፍቲ ክረክቡኦ ዝክእሉ። ተሳተፍቲ ብምንም መልክዑ መንነቶም ኮነ ሽሞም ኣይግለፅን ከምኡውን እቲ ዝእከብ መረዳእታ ብስሩ ግላዊ ኣይኮነን። ይኹን እምበር ብጉጅለ ስለንዘራረብ ምስጢር ምዕቃብ ውሕስና የብልናን። ነቶም ኣባላት ጉጅለ እቲ ምይይጥ ክዕቅብዎ ክንላቦ ኢና። እቲ ከባቢ ገጠር እዉን ኣበይ ምኻኑ ኣይግለፅን። ምስጢር ንምዕቃብ ኣብ ምግላፅ ውፅኢትን ሕትመትን መፍለይ ቁፅሪ እንተዘይኮይኑ ብሽም ዝግልፅ ተሳታፊ ኣይህሉን።

## ምዕቃብ መረዳእታ

እቲ ዝተኣከበ መረዳእታ ብመምርሒ እቲ ዩኒቨርሲቲ መሰረት ብምስጢር ቁፅሪ ኣብ ዝተዓፀወ መርበብ ሓበሬታ ሞናሽ ዩኒቨርሲቲ (ኣብኣርካይብ ዝባሃል) ተዓቂቡ ንሓዋሩ ይቅመጥ።

## እቲ መረዳእታ ንካሊእ ምጥቃም

እንድሕር ደኣ ተሓቲሙ፣ መንነት ተሳተፍቲ ኣይግለፅን ሓፈሻዊ መረዳእታ ኣብ ቐፃሊ ንካሊእ ምርምር ክንጥቀመሉ ንክእል ኢና።

## ውፅኢት

ውፅኢት እዚ መፅናዕቲ ኣብ ደረጃኡም ዝሓለወ ዓለም-ለኻዊ መፅሔታት ክሕተም ከምኡውን ኣብ ትዛመድቲ መድረኻት ክቀርብን እዩ። እቲ ውፅኢት ንቶም ተሳተፍትን ትካላትን ብዝሕትዎ መሰረት ንክወሃቦም ፃዕሪ ክግበር እዩ።

ጥርጥን

አብዚ መፅናዕቲ ( መለለይ ቁፅሪ:13402)፣ ዝኮነ ርኢቶ ኮነ ሓሳብ እንተሃልይኩም ነዚ አብ ታሕቲ ትገለፁ ዘሎ አባል ኮሚቴ ስነ ምግባር መፅናዕቲ ኮሌጅ ጥዕና ሳይንስ ዩኒቨርሲቲ መቐለ ከትረክብዎ ትክእሉ ኢኩም፡፡

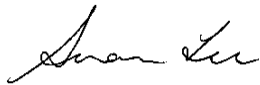
አቶ ደስታ ሃይሉ

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ኢ-መይል: [destahailu19@gmail.com](mailto:destahailu19@gmail.com)

ፋክስ: +251344 416681

የቅንዓለይ,



ተሐባባሪት ፕሮፌሰር ሱዛን ሊ



## Appendix 3C: Focus Group consent form

### English Version



### CONSENT FORM

#### For Focus Group (community members)

13402: Investigation of a sustainable public health approach to the provision of palliative care in Ethiopia: A case study

Chief Investigator: Associate Professor Susan Lee

Student Investigator: Atsedie Aregay

I have been asked to take part in the Monash University research project specified above. I have read and understood the Explanatory Statement, and I hereby consent to participate in this project.

<b>I consent to the following:</b>	<b>Yes</b>	<b>No</b>
I agree for audio recording during the interview	<input type="checkbox"/>	<input type="checkbox"/>
I agree that the data samples that I provide during this research may be used by the researcher in future research projects	<input type="checkbox"/>	<input type="checkbox"/>
I agree in the event of any distress the researcher will stop the interview and provide emotional support.	<input type="checkbox"/>	<input type="checkbox"/>

**Name of Participant** \_\_\_\_\_

**Participant Signature** \_\_\_\_\_

**Date** \_\_\_\_\_

## Tigrigna Version



MONASH University

ናይ ፈቃደኝነት መግለጺ ቅጥዒ

አባላት ሕብረተሰብ (ናይቲ ከባቢ ን ሃገራዊ ግብረ ሰናይ ትካላት፣ ባህላዊ ሓሻይም፣ ትወከልቲ ሕብረተሰብን መራሕት ሃይማኖትን)

13402፡ አብ ሰሚን ኢትዮጵያ ዘላቂ አቀራርባ ጥዕና ሕብረተሰብ ንኩለንተናዊ ክንክን ብጽኑዕ ሕማም ወይ ደማ ሕዳር ሕማም ዝሓመሙ ክፋላት ሕብረተሰብ ዝካየዱ ዳህሳስ ፡

ዋና ተመራማሪት፡ ተ/ፕሮፌሰር ሱዛን ሊ

ተመሃሪት ተመራማሪት፡ አፀደ ፋንታህን አረጋይ

ኣብዚ ልዕል ክብል ዝተገለፀ ዝተገለጸ ናይ ሞናሽ ዩኒቨርሲቲ መጽናዕቲ ንክትሳተፉ ጠይቀ ነይረ፡ እቲ ዝተገለጸ መብርሂ አንቢቦ ከምኡውን ተረዲአዮ፡፡ ኣብዚ መጽናዕቲ ን ምስታፍ ፈቃደኛ እየ፡፡

ኣብዞም ዝስዕቡ ፍቃደኛ እየ፡	እወ	አይፋሉን
ኣብቲ ቃል-መሕትት ድምጺ ን ክቅረጽ ይስማዕማዕ አለኩ፡፡	<input type="checkbox"/>	<input type="checkbox"/>
እቲ ዝህቦ መረዳእታ እዚ መጽናዕቲ ምናልባት እታ ተመራማሪት ን ንቐፃሊ መጽናዕቲታት ንክትጥቀሙ ይስማዕማዕ አለኩ፡፡	<input type="checkbox"/>	<input type="checkbox"/>
ኣብዚ ቃል-መሕትት ዝኮነ ዘይምርግጋዕ እንተጋጠሙ፣ እታ ተመራማሪት እቲ ቃል-ምሕትት አቋሪፃ ደገፍ ስነ አእምሮ ክትገብረላይ ይስማዕማዕ አለኩ፡፡	<input type="checkbox"/>	<input type="checkbox"/>

ሹም ናይ ተሳታፊ

ፊርማ

ዕለት

## Appendix 4: Monash University Human Research Ethics Committee Approval Certificate



This is to certify that the project below was considered by the Monash University Human Research Ethics Committee. The Committee was satisfied that the proposal meets the requirements of the *National Statement on Ethical Conduct in Human Research* and has granted approval.

Project ID: 13402

Project Title: Investigation of a sustainable public health approach to the provision of palliative care in North Ethiopia

Chief Investigator: Assoc Professor Susan Lee

Approval Date: 07/08/2018

Expiry Date: 07/08/2023

**Terms of approval - failure to comply with the terms below is in breach of your approval and the Australian Code for the Responsible Conduct of Research.**

1. The Chief Investigator is responsible for ensuring that permission letters are obtained, if relevant before any data collection can occur at the specified organisation.
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by MUHREC.
4. You should notify MUHREC immediately of any severe or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash letterhead, and the Monash University complaints clause must include your project number.
6. Amendments to approved projects including changes to personnel must not commence without written approval from MHUREC.
7. Annual Report - continued approval of this project is dependent on the submission of an

Annual Report.

8. Final Report - should be provided after the project. MUHREC should be notified if the project is discontinued before the expected completion date.

9. Monitoring - the project may be subject to an audit or any other form of monitoring by MUHREC at any time.

10. Retention and storage of data - The Chief Investigator is responsible for the storage and retention of the original data about the project for a minimum period of five years.

Kind Regards,

Professor Nip Thomson

Chair, MUHREC

CC: Emeritus Prof Margaret O'Connor, Mrs Atsede Aregay, Dr. Jill Stow, Dr. Nicola Ayers

**List of approved documents:**

<b>Document Type</b>	<b>File Name</b>	<b>Date</b>	<b>Version</b>
Consent Form	Leaders Consent Form	29/06/2018	Final
Consent Form	Community Consent Form	29/06/2018	Final
Questionnaires / Surveys	Survey	29/06/2018	Final
Supporting Documentation	Advertisement or poster	29/06/2018	Final
Supporting Documentation	Leaders question framework	29/06/2018	Final
Explanatory Statement	Community Explanatory Statement	05/07/2018	Final
Explanatory Statement	Leaders Explanatory Statement	05/07/2018	Final
Explanatory Statement	Nurse Survey explanatory statement	05/07/2018	Final

Explanatory Statement	Community Explanatory Statement 2	30/07/2018	2
	Leaders Explanatory Statement 2	30/07/2018	2
Explanatory Statement			
Explanatory Statement	Nurse Survey explanatory statement 2	30/07/2018	2
Supporting Documentation	WHS Risk Register Export	30/07/2018	1
Explanatory Statement	Nurse Survey explanatory statement 3	06/08/2018	3