Understanding the notions of ‘Good Death’ in Bangladesh: A critical exploration

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Abstract

There is growing interest globally in the way care is delivered to people at the end of life. Every context has its own complexities regarding the provision of appropriate care to patients at this point. However, what constitutes a ‘good death’ and how end-of-life care is provided to dying patients is culture specific. Although there is no formal definition of a good death, in general it refers to culturally prescribed ways of providing care so that a patient can die peacefully. Despite various notions of a good death existing in different cultures and contexts, western ideas of patient autonomy, choice and agency appear to be privileged as key components in institutional palliative care practice around the world.

This thesis examines the perceptions, practices and experiences of a good death in a palliative care setting in Bangladesh and compares and contrasts these to the notions of good death in western settings. The objectives of the study are: to understand the notions of a good death among healthcare providers, dying patients and their family caregivers in a Bangladeshi context; to understand how these stakeholders negotiate the idea of a good death; and how current palliative care practices work to ensure a good death. The study uses data from 30 in-depth interviews and from ethnographic observation of palliative care practices in the Centre for Palliative Care (CPC) and its two community-based projects in Dhaka, Bangladesh. The key findings of the study are: first, despite there being four components of total care (physical, mental, psychological, and spiritual) in western settings, the providers in this study conceptualise these as only two categories: physical care, and non-physical care. Although physical care is hampered by the opioid unavailability, a good death is still provided through non-physical care, in which a family-like relationship is built between patients and providers. Second, despite providers anticipating that patients will achieve open awareness of dying in their final days to ensure their ‘good death’, patients’ awareness of dying is experienced differently through the intervention of their family members. Third, rather than the importance of patient autonomy, choice, and agency found in western palliative care settings, more family-centric notions are revealed through mutual obligations, relational autonomy and interdependence between the patients and family caregivers in this study. The thesis concludes that despite there being some common end-of-life care practices worldwide, different understandings of end-of-life care exist in Bangladesh, which contribute to how plural end-of-life care futures can be understood.

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Acronyms

BSMMU- Bangabandhu Sheikh Mujib Medical University

CPC- Centre for Palliative Care

EIU- Economist Intelligence Unit

WHO- World Health Organization

WHPCA- Worldwide Hospice Palliative Care Alliance

UK- United Kingdom

NHS- National Health Service

US- United States

Glossary

Momotamoyee Korail- Compassionate Korail

Momotamoyee Narayanganj- Compassionate Narayanganj

Gusthi- Clan or Kinship network

Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree and does not incorporate any material already submitted for a degree.

Signed

Dated 22/11/2023

Chapter One- Introduction

Overview

This study investigates the healthcare providers, dying patients and their family caregivers in the Centre for Palliative Care (CPC) in Dhaka, Bangladesh, in order to understand the notions of ‘a good death’ in this setting. The study explored how the healthcare providers deliver end-of-life care, and how the terminal patients receive palliative care and what the family members of their dying relatives do at the CPC and its two community settings: Compassionate Korail (in a slum in Dhaka) and Compassionate Narayanganj (in Narayanganj, a city close to Dhaka). As the study was carried out over all three settings, throughout the thesis when I describe the three settings together, I refer to them as ‘the centre’ or as ‘the palliative care settings’; when I describe the CPC, I refer to it as the CPC; and when I describe Compassionate Korail and Compassionate Narayanganj, I refer to them as ‘the community settings’, or, individually, as simply Korail and Narayanganj. In the following chapters of the thesis, when I use the word ‘west’ or ‘western’, I refer to the countries mostly from the western Europe and northern American countries. The study was based on in-depth interviews with providers, patients and family caregivers, and ethnographic observation of the delivery of palliative care at the centre.

As palliative care has only recently emerged in Bangladesh and little social scientific research has been conducted on the understanding of palliative care in Bangladesh, this study is an effort to fill the knowledge gap that exists. Among various aspects of palliative care, this study explores notions of a good death, as it is suggestive of the cultural understanding of how end-of-life care can be best provided in a setting, and can contribute to knowledge about how to care for the burgeoning dying population in the coming decades. In addition, the study investigates the understanding of a good death in relation to end-of-life care among the participants. It relates to the study of global discussions of end-of-life care, mostly in the western countries.

The fieldwork for the study was conducted in 2020, when the world was experiencing the first wave of the Covid-19 pandemic. Despite the major challenges and difficulties this presented, the study has benefitted from the discussions that took place during the pandemic on the subject of a good death. The study has also reflected the changes that took place around the world and in Bangladesh due to the pandemic.

Background

Global interest in end-of-life care is on the rise, due to demographic and epidemiological reasons (Cohen & Deliens, 2012). The population of the world is both ageing and increasing, and the number of people dying each year has risen recently. For a major portion of the population, the process of dying may become more prolonged, as there has been a considerable shift away from communicable diseases towards long-term conditions. The chronic nature of these conditions gives rise to the idea of ‘terminal illness’, which means death within years, rather than months, weeks or days (Walter, 2003). For these reasons, and because of unpredictable trajectories of dying, the quality of end-of-life care has become an important issue for healthcare professionals, researchers and policymakers (Cipolletta & Oprandi, 2014).

There is growing interest around the world in the manner in which care is delivered to people at the end of life. Also, there are many complexities to the challenge of providing appropriate care to individual patients at the end of life across different contexts. What happens at the end of life and what should be considered appropriate care before death, refer to the different ways of dealing with death in different cultures and countries. For these reasons, ideas about how we die, what constitutes a good death and what are the appropriate societal responses to the task of delivering culturally relevant and sustainable forms of end-of-life care in different settings are all issues that have been discussed widely in recent times. Cultural differences are particularly in evidence in end-of-life situations, where there are specific ideas about what a good death entail. Therefore, there is no globally accepted definition of a good death yet.

Although what happens at the end of life and what would improve care is still being questioned, the idea of a good death has emerged over time (Clark, 2016). By the 1960s, medical, nursing and social work interpretations on the care of the dying began to flourish, mainly in high-income countries situated in Europe and North America. The idea of a good death there was first manifested in a body of new writing on the subject which contributed to the establishment of services at the institutional level. This manifestation not only institutionalized modern ‘hospice’ and ‘palliative care’ centres, but also disseminated the idea in association with teaching and research. The work of Cicely Saunders and her associates was key to this. Social scientists, health professionals and older people themselves have also offered diverse definitions and perspectives on the idea of a good death. A literature review on what constitutes a good death from the perspectives of patients and health professionals in Europe and North America included the following attributes, listed in order of frequency of appearance in the literature: being in control, being comfortable, a sense of closure, affirmation/value of the dying person being recognized, trust in care providers, recognition of impending death, beliefs and values being honoured, burden being minimized, relationships being optimized, appropriateness of death, leaving a legacy, and family care (Kehl, 2006). However, authors have also argued that a good death depends explicitly on the social context, and specifically on the degree of secularization, and of individualism, and on the length of time it takes to die ('quick' or 'slow') (Walter, 2003). From the early 1980s, the World Health Organization (WHO) turned its attention to the wider issue of palliative care and set out scalable solutions to these issues. Thus, the WHO endorsed the principles of palliative care in the global context (Clark, 2016).

In contrast to these high-income countries, different concerns and practices around a good death are evident in other contexts. Culture frames the way people nurture the idea of end-of-life care and its practices (Evans et al., 2012). In contrast to European and Northern American countries, most deaths in sub-Saharan Africa and South Asian contexts take place at home (Gysels, 2012). A systematic study of end-of-life care in sub-Saharan Africa stated that the emphasis is on the burial process rather than on the dying person. The process of dying is confined to the seclusion of the house and the funeral is a public event, as was found in a study by Gysels et al. (2011). Kellehear proposed the idea of 'compassionate communities', in which, end-of-life care does not call for western-style institutions; rather it is the responsibility of everyone in the community (Kellehear, 2005). Abel and Kellehear (2016) suggest that a good death can be achieved through community engagement, network development and the creation of compassionate policies. In a study focused on Bangladesh, the way that people there define a good death as being one that takes place in the presence of loved ones was explored. This study also showed that the response to terminal illness and death varies according to local worldviews, which may include beliefs in rebirth, or a belief in life after death, as an integral part of life (Joarder et al., 2014).

Despite the notion of a good death not having a singular global narrative, the 'quality of death' ranking produced by *The Economist*(2015)implies that developing countries should aspire to the level of quality of death of the top-ranking western countries, which is characterized by medicalized and institutional death. The 2015 Quality of Death Index produced by The Economist Intelligence Unit calls for a common notion of a good death, which implies that common end-of-life care goals are to be achieved by all countries. This index evaluated 80 countries, among which Bangladesh was in position 79, just above that of Iraq; the UK held the first position. The suggestions prescribed involved adopting several characteristics of the countries ranked as having a high quality of death: training of doctors and nurses, wide availability of opioid analgesics and investments in palliative care services.

Despite there are diverse notions of good death around the world, in both high-income and lower-middle income countries, death index of *The Economist* suggests to follow common goals for all the countries. The present study seeks to challenge the narrow conceptualization of good death that is implicit in the common goals suggested in the index.

Very few numbers of palliative care centres are established in Bangladesh, mainly in Dhaka city. Bangabandhu Sheikh Mujib Medical University (BSMMU) in Dhaka, which is the only medical university in the country, recognized palliative care as one of its key objectives and began to provide some rudimentary services in 2007. A Centre for Palliative Care (CPC) was formally established in 2011. The present study took place in the CPC and its two community settings. Palliative care is emerging in Bangladesh since the last decade. However, there’s no end-of-life care policy yet. As the notions of a good death are discussed around the world and palliative care has recently begun to take hold in Bangladesh, the current research investigates how palliative care is delivered and how the providers, dying patients and family caregivers perceive the meaning of a good death.

Argument of the thesis

The central argument of this thesis contends that, despite the common end-of-life care goals, emphasized in The Economist's Quality of Death Index (2015), there exists room for embracing an alternative approach to end-of-life care. The core of this argument is grounded in the differences ‘values’ and ‘logistics’ between west and the countries from the global south. As characterized by Zaman et al. (2016), the distinction is noteworthy. 'Value' denotes one's subjective judgment about what constitutes a good death, while 'logistics' encompass the arrangements to actualize the stated 'value.'

Considering the top countries (which are mostly from the wester Europe and other developed countries prevailing western ideals), the death index implies that optimal palliative care is best delivered through institutionalized, formalized, or professionalized arrangements, primarily via specialized palliative care settings, such as opioid/professional care in hospices, hospitals, or specialized care homes. The prominence of high-income countries in the index underscores the influence of Western ideals on the suggested elements of specialized palliative care. These elements, drawn from aspects of good death predominantly followed in the West, emphasize patient autonomy, upholding patient choice, and ensuring informed decision-making regarding terminal conditions.

However, lower-middle-income countries, particularly those in the global south, may hold different values. The compassionate community model, exemplified by the Kerala model in India, illustrates an alternative approach where palliative care is community-based, utilizing neighborhood networks and volunteers. This model contrasts with the formalized arrangements prevalent in Western countries. Likewise, the study posits that Bangladeshi notions of good death may encompass distinct values and logistics in the delivery of palliative care.

The thesis aims to reiterate the proposition that, an implicit tension or inconsistency between the values and logistics existing in Bangladesh and those prioritized in The Economist's ranking. The ranking introduces two-fold complications: the imposition of a common pathway for global palliative care provision and the ‘follow west’ mindset of policy makers in Bangladesh due to the ranking's influence. Consequently, the study, by exploring Bangladeshi notions of good death, contends that the country's unique socio-economic reality makes the uncritical transfer of Western palliative care arrangements both undesirable and unattainable. The study concludes that alternative notions of good death, aligned with the realities of Bangladesh, must be explored. Rather than blindly following Western paradigms, the thesis offers a critique of Western notions of good death.

Furthermore, the thesis asserts its empirical contribution by demonstrating how a 'follow west' mindset may not be conducive to effectively addressing the increasing challenges of end-of-life care in the country. Instead of advocating for a singular approach, the study suggests the possibility of finding an alternative pathway, a perspective elaborated upon in the subsequent finding sections and the concluding chapter.

Rationale and research questions

Although a lot has been written on the idea of a good death in the context of developed countries, very little is known about the notion of a good death in lower- and middle-income countries such as Bangladesh. This research will contribute to generating new knowledge on the subject of a good death in the context of Bangladesh. Also, as life expectancy is increasing and the proportion of the population living into old age is growing in Bangladesh, this research aims to reflect on the local notion of a good death and guide the future direction of palliative care, a newly emerging medical field in Bangladesh, in a way that is sensitive to social, cultural and economic conditions in Bangladesh. These insights are required for future palliative care policy in Bangladesh, which can also be helpful for other, similar, lower-middle-income countries.

Based on the rationales of the research, the research questions are:

1. What are the notions of a good death held by different stakeholders (healthcare providers, dying patients and their family caregivers) in a palliative care setting?

2. How do these stakeholders participate in a palliative care setting in Bangladesh?

3. What are the current practices of care that help to ensure a good death in a palliative care centre in Bangladesh?

4. How does the idea of a good death in Bangladesh compare with the practices of a good death in palliative care around the world?

Reasons for prioritizing Palliative Care in the Exploration of a Good Death:

In delving into the understanding of a good death within the context of Bangladesh, my primary focus is on palliative care, eschewing alternative settings or sources for specific reasons.

Three key rationales underline this choice. Firstly, due to the increasing numbers of dying in lower-middle income countries and as it is widely acknowledged that palliative care might provide an institutionalised good death (McNamara et al., 1994; McNamara, 2004), exploration of good death is becoming significant in recent times. The notions of good death, which means delivering death in a palliative care centre unifying the ideal of dying with dignity, peacefulness, preparedness, awareness, adjustment and acceptance (Hart et al., 1998) is significant in recent time. The significance lies in the escalating numbers of death due to diseases like cardiovascular ailments, cancer, chronic obstructive pulmonary diseases, infectious diseases (e.g., HIV/AIDS, multidrug-resistant tuberculosis), and complex humanitarian emergencies in lower-middle-income countries. These conditions not only inflict suffering but also necessitate pain management and palliative care, creating an imperative for intervention in this domain. Furthermore, a substantial 78% of adults in need of palliative care reside in low and middle-income countries, with a projected 83% increase in total deaths within these regions by 2060 (Sleeman et al., 2019). The overwhelming majority of children requiring palliative care are also concentrated in these regions, with 98% belonging to low and middle-income countries, particularly those in lower income countries (Knaul et al., 2015).

Secondly, the emerging development of palliative care in Bangladesh merits attention. Limited initiatives, mainly in Dhaka, the capital, include hospital-based and community-based palliative care programs. Despite there are ample research on the notions of good death in western countries, there is a paucity of research on the topic in Bangladeshi context. My focus, therefore, centers on scrutinizing the practices of emerging palliative care services in Bangladesh to illuminate the understanding of a good death.

Thirdly, the ranking of Bangladesh (79th out of 80 countries) in The Economist Intelligence Unit's 2015 Quality of Death Index prompts a critical examination. This ranking has stimulated discussions within the healthcare landscape and the media on enhancing the quality of death in Bangladesh. However, a nuanced approach is necessary to discern which kinds of palliative care should be improved. Uncritical transfer of the ranking that mostly adheres to the notions of good death that are implicit in the standards of formalized and professionalized health services of the west may not align with the complex realities of death and dying in Bangladesh. Therefore, my objective is to contextualize this ranking, fostering a critical reflection that avoids uncritically adopting suggested guidelines, similar to the selective embrace of various aspects of modernity in many postcolonial nations.

Discipline

Primarily, this study fits into the disciplines of medical anthropology or medical sociology, as determined from various aspects such as research questions, literature references, data collection methods, and the study's implications. Emphasizing the cultural dimensions of a good death in palliative care center in Bangladesh, the research explores the influence of culture and lifestyle in interactions among dying patients, patients, and family caregivers, with a specific focus on palliative care. Employing qualitative methods, particularly in-depth interviews and ethnographic observations, the study aligns with the conventions of medical anthropology or medical sociology.

Examining the literature used in the research provides another lens to identify its disciplinary orientation of medical anthropology or medical sociology. Although primarily rooted in social sciences, the literature encompasses a diverse range of perspectives related to palliative care. Notably, the study engages with palliative care literature that, while not directly social science research, offers insights into the cultural and lifestyle aspects of the society under investigation. Acknowledging the dominant medical component in palliative care research, the selected literature is purposefully chosen to extract information and analysis relevant to social elements, even if not explicitly from social anthropology or sociology.

Additionally, the study draws from social scientific research predominantly conducted in Western Europe and North America. These studies shed light on patient preferences during the time of death, influencing the design of palliative care to accommodate preferences such as autonomy, agency, and dignity. Furthermore, these studies explore the prevalent ideas and understandings about death in Western countries, thereby reflecting Western perspectives on a good death in palliative care.

Expanding its scope beyond medical anthropology or medical sociology, the study also partially incorporates insights from gerontology and death studies, reflecting a multidisciplinary approach.

Th research also intersects with post-colonial studies to some extent. The inclusion of post-colonial studies introduces a critical theoretical analysis of history, culture, and literature, enriching the study's broader contextualization. The study provides a critical analysis of The Economist's (2015) ranking, implicitly suggesting that a good death is best achieved through formalized care structures that prioritize institutionalization and professional involvement—predominantly observed in Western contexts. The top-ranking countries (UK, Australia, New Zealand, Ireland, Belgium) implicitly endorse the idea that the Western model of palliative care, prevalent in developed nations, should be followed by lower-ranking countries. By delving into the concept of a good death in Bangladesh, a lower-middle-income country, the study contends that the socio-economic reality of Bangladesh diverges significantly from that of the top-ranked nations. Consequently, the adoption of such a model might be considered as both undesirable and unattainable.

The study underscores the need to recognize alternative notions of a good death that align with the realities of Bangladesh. Rather than unquestioningly embracing Western paradigms, the research offers a critical evaluation of Western ideals surrounding end-of-life care. In this regard, the study extends its inquiry into post-colonial studies, highlighting the importance of contextualizing notions of a good death within the historical, cultural, and socio-economic framework of Bangladesh. The conclusion posits that, in rejecting a blind emulation of Western standards, there is an opportunity to unearth and embrace culturally and contextually relevant perspectives on a good death.

Outline of the thesis

The thesis is presented in nine chapters. Chapter one introduces the research and states its relevance, briefly describing the background of the research, its aims and contribution.

Chapter two is the literature review section of the thesis. It starts with a discussion of death and dying, followed by a description of the emergence of hospices and palliative care in the 1960s and how the idea of a good death was institutionalized in palliative and end-of-life care in many high-income western countries. The chapter concludes by highlighting the different cultural understandings of a good death across cultures and countries.

Chapter three gives an overview of Bangladesh, providing a brief historical, social and cultural background. In addition, it also briefly describes the healthcare situation in Bangladesh.

Chapter four is the methodology chapter. It describes the epistemological importance of qualitative research and gives an historical overview of the methods used in the research of death and palliative care. It provides details of the settings where the fieldwork took place, and states how many participants took part, how they were selected and how the data analysis was done. This section also explains the disruption resulting from the pandemic, and states the ethical considerations involved in the research.

Chapter five to Chapter seven are the findings chapters. Chapter five describes the role of the healthcare providers in the palliative care settings. Chapter six focuses on the awareness of dying of the patients and family caregivers. Chapter seven describes what the family caregivers and their dying relatives think about what constitutes a good death.

Chapter eight describes my reflections on the pandemic. It also explains how the palliative care settings have been affected by the pandemic.

Chapter nine summarizes the concluding thoughts of the study.

Chapter Two- Literature Review

Introduction

End-of-life care is an emerging health concern throughout the world. Care before death has been changing over recent years since the emergence of the modern hospice movement in the 1960s in the UK. Over time, care of different terminally ill patients contributed to developing an idea of a good death in the death studies literature. The quality of death has recently become an indicator among countries giving a measurement of ‘quality of life’ across the world. The ‘quality of death’ rankings published by *The Economist* in 2010 and 2015 are examples of death being used as an important indicator (*The Economist*, 2010, 2015). Hospices, palliative care, home care and community palliative care are the main providers of end-of-life care in different parts of the world. My research aims to understand end-of-life care practices in the city of Dhaka in Bangladesh. While studying the current practices of end-of-life care, I also explore the cultural understanding of the notion of a good death among the patients, carers and the healthcare providers in three palliative care settings in Dhaka city.

In this chapter, I first discuss the scenario of death and dying around the world and the importance of providing end-of-life care to a burgeoning number of dying people in the future. Next, I describe the context to the study, in relation to the disparity of access to end-of-life care in Bangladesh. Following that, I discuss the historical evolution of the notion of a good death and the emergence of hospice and palliative care in the UK and later in other western European and North American countries, which are, in general, high-income countries. In the following chapter I consider the development of the community palliative care model in low- and middle-income country settings, focusing mainly on sub-Saharan Africa, India and Bangladesh, thereby exploring the provision of end-of-life care in contexts that differ in relation to the idea of a good death. This chapter portrays different local worldviews in terms of the meaning of a good death, and differences between resource settings in high-income countries and those in low- and middle-income countries. In this manner, I examine whether there are common values in end-of-life care, and explore pathways for tackling the disparities in end-of-life care in Bangladesh.

Rationale for selection of literature

Although there are much academic discussions of the good death, the focus of this thesis is on the end-of-life care related discussions about achieving good death. The development of the concept ‘good death’ was predominantly by academics and clinicians working in end-of-life Care, or palliative care. However, most work has been conducted in western European and north American countries. The current study aims to contribute to understanding how the concept of good death differs in Bangladeshi settings. Researchers have questioned the universality of this concept and argue that the elements of a good death can vary from culture to culture and differentiating the global north from the global south leads to some generalizations: secular vs. non-secular societies, individual vs. collective societies, formal vs. informal medical systems, etc (Chapter Two). I focus on the Bangladeshi variation of the palliative care-related ideas of good death. Due to the paucity of research in global south countries, I also selected literatures of other perspectives, such as the dying phase, moment of death and post-death practices or funeral rites (Chapter Three). However, my focus revolves around the issues of good death in palliative care, and the contribution of the study remains to understand the scope and nature of palliative care in Bangladesh. By looking at the notions of good death amongst the providers, family caregivers and the patients, the study explored whether a common notion of palliative care is required around the world or if culturally-tailored provisions are essential.

Global aspects of death and dying

Firstly, a global picture of death and dying is presented in order to contextualize the research in Bangladesh. Walter (2017) argued that demographics make death and dying a “global twenty-first century issue”. Many high-income countries experienced a “post-war baby boom”, which will lead to a dying boom from 2020 to 2050 (Walter, 2017, p.1). On the other hand, many of the low- and middle-income countries will experience a larger number of deaths in the twenty-first century due to the fact that an “unprecedented number of babies survived” in the latter half of the twentieth century, as a result of public health initiatives (Walter, 2017). It is estimated that the global annual death rate, which is now around 56 million (WHO, 2014),could reach around 90 million in the middle of the century. This rise will be due to fertility rates over the previous four decades having been in decline around the world. In the low- and middle-income countries, specifically, death has moved from infancy and childhood to old age.

Along with the ageing population and the management of their death and dying, there are issues of access to palliative care. (Palliative care and its development will be explained later in this thesis; for now, I conceptualise palliative care as being described as a specialized service comprising multiple professionals, i.e. doctors, nurses, psychological counsellors, chaplains, art therapists and volunteer carers. Palliative care prioritizes the management of pain before the death of a patient). According to the WHO, there are over 20 million people annually that benefit from palliative care at the end of life (WHO,2014). However, it is observed that the highest proportion of adults (78 per cent) who could potentially benefit from palliative care but do not have access to it are living in low- and middle-income countries, while the most developed end-of-life care provision is found in high-income countries. In a recent study, Sleeman et al. (2019) projected the increasing burden of health-related suffering by 2060, stating that 83 per cent of these deaths will occur in low- and middle-income countries. Serious health-related suffering will increase in all regions, with the largest proportional rise being in low-income countries (a 155 per cent increase between 2016 and 2060).

Despite the number of people needing palliative care in low- and middle-income countries, there has been little research about how the people of those countries perceive the idea of a good death and how end-of-life care practices are being structured. These services are provided by community or privately owned institutions and the state. At the emergence of the modern hospice movement, most institutions were charity based. Currently, many wealthy countries have a national integrative policy of palliative care. End-of-life care in high-income settings is specialized and expensive. It is labour intensive and unsuitable for the less predictable dying trajectory of frail old age or heart disease, and is not cheap (Walter, 2017). This is why the concept of ‘compassionate community’ has become popular recently, referring toa ‘community’ – whether a city, a village or a dying person’s social network – participating to treat the terminally ill patient, as championed by Kellehear (2005). He proposed that palliative care is not only the concern of professionals; rather, it is the responsibility of everyone in the community. The Indian state of Kerala provides a large-scale and long-running model of how a compassionate community can work at the end of life. Local networks of 10 to 15 volunteers identify chronically ill people in their neighbourhood, organize appropriate care and liaise with medical services. The Kerala scheme covers a population of over 12 million people (Kumar and Palmed, 2007).

Epicurus once said: “The art of living well and dying well are one” (Cited in Smith, 2000, p.129).Since the emergence of the modern hospice movement, and, later, with the development of palliative care, the philosophy of a good death has incorporated notions of autonomy and control on the part of patients, mostly in wealthy countries such as the UK, the US and some other western European countries (Stoddard, 1978; Logue, 1994).

Despite the debate over how to ensure quality end-of-life care, people aspire to a good death at the final moment of their life (Smith, 2000). However, it is interesting to note that, according to a systematic review, 90 per cent of palliative care studies focus on only a few European countries (Pastrana et al., 2010).The idea of a good death has evolved over the years. It has been interpreted in diverse ways and analysed through several anthropological, sociological and historical definitions. Mak and Clinton (1999) suggest that a good death involves a complex set of relations and preparations that are not separate acts but a series of social events (McNamara et al., 1995, cited in Mak & Clinton, 1999) and that comfort and relief from pain and suffering are among the most cited elements of a good death (Weisman, 1988). They propose that the emphasis on freedom from pain accounts, to some degree, for confusion between notions of a good death and euthanasia.

Palliative care emphasizes that the sufferings of the patient should be reduced and that troublesome and debilitating symptoms should be controlled to enable a good death (Mak & Clinton 1999). The WHO also states that freedom from pain is an essential element of a good death in order to leave the patient physically and mentally “capable of reaching whatever goals he or she may want to achieve before death” (WHO, 1990, p.57). Additional aspects of a good death include completion – the idea that death is essentially ‘good’ when it occurs ‘on time’, when a person has completed their span of life or has a sense of readiness related to their style of life and to their aspirations and goals in life (Hinton, 1967; Shneidman,1973). Acceptance and autonomy are further elements of a good death to have been identified (Frith et al., 2013; Hart et al., 1998). Achieving acceptance is seen as a gradual process, as is explored in Kubler-Ross’s work; this process begins when the patient becomes aware of impending death, but as death becomes closer people may need help in giving meaning to their lives (Weisman, 1972). Other elements of a good death include the public preparations for death, saying farewell to family members and staff (Kellehear, 1990). It is also important to complete ‘unfinished business’: by making personal and social preparations, including resolving residual conflicts and satisfying remaining wishes (Weisman, 1972). These elements of a good death are supported by a study by Steinhauser et al. (2000), which identified six themes that characterized a good death: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person. Steinhauser et al. also noted distinct differences between groups (patients, family members, physicians, nurses, social workers, chaplains and volunteers), which were shaped by social and professional roles. Physicians’ understandings differed from the others: their suggestions for options to ensure a good death came from a biomedical perspective. However, patients, family members and others offered different components related to the quality of dying (2000). Kellehear (2001) suggested several aspects that are important for a good death: adjusting to the different cycles of illness and treatment, the legal, financial and religious preparations for death, disengagement from work and the bidding of farewells.

These notions of a good death have evolved with the development of specialized palliative care services. Diverse literature on death and dying has presented many arguments over the varied meaning of a good death in terms of culture, lifestyle and different resource settings (Walter, 1994, 1998, 2017; Kellehear, 2005, 2012). However, the debate became even more interesting after the publication in 2015 of a global ranking index on the Quality of Death. The study was done by The Economist Intelligence Unit andthe index evaluated 80 countries,among which Bangladesh was ranked in position 79, just above Iraq in position 80;the UK held the first position in that index. The study examined 20 quantitative and qualitative indicators across five categories: the palliative and healthcare environment, human resources, the affordability of care, the quality of care and the level of community engagement. The suggestions from the study prescribed that several characteristics of the countries with a high quality of death should be adopted: training of doctors and nurses, wide availability of opioid analgesics and investments in palliative care services.

Nevertheless, there are some complexities to be aware of regarding the idea of a good death or of the quality of death. While studying how American hospitals shape the end of life, Kaufman (2005) argued:

> People today want things from death, and their desires are both contradictory and unprecedented. Many want dying to be an experience that can be characterized as “good”, yet persons near death and those who care for them often perceive it as difficult or painful, harrowing or humiliating. People want death to be made comfortable by the tools of medicine, which they expect can eliminate both the disturbing visible signs of the body’s disintegration and the patient’s experience of suffering…Many want to control the way death happens for themselves and their loved ones by planning ahead for it, yet few are actually prepared for the moments when decisions must be made or for the kinds of questions that will emerge when death is near. (Kaufman, 2005; p.3–4)

Addressing these nuanced realities of end-of-life care throughout the world, the question remains whether these nuances apply globally to death and dying or only in the US? This research is an endeavour to contribute to the practice of end-of-life care and the understanding of a good death in Bangladesh. It has already been mentioned that there has been no extensive academic research about end-of-life care practices in Bangladesh thus far. According to the 2013 National Institute of Population Research and Training in Bangladesh Report, Bangladesh has a burden of 600,000 patients who are not curable, and has only six Dhaka-based comprehensive palliative care programmes at present.

Moreover, the question is, what kind of provisions are available to serve the increasing number of dying people in Bangladesh? There are questions to be considered regarding the principles of the existing palliative care model, by which I mean the organizational and institutional values of the palliative care model. However, the concern here is over what provisions are available for the management of death and dying in Bangladesh. Do they convey an understanding of a good death and of ‘peaceful dying’ like that which has been established in the palliative care model developed in high-income countries?

Here, I explore the ethos of a good death in high-income countries, comparing it with that of low- and middle-income countries. While exploring the ethos of a good death, I portray the historical development of the hospice and its evolution into palliative care in high-income countries. Contextualizing palliative care institutions and their development, I illustrate palliative care provisions and practices in low- and middle-income countries. Next, I frame my analysis inthe context of a broader question: does palliative care provide a good death? If so, how do practices vary between high-income countries and low- and middle-income countries, including Bangladesh?

In addition, given the background of my research described above, the present research aims to understand the notion of a good death among different stakeholders (health professionals, patients and carers) in Bangladesh in the current context, and explores how, within the local context, the aforementioned stakeholders in Bangladesh understand the notion of a good death. This research can inform the future direction of palliative care, a newly emerging service in Bangladesh, in a way that is sensitive to the social, cultural and economic conditions of the country.

Before engaging with the question regarding the situation of end-of-life care in Bangladesh, which constitutes the aim of my research, Ilayout the common ground forthe discussion of issues regardingend-of-life care provision around the world,as these issues need to be opened up for further investigation. Firstly, I discuss the dominant narratives on death and dying across the world. These discussions emerge from the context of modern western countries, by which I mean western European countries and some North American countries, which are, in general, high-income countries. As mentioned earlier, 90 percent of the existing research is based on high-income countries, which are mostly situated in the western contexts described here. A description of the way death and dying is formulated as a problem in the western context is given in the following section.

Formulation of death and dying as a problem

Cultural differences become evident in end-of-life situations. However, some idea of a good death is practiced in the west (McNamara et al., 1994; Hart et al., 1998; McNamara, 2004). In modern western societies, there are two dominant narratives of history: one is the progress narrative and the other is the nostalgic/decline narrative. These two dominant narratives also exist in the discussion of death and dying. In terms of the progress narrative, the achievements of medicine and public health in tackling diseases and extending humankind’s longevity are highlighted (Walter, 2017). Rather than examining the progress narrative further, I will focus on the decline/nostalgic narrative. In order to understand death and dying as a problem it is important to locate the decline/nostalgic narrative within the context of socio-historical forces that later stimulated the development of hospices and palliative care in the UK and in other high-income countries. Palliative care in the west enables the relief of symptoms ensuring the psychological, social and spiritual wellbeing of patients whose disease is no longer responsive to curative treatment. A central principle of palliative care here is the provision of assistance to ensure a good death (McNamara et al., 1994); however, the definition of this is not always clear. Among the many perspectives and definitions of a good death, I focus on the understanding of death and dying in the west,to explore perceptions and practices of palliative care originated there. I explore the historical journey of the idea of death and dying in order to understand its connection with the notions of good death and development and expansion of palliative care around the world.

Regarding the nostalgic account of death and dying, three influential figures are important:the Swiss-American psychiatrist Elisabeth Kubler-Ross (1969) on dying;the French historian Phillippe Aries (1974) on the western attitude to dying; and the English anthropologist Geoffrey Gorer (1965) on grief. Their work argued that in the twentieth century most people die in hospitals, in the presence of physicians who are strangers to them, most of whom are reluctant to talk about death. Rather than talking about death, they use euphemisms to communicate with the patients. This not only denies the human dignity of an individual, but also perpetuates the erosion of community and religion, they argue (Walter, 2017; Lawton, 2000; Seale, 1998). Here, community refers to the geographical social setting, comprising neighbours, friends, relatives and family members living nearby.

Later, and emerging out of these explanations, grewthe deathdenial thesis or narrative, again in western contexts. Although the narrative has limitations, it influenced the emergence of modern hospice and palliative care in high-income settings during the mid-twentieth century (Tradii & Martin, 2019). Western contexts describe two problems in dealing with death and dying: one claim is that it is hard to talk about death and dying in this context, and the other is that the existing social structures and organizational systems make the contemporary experience of death harder than in earlier times (Sudnow, 1967; Lofland, 1985; Kaufman, 2005). The following sections dicuss the explanationsgiven in the literature regarding why it is difficult to talk about death and dying in modern western contexts.

Reflections on the ‘death denial’ narrative

One common claim is that death and dying in the twenty-first century is unfamiliar to those living in modern western countries; in other words, people there are unfamiliar with death. This unfamiliarity started in the mid-twentieth century (Tradii & Martin, 2019). One of the founders of the narrative, Aries (1974, 1981), claimed that in the late nineteenthcenturythe role of being beside the deathbed gradually shifted from the clergyman to the medical person, and new concerns were raised about how death could be handled spiritually as well as medically. Death in earlier times, according to Aries,led to the deepening of family relations andthe sharing of feeling with a dying relative, followed by sentimental grief after the loss, public rituals of mourning and the observance of a funeral that included everyone in the community. In the late nineteenth century, there emerged a new physical reality regarding the site of death. By this time, the majority of patients were no longer dying at home beside their relatives; rather, they were dying in the hospital, alone. Consequently, hospitals became the centre of discussion as that was the place for dying. Aries argued that the ‘beautiful death’ lost its earlier meaning and was replaced by science and medicine in the mid-nineteenth century. Death meant retreating from family, religious and public dimensions into the isolated spaces of hospitals. Death became“shameful and forbidden” in the mid-twentieth century, according to Aries (1974, 1981).

Simultaneously, Geoffrey Gorer, a British anthropologist, argued in his study *Death, Grief, and Mourning* (1965)that death has become invisible and hidden away from our physical reality. He also claimed that this representation of death is a form of pornography. By this, he meant that its violence and distanced emotional content blunts the viewers’ sensitivities to interpersonal violence and the profound implications of death in the real world (Gorer, 1955). Later, he described western society as “death denying” and described “death as a taboo topic” in relation to mourning rituals, which reflect modern conditions. Gorer argued that English (referring mainly to western Protestant) mourning practices are in a state of anomie (meaning ‘normlessness’, in Durkheimian terms). This means that these societies lack common patterns of ritual to deal with the crisis of death. Death appears to have been severed from its social matrix in these societies. Gorer’s staging of mourning following death included a primary stage of shock, numbness and denial (Glick et al., 1974; Raphael, 1983; Parkes, 1986). Gorer, along with Aries, is considered to be one of the founders of the denial of death thesis within the social sciences (Zimmerman, 2004).

This staging of death denial took an interesting turn in the work of Kubler-Ross (1969). In her staging theory of death and dying she identified denial, anger, bargaining, depression and acceptance, and showed how a death denying social context made people accept the death after a certain stage when the patients enter an institution such as a hospital or care home. Kubler-Ross's influence will be discussed further in the section explaining the features of a good death within palliative care models. It is worth mentioning that the death awareness movement and the modern hospice movement, both occurring during the 1960s, are simultaneous and remarkable developments in the history of end-of-life care provision in the modern western context.

Nevertheless, these works importantly criticized the medicalization of death in hospitals – treating only the patient's bodily failure while ignoring the psychological and spiritual state of mind – and the sequestration of death and dying rituals from the family to the hospital or other care institutions. To some extent, these works also criticized modernity and its consequences for the individual self and for 'personhood' (Seale, 1998; Walter, 1994, 2017; Lawton, 2000). However, the critique of medicalization is best exemplified in the work of Illich (1976). He emphasized that the medicalization of death makes death an isolating experience, where social ties are cut. While explaining the hostile relation between death and medicine he said, "Death is the ultimate form of consumer resistance" to the domination of medicine and its experience (Illich, 1976, p.210).

Later, sociologist Norbert Elias (1985) broadened the arguments of the death denial thesis, explaining that the experience of ageing and dying is a lonely experience in modern western settings. This loneliness happens due to the "civilizing process" which draws a veil over death, and prevents people from talking about it. Through the concept of a 'civilizing process' Elias presents his perception of western societies' construction of the individual's habitus due to structural changes in western society since the Middle Ages and up to modern times. These shifts, according to him, centred on changes in the division of labour and the consolidation of political authority, and the monopolization of physical power. These processes, according to Elias, have led to increasing mutual dependence in western societies and have brought about psychological implications such as self-restraint and control that did not exist before. Therefore, people do not know how to respond emotionally to people who are dying. Bauman (1992) further explored the veil that is drawn to separate dead people from the living, with the designation of the dead as ‘other’ in modern societies.

However, despite the popularity and persistence of the death denial thesis in the west, recently, a pair of articles by Laura Tradii and Robert Martin explored how the death denial thesis is based on loose evidence and ignores societal changes regarding urbanization and demographic shifts. For example, medicalization was criticized by various theorists, as mentioned earlier, and Kellehear took issue with this. He explained that technology-centric medication does not mean denial of death, and that a bereaved person not showing emotion in public does not mean that society is denying death. Kellehear argued that societies and communities will always find different ways of dealing with death, whatever the surrounding situation. The problem with the death denial thesis is that it ignores demographic and urban shifts while explaining the new nature of death and dying (Tradii& Martin, 2019). Lofland (1978) suggested that the death denial thesis served a purpose in a broader movement that is the “humanistic counterculture” denunciation of modern western society as “dehumanising, unemotional, technology dominated and inauthentic”. The point is that the reason the deathdenial thesis remains prevalent among many movement groups and some forums is, according to Cannadine (1981), that there is a longing for, or nostalgia about, an idealized past and, most importantly, it persists because the death denial narrative opens up a critique of modernity and technology. In criticizing modernity, the death-denial narrative bemoans the lack of pre-modern aspects of society, such as being surrounded by family members during death. It also decries the loss of religious notions of death which made death comprehensible. Technology is criticized for dehumanising human life in the final moments of life.

Tradii and Martin did not explore deeper into the criticism of modernity, arguing instead for the need for deeper debate in death studies. However, they drew on the work of Zimmerman (2004, 2007),who argued that the death denial thesis “has been erected as an obstacle by the very discourse that continues to propose to tear it down and remains in this discourse because it is an integral component of it” (2007, p.310). Zimmerman meant that the arena of palliative care needs death to be denied in order to ensure its existence. Moreover, the death denial thesis established a moral perspective in defining the ‘right’ or ‘wrong’ way of dying. The right way is described as a good death and the wrong way is categorized as a bad death. From the above discussion emerge some pointers from which to explore further the emergence of palliative care and its preferred good death. At the end of their article, Tradii and Martin (2017) suggested that academia is now focused on what the living are doing with the dead, rather than looking at an idealized past. If that is the concern of recent academia, I further ask: how do low- and middle-income populations deal with issues of end-of-life care? Nevertheless, it is sensible to understand the history and development of palliative care and the idea of a good death in the western context. The death denial thesis is related to another important phenomenon, the 'death awareness movement', also known as 'the revival of death', in death studies (Walter, 1994, 2017); I explain this phenomenon in the following section.

Reflections on the 'death awareness' movement

The propositions explored in the death denial thesis are inherited to some extent by the death awareness movement (Seale, 1998). The notion that death is a taboo or that death is being denied should be broken: this became the mantra of the death awareness movement during the 1960s and 1970s (Walter, 2017; Lofland, 1978). Among the literature on the death awareness movement, the works of Glaser and Strauss (1965, 1967) are significant.

For six years, Glaser and Strauss conducted intensive fieldwork involving a combination of observation and interviews at six hospitals located in the Bay Area of San Francisco. The purpose of their research was to contribute towards creating end-of-life care that was more rational and compassionate. The investigators observed different aspects of dying within these six hospitals; death at these locations was different for different patients: speedy, slow, unanticipated, or anticipated (Glaser, 1967). The researchers observed nurses and physicians at work. They sat at the nurses' stations, attended staff meetings and talked with patients. They also asked questions and interviewed staff. The theory that emerged from this intense investigation presented an eye-opening view of how patient care was affected by the level of awareness about the dying process on the part of nurses, physicians and patients.

Glaser and Strauss's books *Awareness of Dying* (1965) and *Time for Dying* (1968) explored the detailed scenario of the management of different dying trajectories in a hospital, through which order is maintained in the institution. With the term 'dying trajectory', they conveyed how a person's dying was related to the organization of work in (American) hospitals. The trajectory has one important dimension: duration, which here means, not the actual timing of dying, rather the perceived courses of dying. Health professionals' understanding of dying courses is dependent on the nature of the relevant disease and the expertise of the professionals who handle the case. The temporal organization of work is crucial to understanding the dying trajectory, as this may be very different each time. Most of the time it does not follow the perceived route. So, the organization of care needs to be reconsidered with the changing perception of dying trajectories.

At the time when Glaser and Strauss were writing *Awareness of Dying*(in 1964), most Americans died in hospital. While treating terminal patients, professionals were trained on the technological aspects of dying, but were not given any training on how to inform patients and family members about the impending death. Regarding the question of whether a patient should be informed about impending death or not, two problems were evident: one was technical and the other was moral.

The moral aspects of awareness of dying were much more complicated than the technical aspects of dying. Glaser and Strauss argued:

> Is it really proper to deny a dying person the opportunity to make his peace with his conscience and with his god, to settle his affairs and provide for the future of the family, and to control his style of dying, much as he controlled his style of living? Does anyone, the physician included, have the right to withhold such information? Who will make the decision? The rationale for such a decision is not only a technical one, but also an ethical and moral one. (Glaser and Strauss, 1964)

This problem relating to the awareness of dying emerged for two reasons: the increasing incidence of death in hospital rather than at home, and the longer duration of death due to the changing nature of diseases, from acute to chronic. Acute conditions are severe and sudden and can occur in relation to anything from a broken bone to an asthma attack. A chronic condition, by contrast, is a long-developing syndrome, such as osteoporosis, HIV, heart disease and some types of cancer. Glaser and Strauss asked the following questions: what are the recurrent interactions between the dying patient and the hospital personnel? What tactics are used by the personnel to handle the patients? And, lastly, in which kinds of hospital organizations do these things take place? They discovered that the dying patient's responses varied according to their awareness of their impending death. Awareness became the researchers' most powerful explanatory variable. Their basic research questions were related to the moral basis of a good death, and Glaser and Strauss claimed that these considerations were ethical and moral (Seale, 1998).

In *Time for Dying* Glaser and Strauss explored the relationship between timing and the variable of awareness. Both were discussed in the context of achieving order in modern hospital management. They proposed that it is essential to provide more training in terminal care in nursing and medical schools, and to focus on the necessity of learning improved ways of communicating with dying patients and their families; they also emphasized the value of planning and reviewing not just technical but also psychosocial care, including helping the bereaved (Seale, 1998; Walter, 1994, 2017).

Besides the ground-breaking interactionist study in hospital, Sudnow's (1967) doctoral research is another example of how death is perceived in hospitals. Within two American hospitals he observed the behaviour of hospital staff around the occasions of death and dying. The staff were found carrying out their work according to the routine organization in the hospital, including handling bodies, noting information on each patient, diagnosis and prognosis, medical experimentation and teaching. Despite the death of a dying patient being perceived as a loss to the family caregivers, the staff's view was related to the organization of work in the hospitals and priority was given to the organization of death and dying. Sudnow observed that the dying patients were kept isolated in a side room in the hospitals. These scenarios illustrate the idea that other than curative medicine there was seen as being no reason to treat patients. Care before imminent death was ignored.

Meanwhile, the emergence of modern hospices in the mid-twentieth century and of palliative care later on brought about some significant changes regarding the care of terminally ill patients. These changes instituted a holistic vision of patienthood that extended to the inclusion of family members in decisions about which care should be given and how it could be given to the patient, which was absent in the hospital setting (Armstrong, 1986;Walter, 1994;Seale, 1998). Abel (1986) argued that the modern hospice movement and palliative care deprofessionalized care, meaning that the paternalistic relation between doctor and patient had been minimized in hospices. The paternalistic relation refers to the model in which decisions are taken by the healthcare professional in order to benefit the patient or the society as a whole. Modern hospice and palliative care values questioned this paternal relation between doctor and patient and regarded it as ‘hierarchical’ and ‘unequal’. Along with these significant notions, other ideas were developing which were incorporated as part ofa good death in hospices and palliative care. However, by the end of the twentieth century and at the advent of the twenty-first century, other trends of palliative care developed to emphasize explicitly the social dimensions of palliative care and to promote the notion of ‘compassionate communities’; these trends argue that “palliative care is everybody’s business” (Kellehear, 2005).

In the following section, I explore the emergence of palliative care along with its underlying principles in order to aid understanding of the historical and ideological impetus and the institutionalization of a good deathwithin mainstream notions of palliative care (McNamara et al., 1994). McNamara’s study focused on the institutionalization of good death in Britain and North America.

Palliative care

Since 1990, the WHO has adopted two definitions of ‘palliative care’. According to the most recent definition, which is still current, palliative care is:

> 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. (WHO, 2002)

Although there is a clear definition, people working in palliative care have recently become aware of its growing complexities and nuanced reality. Clark (2019) argued that the debates that explore the existing definition reflect features of the hospice approach developed in high-income countries. There was also a significant drive to move beyond cancer, the disease that had defined the approach of the modern hospice movement. Consequently, there are emerging trends to develop different palliative care specialties for different diseases. Definitional issues become complex in terms of incorporating paediatric palliative care, distinguishing circumstances for homeless people, and making special arrangements to provide for the needs of ethnicity and the politics of identity. Complexities have arisen regarding the “limitations to the global spread of the field”, described as “post-colonial palliative care” (Zaman et al, 2017; Clark, 2019). My focus is on the reflection of hospice ideals in the existing definition of palliative care, because the 2015 Quality of Death Index compiled by The Economist Intelligence Unit operationalized the same definition in order to make its recommendations.

The development and expansion of palliative care in high-income countries

Palliative care has developed out of modern hospice care achievements in the 1970s and 1980s (Clark, 2016). As a place to care for the dying, the history of hospices goes back to the fourth century with the establishment by Fabiola of a hospice for pilgrims, staffed by religious orders. However, It was during the 1960s that ‘hospice’ became a term that described both a place and a philosophy of care that could take place in a wide range of care settings.

The modern hospice movement emerged during the late 1960s. Notably, hospices developed as a response against the ‘depersonalized care’ of dying people in hospitals. The pioneer impetus was initiated by Dame Cicely Saunders in 1967 with the founding of St Christopher’s Hospice in the UK. Palgi and Abramovitch described it as “one of the newer cultural modes of relating to dying people” (1984, p.404). St Christopher’s Hospice became a prototypical example for future developments across the UK (Lunt, 1985). The emergence of hospices questioned the impersonal, medicalized and technological management of death occurring within hospitals (Abel, 1986; James, 1994). Hospice pioneers argued that death should be regarded as a normal and natural part of life, rather than seeing it as a failure (Saunders mentioned in Lawton, 2000). Hospice philosophy championed the philosophy of ‘total pain’, focusing more on care, and on the quality rather than the quantity of a patient’s life. Patients were neither subjected to aggressive life-sustaining strategies nor to excessive technological interventions during the terminal days of their lives (DuBois, 1980).

The concept of ‘total pain’ embraced a multidisciplinarity which Saunders established through the ideology developed at St Christopher’sHospice. ‘Total pain’ is the result of the enormous research, teachings and efforts of St Christopher’sHospice. It is also evident that Saunder’s prime focus was on treating both physical and mental suffering at the end of life. Nurses and health professionals tried to understand the dying patient’s sufferings in a multifaceted way. Unlocking the door of pain, nurses were opening up the other stresses of the dying patients, which required interventions from multiple perspectives (Clark, 2012).

Moreover, the notion of ‘personhood’ became remarkable in the treatment at St Christopher’sHospice. Saunders dedicated her research solely to understanding the problem of pain relief for two main reasons. Firstly, she advocated throughout her life against the idea of euthanasia, in which proponents defended their rationale for assisted suicide at the end of life with the claim that the terminal patient could not bear the burden of excessive medicine and its consequences. Saunderswanted to find new medicines which wouldtreat the patient as a whole and relieve pain, in contrast to the idea of curative medicines that targetted syndromes but caused pain. Secondly, it was important to understand the patient, and listening carefully to them became a new moral philosophy in hospice settings. This is how the concept of ‘total pain’ matured over time (Clark, 2016). Pain is not just about the physical, but is related to a patient’s mental, social and, most importantly, spiritual wellbeing. Thus, St Christopher’s Hospicedistinguished itself not only as a place of spirituality but also as a pioneer institution for terminally ill patients. It became the heart for three distinct activities: clinical care, teaching and research.

Before exploring the underlying principles of palliative care, its evolution and expansion is discussed here. The modern hospice movement gained popular support, remarkably, at a grassroots level. By the time hospices were expanding in the UK, different community groups – schools, churches, women’s groups, charity organizations and voluntary organizations – became involved in hospice activities through unpaid work in terms of counselling and different administrative tasks (Field & Johnson, 1993).

At the onset of the early 1970s, many local initiatives by individuals and groups contributed to raise funding for new hospice buildings despite the challenges of economic recession. However, although there was a remarkable urge to develop more hospices, problems arose regarding the running of the hospices (Lawton, 2000). The UK National Health Service (NHS) was under pressure to intervene in the maintenance of the hospices, for which the NHS did not have any plans. Due to this emerging situation, the NHS initiated partial assistance to many of the hospices by the end of the 1980s (Taylor, 1983; Lawton, 2000).

Lawton (2000) argues that due to organizational and economic pressures the hospice movement restructured its content and management to incorporate the framework of the NHS. During the early 1980s, significant charitable organizations such as the National Society for Cancer Relief (NSCR) decided to provide running costs for hospices, with the condition that the NHS would take responsibility for their management. As a result, the first NHS hospice was founded in 1975, and by 1994,50 out of a total of 193 inpatient hospices received joint or separate funding from the NHS and NSCR (Directory of hospice services in the UK and Republic of Ireland, 1994; Lawton, 2000).

These reforms together with NHS intervention resulted in significant changes in the organizational framework of hospices with standards being ensured by means of audit and evaluation (Walter, 1994). By this time, hospice care and palliative care were then commonly thought to be synonymous, although palliative medicine, in fact, only became an accredited medical specialty in 1987 (Ahmedzai mentioned in Lawton, 2000). There had also been a diversification of the early hospice approach, which encouraged the establishment of inpatient units in home care, day care and other services (Seale, 1989).

Initiatives took place between 1967 and 1991, with elements of palliative care being established at various times. For example, Sweden established a home care service in 1977, home care was established in Italy in 1980, and Spain established an inpatient palliative care unit within a hospital in 1984.Consequently, hospice or palliative care spread to almost every industrialised country in the world. Clark (2015) noted that the extent to which palliative care was developing as a specialism also varied considerably, although this tended to reflect the degree of palliative care services or the relative affluence of specific countries.

Despite the expansion of palliative care services in high-income countries by the end of the twentieth century, researchers raised concerns about the shifting nature of the organizational framework of the hospices being incorporated within the formal health care system (Clark, 1993. Because the hospice movement started as a critique of the practices occurring within hospitals, it initially, and intentionally, emerged outside the formal health care system. Ahmedzai (1993) argued that hospice services were “entering into partnership with the same system that they break away from” (Ahmedzai, 1993, p.142), meaning that they were compromising with the ideological tenets of the early hospice movement.

Critiques pointed to the routinization within NHS-sponsored hospices, with a shift to focusing on physical symptoms rather than on the spiritual, emotional and social care of dying patients (Abel, 1986; James, 1986). As Walter has likewise argued, “it is easier to demonstrate effective pain control, high bed occupancy and financial cost per patient than to demonstrate real attentiveness to patients’ wishes” (1994, p.167). The difficulties were regarded as a challenge to and a depersonalisation of the ethos of the early hospice movement (Walter, 1994).

Despite the expansion of hospices and palliative care in high-income settings, the internal contradictions of some of the principles were evident. The philosophy of a good death is described in the following sections, highlighting the nuances between the earlier hospice philosophy and more recent palliative care operations in high-income countries.

The ideals of a good death within palliative care in high-income countries

It is important to understand the shifting idea of what constitutes a good death, as recent trends in end-of-life-care services currently face new challenges in providing quality palliative care around the world. Although it is known that end-of-life care should be culture specific and dependent on social settings, the dominant services and their provision spread around the world from a few high-income countries in western Europe and North America. It is, therefore, worthwhile understanding the values and development of the idea of a good death in high-income settings in order to explore the situation in a low- or middle-income setting such as Bangladesh.

With the intrusion of medicine and medical technological priority, healthcare institutions seek to provide a planned service and the rational investigation of diseases. Therefore, tensions echo the shifting of a new era in every aspect of death and dying. These aspects are changes in mainstream diseases, the redefinition of individual preferences and the loosening of social ties in different societies. Due to the tensions in these aspects, there have been compromises with the founding hospice ideals. Tensions emerged between the maintenance of hospice ideals and the maintenance of organization. The trend towards the institutionalization of a good death makes the provision of palliative care an unmanageable ambition due to the tensions of this new era (McNamara, 1994, 2004).

Although there has been no formal definition of a good death within palliative care, a set of standards and values has evolved in the hospitals, hospices, care homes and palliative care institutions of high-income countries over the past decades. However, there are questions regarding whose good death it is, and whether these ideals can be analysed as being those of caregivers, healthcare providers or, most importantly, patients.

Exploring these uncertainties, Cottrell and Duggleby (2016), discuss the theme of the ‘denial of dying’. Due to the uncertainties of recent disease and the unpredictability of the timing of death, earlier notions of a good death were disputed. The earlier notion of a good death, which came to beknown as ‘revivalist’, was influenced by hospice philosophy. The ‘revivalist’ notion of a good death argues that due to the hospice movement in the 1960s an acceptance of death has emerged in western society (Walter, 1994; Seale,1998). Acceptance of death, awareness of death, making dying peaceful and free from pain, and dignity during dying as an autonomous person: these components were the cornerstone of the hospice movement and the components of a good death (Seale, 1998; McNamara, 2004).

Hart et al. (1998) argued that there were questions regarding who defines a good death. Does the definition reflect the wishes of the dying patients and the caregivers? Or, are the ideals of a good death evolved in hospices and palliative care centres and then imposed upon the patients and caregivers?

The imposition of the ideology of a good death upon the patients and caregivers is discussed in detail in a study by Cottrell and Duggleby (2016). In an integrative literature review, they explored the idea of a good death in western countries from the perspectives of patients, caregivers and healthcare providers. They reviewed 39 articles, published between 1992 and 2014, and analysed four themes: good death as control; the wrong good death; the threatened good death; and the denial of dying.

Within the first theme, Cottrell and Duggleby discussed the literature around the idea of ‘control’ in terms of three categories. The first category concerns the planning and preparation for death. If the dying patients and their caregivers are able to plan and prepare for death, then the death is good (Broom, 2012; Zimmerman, 2012). This implies that patients and their families can make choices about how to prepare for death. A prepared death is labelled as a ‘dignified death’ in the reviewed literature (Carr, 2003, p.227; cited in Cottrell & Duggleby, 2016). Seale (2004) argued that the death is ‘bad’ if it is unplanned or unmanaged. The literature suggests that the preparations for dying should be in ‘order’, to ensure a good death (Cottrell & Duggleby, 2016). The preparations for death, according to them, should be controlled if it is to be seen as ‘good’.

The second category of controlling death can be explained in terms of the place of death. Since the 1960s, the hospice movement has promoted the idea of death taking place in the home or a home-like environment (Borbasi et al., 2005). If a dying patient's death takes place in their home or a home-like place such as a hospice, then the death is seen as a good one; if they die far from home or in another community, then it is seen as a bad death (Seale, 2004; Wilson, 2009).

The third category of control, according to healthcare professionals, is that dying patients can achieve a good death if they follow some socially accepted way to die in terms of their care. There is a strong cultural script on the ways to achieve this, and denial or failure to follow this script means that the death is not a good one.

In all these categories, acceptance of death is seen as an essential component for both the patients and caregivers (Hart et al., 1998; Walter, 2004; Borbasi et al., 2005; Kellehear, 2007; Zimmermann, 2007). Denial of death does not allow patients and their families the opportunity to participate in achieving a good death. The good death ideology points towards the responsibility of individuals in agreeing to achieve it (Zimmerman &Rodin, 2004).

The second theme analysed by Cottrell and Duggleby (2016) is 'the wrong good death'. This refers to inconsistencies between hospice or palliative care centre provision and the dying patient's desire. If the ideals of a good death in end-of-lifecare institutions do not reflect the patient's desires and wants, there can be problems. Gott (2008) showed that many cardiac failure patients want neither autonomy nor the awareness of dying suggested by hospice provision. Zimmerman (2007) described this as a 'disjuncture' between the normative discourse of a good death and the patient's real experience.

The third theme, 'the threatened good death', means that due to an ageing population, with increasing longevity and a prevalence of Alzheimer's, delirium or senile dementia, and many other diseases, the earlier elements of a good death are called into question. The existing ideology of a good death in western countries was influenced by the hospice movement and was mostly based on dealing with cancer. Although cancer is still a leading disease, slow and prolonged deaths due to chronic illness will overtake the incidence of death due to cancer (McNamara &Rosenwax, 2007). Cancer deaths are more predictable and there is a clear dying trajectory seen among such patients (Clark, 2016; Abel &Kellehear, 2016). Relief from pain is a common element of a good death among cancer patients, although this can vary in the case of patients dying from chronic diseases; for example, dyspnoea or breathlessness can be a more 'feared' symptom among these types of patients. (Gott, 2008, p.1117). Thus, changes in patterns of disease bring different understandings of a good death, and the ideology of a good death is in transition in western countries. Due to this transition, uncertainties regarding the idea of a good death are emerging.

McNamara (2004), further elaborated the idea that the hospice model of a good death had become incompatible with the atmosphere of patient autonomy and consumer choice. She conducted her fieldwork in Australian hospices and argued that there had been a failure to facilitate a conventional good death. McNamara states that these hospices have compromised on the ideology of a good death by focusing more on relieving physical symptoms, rather than on providing holistic care.She described this trend as a ‘good enough death’. This can be explained as the transfer of responsibility from the social collective to the individual who is dying. In the earlier model of a good death, the social collective meant the family, relatives and multiple professionals, who were involved together in ensuring a peaceful death for the dying patient.

Regarding the shift in the ethos of a good death, McNamara (2004) further claimed that healthcare providers found it difficult to provide for the psychological, social and spiritual needs of dying patients. In contrast to the relief of physical pain and symptoms, other aspects of holistic palliative care are less easy for providers to manage. McNamara also argued that the healthcare providers consider there to be a conflict between the dying individual’s choice and societal expectations in high-income settings. Although McNamara did not reach a conclusion about why the notion of a good death was becoming more medicalized, she drew on western society’s inability to talk about death publicly. For these reasons, it is considered that treating the physical aspects is more rational and organized than considering other components, such as the psychological, mental and spiritual needs of patients. McNamara described this tendency as a ‘good enough death’, which involves establishing a hierarchy of care where the more medicalized aspects of palliative care get priority.

Emerging from the above discussion are certain issues that need to be explored. First, why do the healthcare providers think that there is a conflict between an individual’s choice and societal expectations? Does this indicate a shift towards a new understanding of death and dying? Linked to this, there have been recent discussions about the notion of choice among dying patients. Is it the same as a healthy person’s rational choice or do the vulnerabilities of the dying patient’s ‘self’ remain unexplored? Second, why is death still regarded as taboo, or why is there a problem of communication regarding death and dying among members of society in high-income settings? Third, if there is increased medicalization in palliative care settings in high-income societies, what will the situation be for low- and middle-income societies, where it is more cost effective to provide for the psychological, social and spiritual needs of dying patients than for their medicalized needs?

From the above discussion of McNamara's work, it seems unclear why palliative care institutions focus more on relieving physical symptoms than on providing 'holistic care' to dying patients. It is not clear whether the changes in diseases are making individual preferences more manageable or the social components of high-income settings are failing.

Thus, there is more to be explored regarding the complexities underlying the prioritizing of individual choice in palliative care institutions. However, there are many instances where researchers explain the relief of pain as a trend towards burgeoning medicalization, routinization and bureaucratization within palliative care practices in most high-income settings, and elsewhere (James & Field, 1992; Clark, 1993). According to McNamara (1994), there is a tension between the ideals of a good death and the maintenance of palliative care institutions.

However, an interesting study recently explored a more nuanced view of the institutionalization of a good death in Austria, which is a high-income country in western Europe. Here Lang (2020) argued that although institutionalization has been regarded as having negative consequences for the overall quality of life of dying patients, within such institutions it is still regarded as a priority to relieve physical pain and provide 'holistic care'.

However, Lang makes some important observations regarding the challenges of providing a good death in Austria. There is a polarized view in Austria about what a good death is. Lang termed these views 'restrictive' and 'permissive' positions, referring to whether they restrict or permit the idea of assisted suicide or killing on request. Earlier positions argued that if proper medical and social support can be provided to dying patients, they will not seek assisted suicide or killing on request. On the other hand, later positions have explained that palliative care is not opposed to euthanasia. There is a certain threshold beyond which the ability of palliative care centres and hospices to provide a good death for their patients is limited. According to civil society in Austria, euthanasia laws should be liberal so as to allow the practice of personal autonomy; this reflects the liberal social order in Austria.

However, even in the UK and other high-income countries where the quality of death is ranked as the best in the world, questions arise over the internal contradictions of palliative care provision. According to an integrative literature review (Cotterell & Duggleby, 2016), a good death was found to be regarded as a social control, meaning the ideals of a good death result in instructions which have to be maintained by the providers. Sometimes, it is regarded negatively as a model for controlling the dying process for both dying individuals and those who provide their end-of-life care. The ideology of a good death cane be seen to be inconsistent with the dying patients' desires because of new trajectories of dying and an increasingly ageing population (Kaufman, 2000; Walter, 2003; McNamara &Rosenwax, 2007).

According to Lynn and Adamson (2003), there are four types of dying trajectories: 1) sudden death; 2) terminal illness, such as cancer, which is followed by a rapid decline; 3) organ failures reduce subsequent functioning, often stable; 4) prolonged dwindling in case of frailty and dementia.

First, dying well is aspirational and a good death represents an ideal type that may not be achievable in practice. Second, a good death requires labour to make the death good – either the professional labour involved in helping individuals to accept death or relieve pain, or the biographical labour undertaken by family and friends to place the death in the context of the individual's life. Third, creating a good death places obligations and responsibilities on all those involved in the dying process – professionals, friends and relatives and the dying person themselves – who are positioned differently in respect of good or bad deaths. Finally, with the growing importance of rhetoric about individual autonomy and choice, responsibility shifts from the social collective to the individual who is dying, who must make decisions about how they want to die. As McNamara notes, "dying people are expected to live well until they die and make their own choices in this process"(2004,p.936).

Regarding the prevalence of choice in end-of-life care, Borgstrom (2014), in her doctoral thesis, showed how choice is resonated in the English end-of-life care policies. Her argument direct towards the understanding that the patients are required to choose even the patient's choice is not to make choices that indicates a neo-liberal governmentality.

Uncovering ‘Patient autonomy’

While studying the hospice movement in Australia, McNamara et al. (2004) argued that there had been a remarkable shift within palliative care away from the earlier modern hospice movement. According to them, the original modern hospice movement revived the autonomy of patients amid a medicalized environment in which patients had no agency. Here, the transition from hospice to palliative care signified the earlier hospice movement as idealistic, while later it focused on the nature of treatment rather than on holistic care as suggested by the philosophy of ‘total pain’. Hospice care was thought to connote “custodial or less than optimal care” (Saunders, 1993, p.79, cited in McNamara et al., 2004).

Moreover, according to McNamara et al., both the earlier modern hospice movement and recent palliative care encapsulate the notion of ‘patient autonomy’. However, there is a tension between the earlier notion of autonomy in the hospice context and the idea of patient autonomy in recent palliative care contexts. In the hospice context, patient autonomy is practiced within the confines of communal tradition, meaning that their choices and wishes are to be exercised with the involvement of the family members. The idea of autonomy became complicated when debate over euthanasia emerged in high-income settings. Although euthanasia is not a central concern in my research, it needs to be explored to understand the nuances of patient autonomy in recent palliative care settings.

The tension between earlier and later notions of autonomy has become more complex as the ‘postmodern condition’ makes choices more fragmented (Giddens, 1991; Bauman, 1992). A crucial element of the postmodern condition is the uncertainty realized in the individual patient’s decision. The uncertainty poses a threat to the hospice ideology of providing psychological, spiritual and emotional support besides medical treatment in order to ensure a good death. In the new transition the focus is more on a ‘good enough death’ rather than on a good death.

> The palliative care philosophy gives credence to the multiplicity of beliefs and communication patterns evident in the collective of dying patients and this is seen in the articulation of a good enough ethic…Medical responses to symptom management appear, in this context, to offer a routinized and more certain response to the uncertainty of dying than the psychological, social, and spiritual counselling needed to help facilitate a good death. (McNamara et al., 2004, p.936).

While patient autonomy has been at the centre of these tensions, Lawton's (2000) arguments draw attention to the complexities of western identities that are dormant in the idea of patient autonomy. According to her, there has been a labelling of the 'bounded' body and the 'unbounded body' in existing hospice and palliative care. The 'bounded body' refers to the healthy body, where disease has not caused disfigurement; whereas the 'unbounded body' means the opposite. Henceforth, the unbounded body – which could not reach to the level of personhood – needed to be sequestrated.

Palliative care institutions started focusing more on the relief of physical pain, which created a tension between the bounded body and the unbounded body. Lawton labelled the sequestration of death as a 'rhetoric of individuality' which reflects, she thinks, the fact that the western philosophical idea of 'personhood' is a 'disembodied conception of the person' (Lawton, 2000, p.82).

Lawton also emphasized that the sociological and anthropological human subject reflects a 'disembodied view' of the self. Later theorists focused on aspects of the body, but it was considered more as a text or a sign, not as the body's material and experiential unit. She referred the works of sociologists (Giddens ,1991) Bourdieu (1977) and others work to explore how the body is not separate from the influence of a cultural milieu. According to them, the western body has become "a project which should be worked at and accomplished as part of an individual's self-identity" (Shilling cited in Lawton 2000:83).

The body as a thing that can be owned or fashioned, by oneself, is a theme that is central in the literature on embodiment. Lawton argued that this notion was 'problematic' as the idea of the body is taken for granted and the body is always seen as a healthy and properly functioning entity.

> The diseased body and flesh; the body that places physical and material constraints upon the self, has received considerably less attention. Indeed, even where the body in illness is allegedly given centre stage, as in much of the literature within medical anthropology and medical sociology, it is not the body as a material and experiential entity which is the focus but, rather the emphasis has tended to remain on the social and cultural consequences of affliction. (Lawton, 2000, p.84)

Lawton's attention is upon the relationship between the deteriorating body and its impact upon selfhood and the way that, in the final days of their lives, hospice patients redefine their selfhood.

The person with a disability is inclined to severely curtail their involvements in the world. One of the terminal patients in palliative care interviewed by Lawton asserted that the patient think himself as a waste of space and another one as burden. Patients' use of these metaphors in the context of their deteriorating condition does not only suggest a loss of self, it also indicates the interdependency of body and mind. The body is disturbed, and it seizes the patient's awareness of mind. There is a connection between a person's declining subjectivity and them describing themselves as a 'burden' on their family.

The patient becomes an object, which denotes a shift in space and time. First, the patient thinks of themselves as an object, then there is an objectivation process in the day-care home and in the hospices. "A patient's bodily deterioration does not simply affect him or her in isolation, it may also impact upon the bodies and selves of the people involved with his or her immediate bodily care." (Lawton, 2000, p.105).

The paradox of 'compassion'

Walter (2017) proposed that it is necessary to deal with the problems of 'autonomy' and of the 'idea of self' in order to deal with death and dying. Before death, the patient becomes vulnerable and carers need to show mutual understanding in order to provide care for the patient. He mentioned the 'relational ethic of care', according to which emotional care is more important than any other form of treatment. He also hints at the de-humanizing effects of care institutions in western society. Western palliative care has seen the institutionalization of the ethic of a good death, which controls and engulfs people's wishes and desires.

Walter suggested developing 'porous institutions', where a compassionate and mutual understanding will prevail. According to him, porous institutions can make way for social involvement in delivering care to terminally ill patients. Recently, a rhetoric of 'compassion' in end-of-life care has been discussed. Compassion is not merely a sense of pity; rather, it is an active engagement with the person in suffering so that the sufferer feels comfort. He argued that the Kerala model of the compassionate community has become successful due to the lack of structural barriers in Indian society in terms of the existence of mutual trust among people. Although there is a sense of privacy and individualism in every society, Indian society and

Bangladeshi society do not have the heightened form of a private self, as is found in western countries (Zaman et al., 2018).

> Public and professional behaviour in Western countries is shaped by strict legal and regulatory codes. These promote the thinking that dying requires professionals because they will know how to conform to regulatory health and safety requirements…The highly institutionalized and professionalised health systems in Western countries function as closed systems with very limited scope for lay participation and engagement. (Zaman et al., 2018, p.142).

They argued that although 'compassion' is energising a movement in end-of-life care, it is hard to imagine the development of a free flow of compassion in western countries due to the existence of their institutional and structural barriers.

Care ethics and end-of-life care

The above discussions reveal that the notions of good death are not just limited to individual autonomy. There is scope to go beyond the limited interpretation of good death, both conceptually and realistically. In the following, for a conceptual scope, the care ethics literature is discussed and for a 'realistic' scope, compassionate community in end-of-life care is discussed. Both help to understand 'good death' beyond the framework of individual autonomy that is dominant in most western high-income countries.

Autonomy is critically and extensively discussed in feminist ethics of care literatures, an approach also widely known as care ethics. It is briefly discussed here in three parts to highlight its relevance to the present study. First, a brief description of care ethics is given. Second, why, and how care ethics is significant in end-of-life care is discussed. Last, I consider how several aspects of care ethics such as relationality, interdependency, and networks of care can broaden the notions of good death.

First, the feminist ethics-of-care approach provides a significant critique of the moral framework of independence and autonomy as considered in policies and practice. According to this approach, recent healthcare policies overlook the inter-relatedness of human beings and the broader social context because of their preoccupation with individual autonomy and independence. Yet care is a fundamental concern for all people. It includes the need for care in infancy, adulthood, and at the end of life before death. Care ethicists argue that such need for care challenges the portrayal of the human as an autonomous, independent being in daily lives (Tronto, 1993). Despite there being numerous dimensions of care ethics, a special focus has been on autonomy. Relationality and interdependence are discussed in contrast to autonomy in care ethics, these aspects are significant in the present study.

As the present study's focus is on the final days of people's life, several works have been mentioned that explored care ethics and end-of-life care. Liz Lloyd (2011,2004,2000) used the care ethics approach to understand the complications of the ageing and dying populations in the UK. Lloyd noted that there lacks a language for those who are dependent on others at the end of life, which is acute at final days in old age. Question was raised to understand the point of emancipation implicated in individual autonomy and independence in the face of death. Tension between the concept of dependence and autonomy was revealed in the study. Only those who have financial capabilities, only they can exercise choice and control. Others cannot. There's more focus on physical needs and individualism. Dependency remains overlooked. Rather, it is also negatively portrayed in social lives. Care ethics can go into deeper by looking at dependency and vulnerabilities at the core of human lives. It can bring new moral epistemology (Lloyd, 2004).

In another study, it is argued that the emphasis in contemporary social and political life on autonomy and independence has led to a highly impoverished view of how wellbeing can be promoted even through the dying process (Kellehear 1999; Lloyd 2000). There is a need to expand vision of what a good death would be, going beyond the assertion of rights and control. Whilst death might be regarded as a supremely individual experience, evidence suggests that, not only the dying individual should be prioritized, but also the involvement of family members and close people are also highly involved in their relative's end-of-life. With care ethics approach, it is possible to think about good death keeping autonomy at a distance (Lloyd, 2011).

In a different study, same author criticised 'personalisation agenda' in older people's care in England. Personalisation agenda means having the potential to create the conditions needed to tailor services to individual needs, and to give service users greater choice and control, including, where possible, control over their own service budgets or direct possession and management of care funds. The problem is, there are different stages in older age in which they are not in a position to make rational decisions. They seek service in a time of crisis in their lives.

Organizational arrangements are not designed accordingly where their vulnerabilities are considered. As personalisation doesn't work like it works for able-bodied, healthy well-being person, it faces complexities when it comes to terminal patients, this is how it is related to my research. The person cannot decide on their own (Lloyd, 2011).

The authors broadly looked at how dependency is not addressed in everyday lives and policies. Therefore, the author calls for consideration of care ethics in end-of-life care. However, present study looks at how palliative care or end-of-life patients in Bangladesh are dependent upon their family members and neighbourhoods at their final days. By looking at this, the present study looks at how such dependencies helps understand good death differently in Bangladesh.

Relationality, interdependence, and networks of care are significant aspect in care ethics. Relational ontology is an essential characteristic of care ethics. It allows for a wider understanding of how relationships are embedded in a social setting. They are not only individuals but also rooted in families, groups, institutions, and nations. In care ethics, relationality captures significant features of people's relationships focusing on reciprocity, dependency, connectedness, and asymmetry. Despite these features are present in all types of relationships, are overlooked or its implications are obstructed in daily lives (Pettersen, 2011). Relational ontology is a characteristic feature of the ethics of care. It depicts an individual not mainly in terms of independence, of control and power, and exercising choices. Rather, it considers individuals as mutually interconnected with others, vulnerable and dependent, often in asymmetric ways.

Interdependence is at the core of relationality. Care ethicists calls for an extension of relationality beyond the private and intimate relationships. For example, they also portray- nations as relational and mutually dependent, rather than sovereign and self-sufficient (Tronto, 1993). In relation to the present study, instead of the patients on their own at the end of life, attention is upon the relational network or networks of care, such as involvement of families, relatives, and neighbourhood in end-of-life care in Bangladesh.

According to care ethics, network of care is known as the sets of relationships within which relationships care givers and care receivers are embedded. Here, care consists between individuals or relational subjects existing within networks of ties and reciprocal connections. These relationships are rooted in dependencies and asymmetries between the care givers and care receivers (Barnes, 2015). In relation to the present study, such networks are the families of a dying patients and to an extent, neighbourhood community. In contrast to western notions of ‘good death, there are examples of how a community network take in caring the dying. Such an example is the concept of ‘compassionate community’. This can broaden ‘good death’.

Similarly, these aspects are also relevant in the concept of ‘compassionate community’. Compassionate community is widely regarded as care for one another at times of crisis and loss is not a task solely for health and social services, but rather is ‘everyone's responsibility’ (Kellehear, 2005). There are now examples throughout the world of community-oriented end of life care in this vein. It is widely argued that perhaps the most refined version of the model is The Neighbourhood Networks in Palliative Care (NNPC) in Kerala, India. For this refined version, it is also widely known as Kerala model. Rather than the individual patient, community involvement is at the heart of this model. Both care ethics and compassionate community are critical of the centrality of autonomy in good death in many western countries. Therefore, relationality, interdependence and networks of care is briefly explained in relation to compassionate community, to understand how it can broaden the understandings of good death.

Conclusion

From the above discussion, the question arises as to whether the autonomy of the patient has complicated the ethics of the palliative care notion of a good death; or whether notions of a good deathare a controlling ideology that dictates palliative care services. In this chapter, I have focused on how the western notions of ‘autonomy’ and ‘self’ have shaped ideas of what constitutes a good death. Western notions of a good death are implicit in today’s understanding of palliative care around the world. The global ranking in the 2015 Quality of Death Index compiled by The Economist Intelligence Unit implicitly suggests that every nation should catch up with the goals and targets set by the ranking. The notions of a good death are rooted in palliative care, which is mostly found in western hospice and palliative care settings. To understand the differences in the understanding of a good death, I explore death and end-of-life care arrangements in non-western contexts in Chapter three. As limited literature from the non-western contexts exists, I describe a brief overview in that chapter.

Chapter Three- Death and dying in non-western world and overview of Bangladesh

In the previous chapter, I explored the historical journey of hospices along with their cultural codes in a western society. By cultural codes, I mean how the cultural values of a western setting are reflected in the ideals of a good death in a hospice, care home or palliative care centre. I also highlighted the complexities of end-of-lifecare services since their inception in the 1960s. I explained why and how recent hospices have diverged from their earlier endeavour– moving from multidisciplinary teamwork (Clark, 2016) and the ethos of 'holistic care', towards the imposition of 'creeping medicalization', routinization and bureaucratization (James & Field, 1992), and 'professionalization' (Kellehear, 2005, 2007). From the late1990s to the present, there is a vast array of literature that argues around the revisioning of 'care' in end-of-lifecare services in western settings. There has been a call for community action to care for the dying outside the professional settings of hospices, care homes or palliative care centres. Despite the discussion on the revisioning of end-of-lifecare in high-income settings, the idea of community faces challenges in those settings (Tapp et al., 2019).

There are two dominant models of end-of-lifecare services around the world. One is the 'service delivery' model, which developed in the UK and later spread to western European countries, the US, Australia and many other high-income countries. The other is the 'community-based' model, which is led by the community rather than by healthcare professionals. One of the best examples is the Kerala model, also known as the Neighbourhood Network in Palliative Care (NNPC) model. A recent study argued that the Kerala model can inspire a pluralistic way of arranging end-of-life care (Zaman et al., 2017). The Kerala model, according to them, not only opens a dialogue on death between different cultures, but also delivers an innovative prescription for managing care for the dying in a resource-limited setting. Regarding end-of-life care services and the discussion of death and dying, there are two important aspects: cultural beliefs about death and dying, and society's arrangements for the care of the dying. As explained earlier, in many western countries institutions such as hospices or care homes developed to manage care for the dying, while this did not happen in low- and middle-income countries: hospice-like institutions are almost absent in these settings.

I now turn to focus on the cultural artefacts of death and dying, and the social arrangements of care for the dying in non-western countries. Before elaborating on the practices of the NNPC or compassionate community model in India, and practices in sub-Saharan Africa, I describe the death rituals and values of various non-western societies. As there is very little academic work on the management of dying in non-western societies, I focus on discussion of the cultural understanding of a good death in these societies. The discussion involves anthropological and sociological accounts of 'deathways' in these societies. Deathways, according to Seeman (2011), refers to the following of certain rituals to manage the dead body in a certain culture.

There is another reason to portray the death and dying rituals of low- and middle-income societies. As the aim of the research is to explore how Bangladeshi people conceive of a good death, there follow some indications of cultural beliefs and practices in Bangladeshi society. In relation to the research aims, I describe how death is understood among non-western communities, including those that are in a western setting. I then describe the concept of compassionate community within palliative care, followed by a discussion of the Kerala model in India and aspects of a good death in a few non-western contexts. I conclude the chapter by focusing on a brief overview of Bangladesh and the recent situation of palliative care in the country.

Death and dying beliefs of diverse ethnicity: experiences from multi-ethnic and multicultural societies

Seeman (2011) argued that five hundred years ago people had an interest in how other people bury their dead. Today, we have no similar curiosity regarding this. Earlier, it was common for strangers to know about each other's death ways: it was a way of knowing about others' way of life. Through the death ways people could understand another society's understanding of the afterlife, the relations between parents and children and the social structure, in terms of understanding how they said goodbye to their dying chiefs. In fact, in earlier times people used to understand other cultures by knowing about their deathways.

Historians, beginning with Herodotus, presented the death ways of other cultures as if they were universal (showing inclusivity): the Babylonians embalmed their dead with honey; the

Issedonians chopped up the dead body, mixed it with other meats and made a special grill. Herodotus was non-judgemental. This curiosity was not only fuelled by unfamiliarity but also by wanting to understand the common intention behind the rituals and the motivations behind burials, funeral processions and memorial feasts (which tend to be universal). Death was a unique category for understanding cross-cultural encounters in the new world. Death served as a common ground that allowed individuals to reach across cultural boundaries and understand unfamiliar peoples.

There are many trends in death-related academic work around the world. Among them, two are prominent: one consists of social scientific works on death and dying by anthropologists, sociologists, social historians and religious scholars and dates to the early twentieth century; the other consists of works inspired by hospice founders, palliative care practitioners, psychologists and medical sociologists since the 1960s. There are now interdisciplinary trends in understanding death, dying and bereavement, which explore the social understanding of death and dying along with the medical practitioner’s management of the care for the dying.

However, there is very little academic research on non-western settings: most research is done in the western world. One reason is that most of the work is not written in English and some cultures still have oral traditions. Another important reason is related to colonialism. Colonialism displaced people, and cultural practices were lost or challenged. The reason behind the difference in the amount of research in different societies is not my research query, although the scarcity of death-related academic work motivated me to explore different ethnicities’ death beliefs and rituals in the context of a multi-ethnic and multicultural society. This is the reason for my focus here on communities of Africans, Southeast Asians and South Asians in western, high-income societies: the US, Canada and the UK. Three notable studies are highlighted: the first was carried out in the US and Canada and explored the death customs of different ethnicities in those societies (Irish et al., [Eds], 1993). The second is about elderly South Asians’ perceptions of ageing, sickness, and death in the UK, which differs from their home country in terms of the cultural understanding and perception of dying well. This study explored their understanding of ageing, and the breakdown of traditional values due to migration (Gardner, 2002). The third study is a sociological exploration of dying and care among migrants in contemporary UK cities. It gives accounts of two decades of the ageing and dying of some of the UK's cohort of post-war migrants, as well as of more recent arrivals.

Death rituals of African Americans in the US

Hosea L. Perry explored how African American people die and mourn in the US. Because death in an African American context has been neglected in formal academic studies, Perry devoted himself to investigating literature, newspaper articles, novels and plays, and interviewed the attendants at many funerals.

Perry argued that, unlike many cultures, death among Blacks is regarded as a celebration of life. Because life is a journey and the dying person has completed their journey through struggles and achievement, after their death the present community members celebrate the joyous moment. According to the African American tradition, white culture's death rituals are more formal and not celebratory like theirs. However, it is also evident that there is no singular pattern of mourning in any culture.

Regarding African Americans' death rituals, some accounts explored the idea that their current rituals are a representation of a blend of African and European customs. Perry explained that during the time of slavery, in the early 1800s and afterwards, the importance of funerals among the slaves was remarkable. There were also some revolts around funerals at that time, due to which slaveholders put restrictions on public funerals, such as not holding funerals in daylight and restricting the number of attendants to no more than 12. At that time, funerals took place at night; this was a cultural continuity with traditions in Africa that allowed the participation of friends from neighbouring farms and plantations without interference with their working hours. They buried the dead as soon as possible to protect them from animals and external threats because their houses had no glass windows and their shutters needed to be left open most of the time. Their burial processions to and from the cemetery were full of chanting, singing and shouting at the grave, and they used to throw dirt into the grave. Practices of grave decoration using broken earthenware and broken pottery were visible, the broken pottery reflecting the West African belief that death resembles to a vulnerable body and to compensate the spirit. According to Genovese, community building was the primary function of all these African American rituals.

Death rituals in Africa

Lee and Vaughan (2008) explored a historical analysis of African ways of death and dying since the early nineteenth century. Lee argued that although there isa large amount of anthropological literature on African ways of dying, no significant research has been done on the impact of colonial administration, urbanization and new technologies of death and dying in African societies. She argued that due to these impacts upon African society, there had been significant changes and re-inventions in African death rituals. Although these new rituals are modern, they are rooted in ancient history.

To the west, African death rituals of mourning are regarded as complex. The mourning rituals mean that the living and the dead constitute the social world in terms of perceiving the dead. Earlier anthropological writing portrayed that death provoked fear in Africa and was a problem for the living. So, there was no shortcut to mourning. The mourning rituals were arranged not by the individual closest to the dead alone, but by the social groups of which they were members. Lee elucidated from Van Gennep's work. She argued that Van Gennep's 'rites of passage' is a structuralist view of death rituals in Africa. According to Lee, views such as Van Gennep's are also a 'colonial anthropological account' which do not reveal the variations in the shifting practice of rituals in Africa. Such views also tended to depict the social meaning of death as an unproblematic process. Lee cites the example of Audrey Richard's differentiation in North Rhodesia, between a Bemba community chief's carefully orchestrated death ritual and a Bemba woman's shameful burial at a crossroads at a distance from the village. The woman had died during childbirth. There were moral concerns in the community over a good death and a bad death. Death rituals were performed according to a moral judgement in that context. Lee stated: "While a good death offered the possibility of reincarnation and a welcome influence on the world of the living, a bad death brought only the spectre of malevolent ancestral spirits." (Lee, 2008, p.345).

However, moral concerns around death rituals signified a metaphor of common African tradition during colonial rule and the decline of traditional authority within African polities. Due to colonial regulations, burials were forced to become more 'civilized' and 'sanitized'. Despite these interventions, earlier moral concerns concerning death rituals persisted.

Some changes have been observed since the postcolonial period; for example, in Cameroon, funerals were seen as new forms of belonging for some autochthonous groups, and anti-retroviral drugs have transformed situation of AIDS patients from one of being ‘near-death’ into one of ‘prolonged life’ (Geschiere, 2005). In Nigeria, heroic narratives of death are portrayed.

Lee and Vaughn assert that it is yet to be tested whether there is a correlation between demographic change and attitudes to death and dying. However, the globalized economy and telecommunication have changed the nature of the funeral rites industry; commodification has been observed in rituals.

Although some consider that commercialization has emptied the spiritual element from African death rituals, Lee and Vaughn rejected this view. According to them, global capitalism is not the only reason behind the commercialization of death rituals. Rather, death rituals have been a form of sociality, belief and exchange in African society since ancient times, andthe incorporation of new technologies and communication has increased the tendency for spiritual engagement with the dead. Lee and Vaughn concluded:

> Evidently, then, the forces of globalization and technological change have helped fashion alternative cultural landscapes within which Africans could re-invent their relations to death and the dying process. That these dynamics could be simultaneously ‘modern’ and deeply ‘historical’ attests to Africans’ extensive and multifaceted engagement with death over the course of the last two centuries. The challenge remains for historians of Africa to explore the development of this complex, and compelling, relationship. (2008, p.359)

Bangladeshi migrants in the UK

Thus far, I have elaborated the death and dying rituals of non-western inhabitants in a developed country, followed by a portrayal of the transition of death and dying rituals in an African context in an age of global communication. However, I have not yet explored notions of death and dying among Bangladeshi people, whether living in Bangladesh or living as migrants in a foreign country.

Although there is a scarcity of literature, there is one work that contributes to knowledge both of Bangladeshi notions of a good death and of dying rituals. Gardner’s account of Bengali elders living in London is a remarkable contribution to the understanding of death and dying among a migrant population. However, it does not provide a detailed picture of the aim and scope of my research. Nevertheless, Gardner’s account provides a picture of cultural conflict between the

Bangladeshi elderly patients' and families' expectations around a good death and the institutional arrangements of a hospice in London.

In the context of institutional care for the dying in St Michael's Hospice, Gardner argues that there seems to be conflict and compromise between the family members of the dying patients and the hospice management. According to the Bangladeshi Muslim community, all those closest to the dying patient need to be by their bedside. This cultural trait and expectation create issues of management for the hospice, as much space is taken up. Sometimes, family members bring home-cooked food for the dying patients to feed their dearest one a favourite meal before dying, which creates concerns over health and safety for the hospice authority.

Language and communication with the dying patients is another contested issue in the hospice. Whenever the nurses or doctors want to ask about a private issue regarding treatment with the patients, they first have to talk to a family member who can understand English. Here, issues of individual choice and rights come up against the issue of communication. Moreover, there is a conflict between hospice ideology and the communal family structure surrounding the patients. Whenever there is a female dying patient who does not understand English, the nurses have to ask permission for treatment or any intervention from the husband or other family members. Together the family members decide and inform the authority, meaning that the female patient cannot exercise her own choice in these matters. Thus, there is a conflict between the UK hospice philosophy of individual autonomy and communal decision making in a Bangladeshi family context.

There is a common belief among some Muslim Bangladeshi migrants in London that more pain felt during death means less pain will be experienced after death. Therefore, many patients and their family members under-report the chronic pain patients experience before death. This is counter to the hospice philosophy of relieving pain before death.

Compassionate communities in end-of-life care

The concept of compassionate community is inspired by the principles of the 1986 Ottawa Charter for Health Promotion which is applied in end-of-life care by community involvement.

Community can be understood as referring to a dying person's social network (Walter, 2017). Kellehear's critique of the palliative care agenda is one of the primary inspirations for the concept. In terms of community involvement in palliative care strategies, the philosophy of health-promoting palliative care which underlines the view that healthcare should be participatory meaning it has to be done with the participation of everyone involved in it (Kellehear, 2005). Rather than institutions dominating over the strength of social networks, the influence could flow the other way around (Kellehear, 2005). At the end of life, care is no longer just limited to elderly patients, and as its expansion has now gone beyond cancer patients there has been a reorientation regarding medical interventions in this provision. Nevertheless, the tension between the institutional meaning and the emergence of new diseases gives priority to community skills in palliative care training and education, rather than clinical interventions. The care of terminal patients is seen, not as a task for health and social services, but as the responsibility of everyone in the family and neighbourhood (Kellehear, 2013). Althoughin the west palliative care championed the use of multidisciplinary professionals to provide holistic care, questions arise regarding the emergence of various professional services. Are individuals able to shape these ideologies of a good death, or are these ideologies being reinforced by the interests and conduct of various influential social institutions of medicine, law, the funeral industry and mechanisms of psychosocial support?

Although the concept of compassionate community is not applied directly in many settings, there are examples of community models which are regarded as large-scale models in end-of-life care. One of the best examples is the Kerala model. The Kerala model started its journey in the 1990s. It is also known as the Neighbourhood Network in Palliative Care (NNPC). It facilitates sustainable and community-driven services to patients who are in need of palliative care. The philosophy of the model is different compared with the care provided in acute illness. Social support is prioritized rather than just the delivery of acute care. The view is that chronic and incurable illnesses are social problems with medical aspects (Kumar and Numpleli, 2005). The Kerala model is a community-owned venture to deliver care to people at the end of life. Palliative care is provided through a community effort to those patients who are in need but have limited resources. This model viewsthe presence of incurable diseases as a social problem, not just as a medical failure. (Kumar & Palmed, 2007; Abel et al., 2011;Vijay & Kulkarni, 2012). The main components of the model are community mobilization and ownership by the community, the involvement of local self-government institutions and the incorporation of palliative care in the primary healthcare system (Kumar, 2013). The model is inspired by the idea of primary healthcare outlined by the WHO in the *Declaration of Alma Ata* (1978). This asserted that primary health care is:

> essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. (Alma Ata, 1978)

In 2010, the model operated in 14 districts in Kerala with a network of 230 clinics. It had a large network of 60 full-time doctors, 150 staff nurses, 200 auxiliary nurses and over 10,000 trained volunteers. Each unit had around 400 patients, and the network of professionals coordinated 2500 patients each week (Sallnow et al., 2010). Besides nursing and physcial care, the network provides free medication, psychological and spiritual care, and provides basic training to the family members. A unique feature of the model is the way it is run. The central premise is the idea of community ownership and the network raises funds from the local community. The majority of contributions come from small donations of a few rupees (Indian currency) from people in the community. The network puts collection boxes in shops, bus stations and schools (Sallnow et al., 2010). The government of Kerala declared palliative care as being part of primary healthcare in 2008. The Kerala model addressed the problems of the incurably ill, bedridden and dying patients, irrespective of their diagnosis, and it quickly attracted the attention of palliative care centres around the world. The model was discussed for its implications for other low- and middle-income countries. Although only 3 per cent of India’s population lives in Kerala, it provides two-thirds of India’s palliative care services. The Kerala model works in the community and takes place outside of any institution such as a hospice or palliative care centre.

There are some features observed in the Kerala model which challenge ideas in palliative care as understood in many high-income settings. As the quality and coverage of healthcare is poor in low- and-middle income countries, the Kerala model network includes patients from all walks of society (mostly people from low-income backgrounds). Therefore, services have been extended to cover patients with various illnesses such as non-malignant diseases (for example, lung diseases). This is linked to the issue of extending the boundaries of palliative care. As the network is funded by the community and includes volunteers from the community, many are cared for who would not qualify for traditional palliative care services. Patients with renal impairment, those with mental illnesses and paraplegic conditions are also included. The model broadened the nature of diseases treated. The volunteer's contribution was acknowledged in regard to social, psychological and spiritual care, along with the needs assessment in the community. Rather than a professional involvement, the volunteer roles highlighted the importance of the involvement of people from the community in order to reach more people in need of care.

The Kerala model is regarded as the best example of how a community model of palliative care works. It shows how palliative care can be delivered differently from the traditional palliative care model, which is based on the western idea of hospices. In the following sections, I describe some different contexts to highlight other understandings of how palliative care can be delivered. A systematic review of end-of-life care in sub-Saharan Africa found that despite the development of various models of palliative care over the last 30 years, due to a lack of resources and infrastructure end-of-life care remains difficult in the African continent (Gysels et al. 2011). The review also showed, importantly, that care is provided at home by informal caregivers, including women, elders and children.

A multi-method study in seven sites in South Africa explored an integrated community-based home care model and found that there was a relationship between dying at home and what was considered to be a good death. The study also concluded that home-based care was a suitable way for low-income countries to improve the experience of dying (Uys, 2003).

Another systematic review found that the new public health approach in community-led end-of-life care practices influenced three aspects: making a practical difference, personal growth and developing community capacity. Sallnow et al. asserted that it is impossible to view end-of-life care issues as being separate from other social issues facing communities, such as poverty, education and inequity in a resource-poor setting (Sallnow et al. 2015). In that systematic review, they prioritized on the role of social networks in fostering wellbeing at the end of life, and found that relationships must be mutual and active rather than passive. These findings have important implications for how social care interventions are structured at the end of life. Peer support networks are a sustainable and appropriate care model, and this study provides evidence of their utility and sheds light on the fundamental components of compassionate care.

In another systematic review on palliative care in South Asia, Singh and Harding (2015) argued that despite there being a huge demand for palliative care in South Asian countries, there were no articles that originated from Afghanistan, the Maldives, Bhutan and Bangladesh until 2015. The majority of relevant studies were done in India. Even within India, most studies were carried out in the south, mainly in Kerala. Singh and Harding asserted that the Kerala model of community palliative care is an ideal model for resource-scarce settings in other South Asian countries.

In the following sections, I give a brief background on Bangladesh.

Bangladesh: Background

Bangladesh emerged as an independent state from Pakistan in 1971 through a war of independence. Even though the country had been plagued by poverty, natural disasters, and foreign debt dependence, after 50 years, Bangladesh is one of the fastest growing economies in the world; the country registered a GDP growth rate of 7.2 % after the pandemic in the fiscal year 2021-22 (Economist Intelligence Unit Country report, 2023).There has been significant improvement in the human development index (HDI, a statistical composite index of life expectancy, education, and per capita income indicators used to measure a country's development by the United Nations Development Programme), in literacy, life expectancy and per capita food consumption. Almost 15 million people have moved out of poverty since the 1990s, and the economy has been growing at 6% annually for many years (World Bank, 2023). The poverty rate fell from 80% in 1971 to 44.2% in 1991 to 12.9% in 2021 (Centre for Research and Information (CRI), 2021). The World Bank notes the economic progress of the country by stating that:

> "When the newly independent country of Bangladesh was born on December 16, 1971, it was the second poorest country in the world—making the country's transformation over the next 50 years one of the great development stories. Since then, poverty has been cut in half at record speed. Enrolment in primary school is now nearly universal. Hundreds of thousands of women have entered the workforce. Steady progress has been made on

> maternal and child health. And the country is better buttressed against the destructive forces posed by climate change and natural disasters" (World Bank, 2021)

Bangladesh’s economic transformation is fueled by three mechanisms: the export-oriented ready-made garment (RMG) industry; significant investments in infrastructure and penetration of microfinance institutions (MFIs); and NGOs working in the country. The RMG industry has lead to a rapid transformation of the economy from agriculture-based to industry-oriented; infrastructural development has helped to connect the formerly fragmented economy; and MFIs and NGOs have significantly helped rural communities (Mahmud et al., 2017). Additionally, remittances from the large Bangladeshi diaspora are also a vital source of foreign exchange reserves (CRI, 2021) and agriculture is self-sufficient in ensuring food production that is supported by government subsidies (Khatun, 2020). Bangladesh is now focusing on formulating various plans and policies to become a middle-income country.

Although there is remarkable progress in improving overall income in the country, social-economic disparities persist, as wealth and power are highly concentrated and the poorer and more disadvantaged segments of the population reap few of the benefits of development, yet relevant public policies to redress the situation are rarely implemented (Rashid et al., 2019). Multiple layers of poverty continue to exist in both urban and rural areas (UNHR, 2023). Challenges remain as Bangladesh’s development has largely been driven by one export sector, the ready-made garment industry, which is highly dependent on workers’ low wages. Overall, therefore, economic progress remains uneven. According to the Population and Housing census 2022 report, almost 2 million people are living in slums (Population and Housing census report, 2022).

These urban poor continue to lag behind in various social indicators including healthcare rights. Foremost in this backwardness is access to healthcare for this population. A 2016 research study analysed health inequality in Bangladesh, and found that income variance is the prime factor behind health disparities (Jahangir et al., 2016). Private health providers contributed to 95% of the health gap, while public providers contributed the least. The study also concluded that healthcare benefit utilisation is pro-rich, and "the poorest people with largest need for health actually received lower benefits" (Jahangir et al., 2016). The Gini Index data available for

Bangladesh from 1982-2016 shows that income inequality has only burgeoned every year, and that Bangladesh is stuck with ever-increasing health disparities.

Although Bangladesh has made progress in primary health care, it still lags behind in secondary and tertiary sectors, which are essential to rise to a middle-income country. There is still a great need to improve access to healthcare for marginalised populations through health equity. Molla and Chi (2017) concluded that about 63% of healthcare costs in Bangladesh are out-of-pocket, which are increasing by the year, the rest being paid by the government. This places an unequal burden on low-income individuals (Molla and Chi, 2017).

Historical background

Before exploring the influence of religious beliefs on social life in Bangladesh, some historical signposts should be explained. Although most people in Bangladesh are Muslim, people of other religions have also historically resided there. It is worth mentioning the background to the formation of national culture after the independence of Bangladesh in 1971. Notwithstanding the historical lineage of Hinduism and Buddhism over the centuries before the advent of the Mughal dynasty in the fifteenth century, two events in the twentieth century shaped Bengali Muslim identity in general (Islam, 1992). During the 1940s, among the people of East Bengal (the name of present-day Bangladesh during the colonial period before 1947) Muslim identity was prioritized, and Bengali identity came second (Hussain, 1997; Islam, 1992). After the independence of India and Pakistan East Bengal became part of Pakistan, based on the majority population's Islamic identity (Schendel, 2009). Complexities intensified as the new ruling elite of East Bengal were unlike either the Kolkata-centric Hindu middle class or the Urdu language-speaking elites of West Pakistan. The emergence of new Bengali Muslim sensibilities held firm during the language movement of 1952, which was against the imposition of the Urdu language (spoken in West Pakistan) as the state language (Umar, 1979). Despite the Bengali language being the majority spoken language in East Bengal, the ruling elites of West Pakistan imposed Urdu against the will of the people of the region. The language movement shaped Bengali nationalism in the following decades and Bangladesh as a separate state emerged in 1971 (Umar, 1979; Schendel, 2009; Hussain, 1997; Islam, 1992). This time Bengali identity came first, and Muslim identity second. After 1971 a nationalistic culture began to develop, based on the

Bengali language and rural folk traditions, influenced by the local religious beliefs of Islam, Hinduism and Buddhism (Murshid, 2018). There is a syncretic tradition of different religions and local beliefs in Bangladesh, reflected in almost every sphere of social life (Schendel, 2009). As the majority population are Muslim, the dominant religious festivals are those of Muslims. In fact, people from all religions participate in these festivals and celebrate together. Every religion practices its own rituals to observe rites of passage such as birth, marriage, and death.

Cultural expectations and views about death in Bangladesh

It is complex to generalise the cultural views about death in Bangladesh as there are people from different religious beliefs, race, and ethnic minority groups. Despite the complexities, general expectations about death are present. Family and religion are at the heart of the cultural views about death in Bangladesh.

Family life

Family plays a central role in Bangladeshi people's lives. It has multiple functions in people's lives in Bangladesh, compared with the role of the family in western countries. Although the numbers of extended families have recently begun to decrease, still a substantial proportion of such families exist in both rural and urban areas of Bangladesh (Zaman, 2003). When the children become adult, they play a vital role in taking care of their parents. The family plays a vital role in both social and economic activities. Individuals consult with their parents and other members in the family before taking any decisions in terms of marriage, education, career and healthcare related affairs (Banglapedia, 2021). However, recently the scenario has begun to change due to rapid population growth, the development efforts of the government and NGOs, and the influence of modern values and development of information technology. With increased rural-to-urban migration, there are a growing number of slums in urban areas. Along with the emergence of development projects, there is also rising unemployment and poverty in Bangladesh (Samad, 2015).

People expect to be surrounded by their family members and close relatives before death in Bangladesh. Parents at the deathbed assume that they will be taken care of by their children during the final days of their lives. They believe that they tried their best to provide everything important for their children when they were young and able. The expectation of receiving care grows out of that belief when they become older or diseased or in deathbed (Amin, 2017).

Joint families or intergenerational families are very common in Bangladesh. Those who migrated to cities for living, try to bring their parents in the cities to take care of them. Parents also expect that from their children. However, such families are not very common today due to rapid urbanization and huge rural to urban migration in the last fifty years (Samad, 2015).

There are certain beliefs that are important when parents get older or are at the end of their life. Parents evaluate their whole life based on those beliefs. Most of these beliefs are borne of family values, such as a traditional belief that people expect to live surrounded by children and grandchildren, and to be loved and respected by them. Children's success is an indicator that they have done their duties well. Family and intergenerational care plays an important role in Bangladeshi older adults' lives. It is an expectation that children will provide care for the older parents at old age. Bangladeshi older adults co-residing with children, being financially, physically and emotionally dependent on them and receiving their care is viewed as normal and appropriate. Therefore, family care is a key component of successful ageing in Bangladesh. It creates great pride and joy for older parents that they are respected, loved, and cared for by children. Intergenerational families are quite common, where three generations live in the same household bonded by love, affection and respect. Older parents take immense pride when they are cared for by their children and their needs are met (Amin, 2017).

The discussion of 'good death' comes naturally at someone's end of life in the family. Such discussions are not related with palliative care. Rather, those are mostly associated with the dying person's family life, whether they are being cared by the family members or not. According to the popular belief in Bangladesh, such a manner of end of life is the result of good actions in life. Notable conditions for a good death, are to die in a good physical condition (i.e., prior to becoming invalid or bedridden), and the successful career achievements of one's children.

How deeply the family is involved during any sickness of their relatives had been explored in an ethnography of a hospital in Bangladesh (Zaman, 2005). Family members and close relatives are conceptualised as ‘silent saviours’ by the researcher. Here, the role of family members is as equally important as the role of the healthcare providers in the hospital. Family members do all sorts of work such as helping with feeding and washing, negotiating with hospital staff, assisting with administering medication, and importantly, providing emotional support in the hospital (Zaman, 2003; Zaman, 2013).

Religious beliefs about death

Religious values are deeply connected with the central role of family members at the end-of-life in Bangladesh. Both family values and religious beliefs are significant in the lives of Bangladeshi people. There are four main religions in Bangladesh: Islam, Hindu, Buddhism, and Christianity. Although many religions, castes and ethnic groups exist, Bangladesh is a Muslim dominated country. Almost 91.04 per cent of the population are Muslim (Census, 2022). Perceptions of death and dying are inspired by the beliefs and values of the major religions in Bangladesh.

According to Muslim belief, after death the *ruh* (Soul/spirit) of the dead will be questioned in the grave, resurrection will take place on the day of final judgement, and based on their actions in the world, they will achieve an eternal place in either *jannat* (heaven) or *jahannam* (hell). Hindu beliefs that are inspired from Indo-Aryan literature of Veda (1000–600 B.C.); *atma* (or soul) is a separate entity than the body; a good *atma* would stay in *sharga* (heaven) and a bad one in *naraka* (hell) for eternity. Old Indian literature *Upanishada* (700 B.C.) discussed reincarnation. Sinners will be reborn as animals or will reborn as humans (Sankrityayan, 1986; cited in Joarder et al, 2014). There is a fusion of Muslim and Hindu beliefs in Bangladesh about what happens after death. In keeping with both of these religions the respondents expressed their belief in the duality of body and soul; and also could demonstrate a clear understanding of what happens afterwards (Joarder et al., 2014).

There are conceptualizations about good death and bad death based on the duality of body and soul, explored in a study on the meaning of death amongst the elderly in a Bangladeshi village (Joarder et al., 2014). When asked to describe a “bad” death, the most commonly reported causes were hanging, poisoning, homicide, and accidents. These, among others, were classified as *opoghat* (Accidental death), and were considered especially bad ways to die because they were not among the kinds of deaths determined by God. Rather, according to half of the respondents, such deaths were the result of one's bad actions. While all participants expressed a belief in some manner of afterlife, responses can be classified into two categories: the permanent separation of soul from body, or the reincarnation of the soul. Both classifications were related to ideas about goodness in life. If one lived a bad life, his soul would be re-born, either in another human being or in some kind of animal. Despite differences in faith and practice, respondents expressed similar explanations of the soul, of death, and of the afterlife. The researchers also found a Muslim respondent expressing faith on reincarnation, which is predominantly a Hindu idea.

The elements of notions of good death and bad death had been described by Madan (1992) in terms of place (*desh* or *sthana*), time (*kala*) and physical state of the deceased (*patra*) at the time of death. As per Madan's paper, home has been recognized by the Indian Pundits as the best place to die; and Bangladesh sharing much of Indian belief system, are also in agreement with Madan's ones (Joarder et al., 2014). Home does not represent merely a dwelling, but rather the microcosm of the universe; where home stands on a sanctified ground (a practice common both in Hindus and the Muslims), and where householders pursue their legitimate worldly goals of self-fulfillment. A second important element was described by Madan as the appropriate time of death; e.g. astrologically appropriate time (for Hindus), or certain prayer times (for Muslims). The third element of good death is the personal condition of the deceased. Good death is ascribed upon the dead person based on whether the last moments were conscious, easy, and peaceful; whether the person spent their life with religious devotions; and importantly whether the person legitimately fulfilled worldly goals of righteous actions, such as marrying off the children, and distributing the property. The last determinant of good death eventually leads to the secular nature of the concerns surrounding death.

Death has been called the 'Great Equalizer' by many, and this may well hold true in the context of Bangladesh's elderly. Males and females alike face more similar challenges in old age— they (for the most part) relinquish responsibility to their children; likewise, they give up their assets. Furthermore, in a culture that explains the nature of death in terms of the goodness of a person, there is less room for gender distinction. This widespread attitude may also be well understood with respect to the old adage: Irrespective of how much is acquired in life, everyone will only be left with "*share' tin hat mati*" (three-and-a-half arm lengths of land; commonly used to mean a grave). Thus, men and women alike were explaining death in similar ways from similar vantage points during old age (Joarder et al., 2014).

Health services in Bangladesh

The health system in Bangladesh is primarily focused on providing curative services targeting maternal and child health and the health of newborns. Since the 1990s, with the development of modern science and technology and with the greater role of United Nations (UN) agencies and NGOs, the health system has gradually shifted its emphasis equally onto health promotion and preventative services and has also expanded its reach. Yet many people in Bangladesh, particularly in rural areas, remain with little access to healthcare facilities. Although Bangladesh has already achieved remarkable progress in the health, socioeconomic disparities still exist that is visible amongst the people of lower income in the country (Rashid et al., 2019).

Nevertheless, Bangladesh has a well-structured health system with three tiers of primary healthcare: Upazila Health Complexes (UHC) at the subdistrict level; Union Health and Family Welfare Centres (UHFWC) at the union level (a collection of a few villages); and Community Clinics (CC) at the village level. These are backed up by the district hospitals providing secondary level care and the tertiary hospitals of various kinds in large urban centres (Islam and Biswas, 2014). From a purely structural point of view, the health system is based on sound principles, covering the entire spectrum of services and care – from health education and promotion to treatment, care and rehabilitation. Moreover, the system is decentralized, covering all districts, subdistricts and rural towns and villages in Bangladesh. The government, thereby, seeks to create conditions so that the people of Bangladesh can reach and maintain the highest attainable level of health. But the government-funded health service delivery is obstructed by insufficient supply of equipment, pharmaceuticals, medical supplies and, most importantly, the behaviour of health workers. A household survey in 2011 found that patients were unhappy with the behaviour of health workers in government hospitals (Cockroft et al., 2011). Because of this, people are turning towards private practitioners and unqualified practitioners, who are also known as ‘village doctors’ or ‘quacks’. Moreover, the apathy of medical personnel who provide the services and their lack of adequate training and experience also disrupts services (Mohiuddin, 2020). Some personnel problems arise from the reluctance of government doctors to be posted in rural areas where facilities such as schools and housing are scarce and also where the potential for private practice is limited. Almost all qualified doctors in government services, especially in Dhaka and the major cities, establish their own private practices that they attend after the office hours of their governmental job. Thus, the tendency is to frequently refer patients seeking governmental health services to these private clinics, where they receive better attention but at a much higher cost than in government facilities. Therefore, as health services are costly in private clinics, they are only accessible to rich people. The exact number of private hospitals and clinics is not known, but these clinics are situated in big cities such as Dhaka, Chittagong and Sylhet (Rashid et al., 2019).

Bangladesh has a good infrastructure for delivering primary healthcare services (Mahmood, 2012). However, due to inadequate logistics the full potential of this infrastructure has never been realized. One survey noted concerns raised about the quality of healthcare services in both privately owned hospitals and public hospitals. Here, findings led to loss of faith in both types of hospitals in the country, low utilization of public health facilities and a large number of Bangladeshi patients visits hospitals of neighbouring countries for their treatment (Andaleeb et al., 2007). A decade later, another study explored health inequality in Bangladesh and found that inequity exists in private hospitals. The study argued that healthcare benefit utilisation is pro-rich, and "the poorest people with largest need for health actually received lower benefits". Private sector care should be more equitable, the study concluded (Khan et al., 2017).

Because of the inability of government services to meet all the health needs of the population, hundreds of NGOs attempt to fill the gap. A study explored how NGOs contributed in several sectors where government couldn’t deliver adequate services; healthcare is one such sector where NGOs contributed (Chowdhury et al., 2020). The NGOs are mainly involved in the provision of primary healthcare in both urban and rural areas. During the first decade of Bangladesh’s existence, the health-related work of NGOs contributed greatly to the formation of a national healthcare delivery system. NGOs helped with the rehabilitation of war-affected people, the training of health personnel as well as the development of new options for rural healthcare. Presently a number of large international NGOs, large national NGOs and hundreds of smaller local NGOs are playing a complementary and supplementary role in Bangladesh’s healthcare delivery system. Due to their flexible, result-oriented management style, NGOs are able to experiment with innovative ways of dealing with the health problems of Bangladesh (Zaman, 2003).

Apart from these biomedical health services, there is also a vast non-biomedical healthcare system operating in the country that includes traditional Ayurvedic *kabirajis*, Yunani hakims, homeopathic practitioners, practitioners of ‘folk’ medicine and faith healers. There is one government-run institute of indigenous medicine, where Yunani and Ayurvedic practitioners are trained.

Chapter Four-Methodology

In this chapter, I describe my methodological approach, data collection tools, the study population and sites as well as the data analysis process. I also describe the process of ethical approval and the challenges I experienced, along with the methodological difficulties I had to face due to the Covid-19 pandemic. I conclude the chapter by reflecting on the reflexivity of my role as a researcher at the field sites.

Methodological approach

My research is inspired by qualitative research principles. Qualitative research aims to discover and describe in detail what a particular group of people do in their daily lives and what the meaning of their actions is. Summarizing the features of qualitative research, Corbin and Strauss (2015) stated that the aims of qualitative research are to: explore the inner experience of participants; explore how meanings are formed and transformed; explore areas that are, as yet, not thoroughly researched; discover relevant variables that later can be tested through quantitative forms of research; and, take a holistic and comprehensive approach to the study of phenomena.

As palliative care has not been extensively researched in Bangladesh and is also a recent phenomenon, I chose to conduct the research using a qualitative approach. In contrast to quantitative research, in which the research questions define categories and variables as precisely as possible, so as to explain how many and what kinds of people share a definite characteristic, qualitative research focuses on the "qualities of things more than their quantity" (Bazeley, 2013, p.3). Qualitative research attends to how the world is understood (Mason, 1996) in people's behaviours and interactions (Strauss & Corbin, 1990). How qualitative data can generate new meanings in a local context can be understood by the following quote from Miles and Huberman (1994), cited by Bazeley (2013):

> They are a source of well-grounded, rich descriptions and explanation of processes in identifiable local contexts. With qualitative data one can preserve chronological flow, see precisely which events led to which consequences, and derive fruitful explanations. Then, too, good qualitative data are more likely to lead to serendipitous

> findings and to new integrations; they help researchers to get beyond initial conceptions and to generate or revise conceptual frameworks. (Miles and Huberman in Bazeley, 2013, p.4)

With the similar motivation of fruitful explanation, I chose to conduct qualitative research to understand how healthcare providers, dying patients and their family caregivers take part in palliative care in a palliative care centre in Bangladesh – how they construct meaning around a good death and how they provide care in the final days of the patients.

Moreover, the qualitative approach is notable in the field of death and in palliative care. There are several groundbreaking pieces of research within the field of palliative care which were done using qualitative research tools. For example, Glaser and Strauss's theorization of 'awareness contexts', characterized as 'closed', 'suspicion', 'mutual pretence' and 'open', in two American hospitals (Glaser & Strauss, 1967); Sudnow's overwhelming analysis of medicalized death in North American general hospitals, which manifested how physicians' absorption with their technical prowess hints at an attempt to overcome the reality and vulnerability of death (Sudnow, 1967); Field's (1989) work on the nursing care of dying patients; James's (1989) exploration of emotional labour in hospices; and Hockey's (1990) anthropological perspective on care in the nursing home and the hospice. David Clark formulated four categories of research in the field of palliative care. These are: health needs assessment; policy formulation, planning and implementation; service evaluation and clinical audit; and, most importantly, sociological, cultural, historical and ethical issues (Clark, 1997).

In the case of my research, I focus on sociological, cultural, historical and ethical issues and their significance for palliative care in the context of Bangladesh. Narrowing it down, I focus on the understanding of a good death in palliative care settings in Bangladesh. I have provided the rationale for conducting the research on a good death in Bangladesh in the literature review section of the thesis. Despite the consideration of cultural differences in the values, beliefs and practices surrounding dying, there has been very little research conducted in low- and middle-income countries.

In order to explore the notion of a good death in a Bangladeshi context I found ethnography, a key qualitative research method, to be the most appropriate approach, as it is powerful in investigating the unwritten but prevalent rules that govern settings (Smith, 2007). The core idea of ethnography is to describe the daily lives of a group of people in a setting, focusing on their routine activities, in order to comprehend the thoughts and behaviours of the group (Brewer, 2000). An ethnographic study can portray not only how complex activities are routinized, but also the implicit skills, decision-making rules and complexities, as well as the discretion utilized in routine work (Smith, 2007).

As I intend to understand the participation of stakeholders (healthcare providers, patients and families) in the setting of a palliative care centre, my prime focus was to portray the daily lives and activities in the centre.

According to Leung, ethnography takes place in natural settings and is characterized by getting to know the culture of the group being studied and gaining a degree of experienceof their way of life before explaining their attitudes or behaviour (Leung, 2002). Savage focused on the time considerations in ethnographic fieldwork; this involves long-term fieldwork for gathering a thick description of participants and the settings, which is possible through the presence of the researcher and their exposure to the participants in the setting (Savage, 2000). According to LeCompte and Schensul, there are seven defining characteristics of ethnography, whichare: 1) to be conducted in a natural setting; 2) intimate and face-to-face interaction with the participants; 3) portrayal of accurate reflection of participant perceptions and actions; 4) utilizing inductive, interactive and recursive data collection to develop local cultural theories; 5) using both qualitative and quantitative data; 6) sociopolitical and historical contextualization of the behaviourof the participants; and 7) concept of culture as a lens through which to interpret the results (LeCompte & Schensul, 2010, p. 12).

Apart from the cultural meanings ascribed to a community or a group, ethnographic research has been influential in healthcare and the medical arena for almost 60 years. Goodson and Vassar (2011) summarized Garro and Van der Geest’s ethnographic work in healthcare settings. Garro’s (1982) study showed how cultural factors tend to be a major influence on the delivery of healthcare in a society. Patients or the inhabitants of any group or community make decisions through a cultural lens that is reflected as a dynamic in the healthcare system. Van der Geest and Finkler (2004) argued how the ethnography of a hospital setting reflects the dominant cultural and belief system of a society.

Considering the rich history of ethnographic research in healthcare, I was motivated to choose it for my research. Additionally, ethnography is considered to be a significant approach in the study of palliative care. It has remarkably enriched understanding regarding the organization and quality of care, decision making at the end of life, the death and dying process, spirituality and religious practices around death (Reigada et al., 2019).

In the present research, data was collected through observation of daily activities, informal conversation, and in-depth interviews with the participants. I explain the rationale for the data collection techniques in the next section.

Data collection techniques

As part of the ethnographic research I conducted in-depth interviews and engaged in participant observation. However, for the first three months, I was not able to conduct face-to-face interviews or observation in the settings due to the university guidelines restricting in-person activity because of the pandemic. Once I received ethical approval again to resume face-to-face interviews and observation, I was finally able to complete my fieldwork. The following sections give details of the data collection tools used in the research.

In-depth interviews

I conducted in-depth, semi-structured interviews with my research participants during the fieldwork. Interviews lasted between 30 minutes and two hours. Almost one-third of the participants had to be interviewed by telephone due to the circumstances of the pandemic. (These aspects are explained more fully in a later section of this chapter.) All interviews were audio-recorded and subsequently transcribed in order to analyse the data. I provided each interviewee with a participant sheet and a consent form to read and sign before starting the interview, in accordance with my ethical approval. The Centre for Palliative Care (CPC) of Bangabandhu Sheikh Mujib Medical University (BSMMU) was the main site from which I recruited interviewees among healthcare professionals, dying patients and their family caregivers. The centre also has two community projects – one in Korail slum in Dhaka and one in Narayanganj, a district city close to Dhaka. Participants were also recruited from these two community projects as well. Whenever I refer to ‘the centre’, I mean the three settings together (the CPC and the two community projects in Korail and Narayanganj).

I began with the interviewing of healthcare professionals, in consideration of the ethical issues raised by Brighton and Sussex Medical School (BSMS) Research and Ethics Governance Committee (RGEC). The committee considered the interviewing of dying patients and their caregivers to be a somewhat risky and sensitive issue. Therefore, I explained to the committee that if I started the interviewing process with healthcare professionals, it would be my way of ‘stepping into the palliative care centre’. Through the initial interviews with the healthcare professionals, I became familiar not only with their ideas, practices, perceptions, feelings and challenges around palliative care practices, but also with institutional factors of palliative care management in the centre, such as how a dying patient gets admission in the centre, how family caregivers play an influential role, and the complications around those families who are not aware of palliative care procedures. Interviews with the healthcare providers helped me to design the interview guidelines for the patients and the caregivers. I took consideration of the vocabularies used by the healthcare professionals in my interview guidelines for the patients and caregivers.

I interviewed twelve healthcare professionals, eight patients and eight caregivers. (Details of my respondents are provided in the section on the study participants, later in this chapter.) The total number of interviews was twenty-eight, out of which nine were conducted over the telephone. Among the nine telephone interviews, only two were with patients and caregivers; the remainder of the interviews were with healthcare professionals. I did not feel comfortable about conducting telephone interviews with the patients and caregivers due to concerns about their mental wellbeing and the stresses they were experiencing. Before each interview, I had an informal chat with the interviewees, which aided me in various ways: this short discussion helped the participants to get along with me and benefitted me by helping me to decide how and when to bring up the topic of death during the interview; it also helped me to understand the patient’s and caregiver’s mental condition.

Interviews with the three groups of participants represented the views and perceptions of all the stakeholders in the palliative care centre. Participants were recruited from each of the three settings included in the research. This enabled the capture of ideas and reflections from diverse contexts. The contexts, settings and the actors will be described more fully in later sections of this chapter.

Ethnographic Observation

I choose ethnography not only for its methodological rigour and richness, but also the suitability of its method for palliative care research. Interdisciplinary healthcare teams such as palliative care teams function in a complex pattern of interactions amongst team members. Such multidisciplinary collaboration is a complex site of care provision, which is subject to an array of personal, cultural, and environmental influences. It differs from many other medical specialties in its broad focus of illness as a physical, social, spiritual and psychological phenomenon, that affects all members of the care team, and the resultant care is the sum of many processes and relationships between formal and informal caregivers (Pype et al., 2018).

There are several other aspects for which ethnography is suited for palliative care research. The context and nature of palliative care in a society, for example, institutional palliative care in western countries and community palliative care in lower-middle income countries. An ethnographic approach helps to explore the differences between societies in these settings. Utilization of technological advances in societies, changes in medical practices due to legislative changes (e.g. cannabinoids, palliative sedation) and social processes (e.g. death cafes, perceptions of palliative care) embody variations or diversities in palliative care provisions in different parts of the world. Ethnographic research allows exploration of these diversities and their influence upon individuals, relationships, and care provision; to make sense of what really is happening in the world of palliative care (Grant et al., 2022).

I choose ethnographic observation to supplement the qualitative data that was obtained through interviews in the present research. Ethnographic observation provides a well-thought-out approach to expound participants behaviours and experiences which has been used in dementia research. A recent article on dementia patients portrays the profound meanings communicated through behaviours and objects by those no longer able to speak, and whose deliberate actions observed by the researcher convey both intention and meaning (Chapman et al., 2019). There are many populations that are poorly represented in research and ethnography may enable a greater understanding of the experiences of the patients of palliative care in Bangladesh. The researcher is not interested in the organization (or the group) *per se* but rather in the behaviours which take place within it (Silverman, 2010).

In ethnography, there are four types of roles in participant observation, according to Singha (1993). These roles are: 1) complete participant; 2) participant as observer; 3) observer as participant and; 4) complete observer. During the fieldwork of the present research, I was neither a complete participant nor a complete observer. To be a participant as observer, the researcher must be a member of the group being studied, and the group must be aware of the research activity. I did not participate as a member of the group, neither did I take any role. Therefore, I took the role of observer as participant.

An observer who is not a member of the group but is interested in participating can conduct better observation and, hence, generate a more complete understanding of the group's activities; however, Merriam (1998) points out that even though the researcher may have access to different people from whom he/she may obtain information, the group members determine the level of information given.

Adler and Adler(1994) noted that although the researcher's membership of the group is minimal in the stance of observer as participant, it will assist the researcher if they observe and interact frequently with the group members in order to develop a relationship with them without participating as a member. The greater challenge, however, lies in understanding *what* to observe. Regarding this, Merriam (1998) noted that the question of what to observe during the fieldwork is dependent on the research questions. Therefore, I designed a topic guide for my observation in accordance with the research questions I formulated.

I took permission from authorizing professionals in the three settings every day before my observation. The patients, their caregivers and the healthcare providers were aware that I was observing care practices in the centre. I observed the patient's admission in the centre, the discussion of caregivers in the waiting room, the doctor's visits on the wards, the nurse's conversation with the patient, care practices in the community settings, weekly *uthaanboithok* ('backyard meetings'), home visits by the palliative care assistants (PCAs) and family meetings. Sometimes I visited the patient's home with the doctors and PCAs. During observation, I took field notes.

Observation of care practices was productive for collecting non-verbal data on the participants' experiences. Besides the in-depth interviews, data from the observation helped me to capture the activities in full spectrum. Observation was sometimes stressful for me. I became mentally upset several times, observing and listening to the conversations between the patients and the caregivers. I discuss my mental condition during the fieldwork in a later section on my positionality. Observation was also productive in terms of being able to cross check my findings from the in-depth interviews. I observed the real actions and practices of the participants during observation. Sometimes I became involved with the caregivers while they were talking to me about their patients and the care of the providers. However, I was not able to do the observation for a significant period of time, due to the university guidelines relating to the pandemic. I was able to undertake my observation from October to December 2020.

Ethical approval

Ethics regulations can severely complicate issues of gaining access to ethnographic field sites (Hammersley & Atkinson, 2007). As this research was to be undertaken in palliative care settings, there were several issues about which the BSMS ethics committee raised concerns, after I first applied for ethics approval in 2019 – broadly, these consisted of: firstly, my research related to death and dying; secondly, my participants were to be dying patients, their caregivers and their providers; thirdly, as I was doing the research on death, they raised the issue of my mental wellbeing during my fieldwork. From March 2020, Covid-19 became another significant issue of concern in my research. Therefore, ethical issues were a constant concern throughout my whole fieldwork due to research-related sensitivity and the fast-changing situation around Covid-19. These concerns are further explained in the following two sections. In the first section I explore the above-mentioned three ethical concerns; in the second section I explain the concerns relating to Covid-19.

Ethical concerns and sensitivity of the research

Despite its essentiality, lack of openness about death and dying makes it difficult to conduct research on the end of life (Kendall et al., 2007). Within social science research, death attracts special attention because of its unique status as a topic that affects everyone. Therefore, questions have been raised over whether it is possible to achieve a ‘critical distance’ when researching a setting or people related to death and dying (Woodthorpe, 2011). In the case of my research, I encountered many concerns from the ethics committee which were related to the difficulties around talking about death and dying with the participants. Surprisingly to me, it was not just the ethics committee who raised eyebrows or expressed concerns about my research: I also received disturbed responses from many of my friends and people I have met since I started my PhD. Whenever I told people about my research topic, they responded with a sad face or shrinking eyes and forehead, 'Oh! So sad! That must be intense for you, na?' or 'Wow! That's so exciting! How're you going to handle that?' Returning to the concerns of the ethics committee, these were focused on three main aspects: death as a topic, the nature of my research participants and my own wellbeing.

Death

Death is one of the very few universal features of life. The knowledge of mortality is the greatest fear of all; despite knowing it to be real, it defies the intellectual faculties of human beings (Bauman, 1992). Besides this reality, it has been recognized that death is a sensitive area of research to explore (Liamputtong, 2007). In addition, unlike other social issues that social scientists are attracted to – for example, gender and sexuality, crime and ethnicity – death is a phenomenon from which no one is exempt (Woodthorpe, 2011). Along with issues regarding the understanding of death in society there have also been concerns about the challenges of researching a good death. These challenges included: designing end-of-life studies, recruiting participants, ethical conduct, and the emotional challenges faced by participants, researchers and transcribers. Here I highlight the challenges regarding the ethical conduct of researching a good death, before describing the concerns raised by the ethics committee regarding my research. One of the key concerns was the awareness of the researcher regarding the knowledge possessed by a dying patient and their relatives about their prognosis. In death-related research, researchers are cautioned or warned not to ask direct questions regarding death and dying. Researchers think such caution reinforces the societal taboos of death and dying that consequently affect the level of confidence of a researcher approaching their work. In line with this, the next concern regards the nature of consent. Patients and their families, who are likely to be in a vulnerable state of health and of mental exhaustion, should be given the chance to reconsider their decision, and to be able to withdraw themselves from taking part in the research even though they had given primary consent (Kendall et al., 2007).

In the case of my research, the ethics committee suggested several times that I should change the statements on the participation information sheet (PIS) and the consent form. I made all the necessary changes in accordance with the committee's concerns. A few examples of the changes suggested by the committee follow.

Regarding the wording of the statements, the committee suggested the following in response to my first application in August 2019: "The Committee thought the project title's reference to a 'good death' is likely to be confronting for both terminally ill patients and their families/carers and requested a softening of the wording, particularly for the participant facing documents." The suggestion applied to the application form, the PIS and the consent form. In replying to my second application form, in October 2019, the committee again suggested concerns related to the softening of the language around a 'good death'. Here is a glimpse of the committee's requested change:

> The Committee had previously expressed concerns related to a softening of the language around a 'good death' in the project title and across the proposal as a whole…Sensitivity toward the participant group and these issues should therefore be demonstrated in the procedures (for e.g. recruitment of participants, discussion of the Participant Information Sheet and Consent Form – should time be given to reflect on these before consent etc. is received to participate?).

Later, I again changed the descriptions in the documents according to their suggestions. Finally, I received ethical approval on 25 February 2020. I have included all versions of the ethical application forms in the appendix section of the thesis.

Continuing the ethical concerns around talking about death, I highlight the challenges of considering the vulnerabilities of patients and their families in palliative care or end-of-life care research in the following section.

Vulnerability and sensibilities of the research

Over the past 30 years a significant amount of literature has been produced regarding the ethics of conducting research on palliative care patients and their families. In the 2000s researchers mostly argued that the dying patients were physically and emotionally vulnerable. Therefore, a rigorous form of gatekeeping was suggested in terms of which types of patient could take part in interviews or other methods of research. The concern was that even a small amount of conversation with patients could result in severe physical exhaustion. There were also concerns regarding comatose patients as they would not be able to take part in interviews. Even more alarming is the patient’s fragile emotional state at a time when they are preoccupied with so many sensitive issues in their life, including the anxieties of settling affairs, handling the knowledge of their terminal prognosis and the emotional distress of dealing with close family members (de Raeve, 1994; Randall& Downie, 1996).

There has been concern raised over whether special ethical consideration is needed for conducting research on palliative care patients. Although researchers have argued that the patients are vulnerable and there are difficulties in obtaining consent forms from them and their families, the challenges are not unique to palliative care research. These challenges are also evident in the fields of geriatrics, Alzheimer’s, dementia, psychiatry and intensive care unit (ICU) patients. Some researchers have suggested adherence to the guidelines of other research areas rather than encouraging special guidelines (Casarett & Karlawish, 2000; Addington-Hall, 2002). A systematic review explored the views of patients and their families regarding their participation in palliative care research. Despite the challenges, patients and families were interested in participating in research, in order to give something back to society and as a way of maintaining their autonomy (White & Hardy, 2010).

During the ethical committee’s evaluation of my application, I had to consider these issues. I completed my PIS and consent forms with consideration of the issues and challenges I mentioned above. Therefore, I made the selection of patients carefully. After several stages of the ethics committee’s scrutiny, I identified the inclusion/exclusion criteria for selecting patients. I excluded patients who could not communicate due to their health condition, because the committee had raised concerns about their emotional and physical vulnerability.

During my fieldwork, I found that many participants among patients and family caregivers did not have issues with talking about their thoughts on dying, care and responsibilities. Instead, it was a difficult task for the providers when they had to talk about the prognosis to the families and patients. I have described the difficulties the healthcare providers experienced in Chapter five and Chapter six.

I encountered fewer difficulties with talking to the patients and family caregivers in the Korail and Narayanganj settings, than I did with the patients and family caregivers in the wards at the

CPC. While I was talking to a male patient being cared for by his son's family in their house in Korail, the whole family sat together with me in their little living room. It was not a gloomy discussion at all. We all talked about the patient's wishes and expectations during the conversation. The patient even requested his PCA to attend his funeral after his death. He requested this of her out of his affection for her, which grew day by day since she had been taking care of him for the last few months. This scenario hints not just at the fact of their interest in participating in the research: I explore this situation from a different perspective, to understand the collective effort of ensuring a patient's end-of-life care in Bangladesh, which I discuss in the findings.

Recognizing the vulnerabilities of dying patients and the emotional state of their caregivers, I sought assistance from providers to facilitate introductions. Given my prior interactions with some providers during permission-seeking from the CPC as a local gatekeeper, initiating contact with them was seamless. Providers I knew extended introductions to their colleagues during ethnographic observations.

As my familiarity grew, providers introduced me to patients and caregivers early in my observation period. This rendered me a recognizable figure in the settings, making it easier for me to approach participants. Soon, I became a familiar presence, with patients and caregivers initiating conversations with me at various times. During my observational sessions, family caregivers even requested small favors, such as calling nurses or doctors. While I refrained from going beyond these minor favors due to concerns regarding cultural sensitivities and ethical considerations, I aimed to strike a balance between involvement and neutrality.

A notable incident during an interview with Azad's mother highlighted the complexities of maintaining ethical boundaries. She, a breast cancer patient, expressed a desire to show me the affected areas of her body, emphasizing the unpleasant odor. In navigating this request, I grappled with ethical considerations on two fronts. Firstly, as this involved a sensitive body part, cultural appropriateness within the family setting was a concern. Secondly, the potential perception of over-friendliness and the associated risks of bias or loss of objectivity as cautioned by the literature weighed on my decision.

Post-incident, my unease stemmed from the realization that ethical approvals often focus on procedural elements, overlooking the nuanced challenges encountered in the field (Robinson, 2020). This vulnerability resonated with Borgstrom and Ellis's (2021) discussion on vulnerability during caregiving, emphasizing the impact of reflexivity on the researcher's dual positionality.

Apart from these challenges stemming from the sensitivity of the research, another critical aspect involved how I built rapport with the participants and how I approached conversations about death and dying with participants, particularly patients and their family caregivers. The intricacies of navigating such discussions are discussed below, considering the sensitivity of the topic and the participants involved.

Rapport building with the participants

Building relationships with patients and staff is at the core of ethnographic fieldwork in healthcare settings (Wind, 2008). Rapport is instrumental in encouraging participants to share insights into their culture (Spradley, 1979). This, in turn, aids the researcher in navigating people and situations to gather data aligned with the research objectives. Essentially, rapport serves to bridge distances, alleviate anxiety, and establish trust with participants in traditional ethnographic research (Glesne, 1989). In my research, similar to other ethnographic endeavors, the rapport played a pivotal role.

Given the sensitive nature of my research, developing rapport was crucial during the fieldwork. I employed diverse approaches tailored to each participant group, beginning with healthcare providers, followed by family caregivers, and concluding with patients. As I was previously engaged in a project with CPC, many providers, including doctors, nurses, and PCAs, were familiar to me. However, a handful of individuals, newly joined to the organization, were unknown. Upon arriving in Bangladesh from the UK for fieldwork, I promptly initiated contact and held meetings regarding the upcoming interviews. Fortunately, most were already aware of my ongoing research, obviating the need for additional time dedicated to rapport building with the providers. However, there were concerns considering the participation of family caregivers and patients. Establishing rapport in challenging circumstances of interacting with terminally ill patients and their caregivers presented sensitivities. To address this, I devised a specific strategy to navigate these sensitivities.

Firstly, I conducted ethnographic observations within the center to familiarize myself with the participants in the CPC. Subsequently, I prioritized interviewing healthcare providers, seeking insights into how they foster strong relationships with patients and family caregivers. They advised me two such insights: the importance of attentive listening and the choice of words during conversations in a subtle manner. Providers cautioned against directly using the term 'death' and suggested alternative and more considerate expressions, supposedly in indirect ways. With the providers suggestions, I commenced my ethnographic observations, utilizing this time to build rapport with patients and family caregivers. Secondly, I spent time in the wards of the centre and visited the homes of several patients. Participants were informed about my research fieldwork, quickly recognizing me as a familiar presence. Following this familiarity, I initiated interviews with family caregivers, sometimes conducting separate sessions and, on occasion, involving them alongside their patients/relatives. Additionally, during breaks, I engaged in conversations with both family caregivers and patients, further strengthening the bonds formed during the observation period. Finally, I conducted interviews with the patients. Prior to these interviews, each time a provider introduced me to the patient and their family caregivers. If I was already acquainted with the patient and family caregiver, I promptly started the interview. If they were unfamiliar to me, I engaged in a brief conversation with both the patients and their family caregivers to foster rapport before initiating the interview. However, despite the rapport building strategies, it was always a bit difficult during the conversation. In the following, I explain briefly how I talked about death with the participants.

Conversation about death and dying

Throughout the conversations, I followed to the suggestions provided by the healthcare providers. I consciously avoided directly using the word ‘death’ or ‘good death’ during the discussions. Although I had a questionnaire for the patients, I chose not to strictly stick to it. Instead, I followed the topic guide during the conversations, tailoring the questions based on the unique circumstances of each patient.

For patients experiencing severe pain and distress, as well as those who were unaware of their terminal condition, I refrained from explicitly mentioning ‘death’ or ‘good death’. In these cases, I delicately alluded to the topic without using direct language. However, for patients who were well-informed about their terminal illness and were relatively more comfortable in terms of pain, I did introduce the terms ‘death’ and ‘good death’ into the conversation. This nuanced approach allowed me to navigate the sensitivity of the subject matter based on the specific conditions and awareness levels of the patients.

My wellbeing

I had not given serious thought to my wellbeing as a researcher until I attended an ethics committee meeting on 7 November 2019. I was requested to attend the meeting with my supervisor. After rigorous scrutiny about my methodology and related ethical concerns, the committee asked me what the plans regarding my wellbeing during the fieldwork were. There was a section about the researcher’s wellbeing in the application about which they were questioning me. I naively replied to them that “I think I will be ok. I can manage my wellbeing on my own.”. Looking at their faces, I could understand that they were not quite satisfied with my reply. Based on the discussions in the meeting, it was suggested that I state a clear plan regarding my wellbeing during the fieldwork.

Researchers’ wellbeing is a significant matter of concern in academia. It is a more important concern when the researcher is conducting research on sensitive topics. In my case, as I was doing research on death, my psychological and emotional wellbeing was a matter for consideration. The emotional challenges facing researchers working on death have been explored, although not significantly, in research. However, it has been suggested that such challenges also exist in other research areas, such as long-term disabilities, domestic violence or child abuse. As death is going to happen to everyone, it is not perceived as being particularly emotionally disturbing for researchers. It has also been found that researchers sometimes re-evaluate their lives after conducting research on death. Therefore, researchers should be able to access adequate psychological support (Kendall et al., 2007).

In the case of my research, the committee suggested that sound psychological support should be in place for my emotional wellbeing during my fieldwork. I met the ethics committee members on 7 November 2019, and I realized the importance of such support within a couple of hours of the meeting. I was returning to my house after the meeting by bus. It is a 40-minute bus ride from the university to my house. I was listening to one of my favourite tracks – *Carry You Home* by James Blunt. While I was listening to it on YouTube, I scrolled down to read people's comments about the song. There were a long list of comments from lots of people who shared their feelings of nostalgia about the song as it reminded them of their dearest person who had died recently, or even a long time ago. I didn't realize at first, but I began crying listening to that song and reading those touching comments. When I came back to my senses, I realized the importance and relevance of the psychological support the committee had mentioned a few hours earlier that day.

Maintaining anonymity

While the pursuit of anonymity is a common objective in research-ethics review policies, it proves to be almost practically unattainable aim in ethnographic and qualitative research. Survey research, with larger sample sizes, facilitates a more straightforward achievement of anonymity compared to ethnographic research, that involves considerably fewer research participants. (Hoonaard, 2003). Anthropologists have grappled with the challenges of anonymization and confidentiality, leading to a variety of creative solutions and strategies proposed by different authors to navigate these complex questions and dilemmas. For example, in the 1970s, anthropologist Van der Geest (2003) carried out research in the rural town of Kwahu-Tafo in southern Ghana, focusing on social ambiguities in extended families, sexual relationships, and birth control. As he became more embedded in the community, his participants were in risks because of the sensitivity of the research. Van der Geest promised to ensure anonymity. However, he also became known in the region. After that, he decided to anonymize his name in the research.

In the context of this research, maintaining anonymity and confidentiality posed a challenge due to the unique circumstance of CPC being the sole center specializing in palliative care, coupled with the limited number of participants. Despite these challenges, I maintained the anonymity and confidentiality of the participants. Prior to starting the fieldwork, participants were presented with a Participant Information Sheet (PIS) and consent form. It was clear in the document that I am committed not to use real names in the thesis or any subsequent publications arising from it. All participants willingly provided their consent to this condition. Consequently, pseudonyms were employed for providers, patients, and family caregivers to ensure their identities remained confidential. However, recognizing the distinctive status of individuals like Dr. Azam (Pseudonym), the founder chairman of CPC, whose identity is easily discernible, presented a unique challenge in anonymization. To address this complexity, proactive steps were taken to engage in discussions with Dr. Azam and other providers to tackle the issues.

After the discussion, all the physicians agreed that if their identity is revealed there will be no complications from their end. They commented that since palliative care in Bangladesh is still in its infancy, this research will give some exposure to their work. By doing this, an additional benefit can be obtained in informing about palliative care through various means. That is how I addressed this issue about anonymity and confidentiality in the study.

In the next section, I state how I anticipated coping with any distressing situation during the fieldwork. I planned that I would consult with the director of the CPC if I felt bad after encountering something sensitive in the field sites. I also highlight the family support I would have during my stay in Bangladesh.

Covid-19 and the impact on my field trip

The first step of my fieldwork was to receive approval from the BSMS ethics committee to start the fieldwork. I have explained earlier the significance of the need for ethical approval for my research. In this section, the challenges I faced in getting ethical approval due to Covid-19 are described.

According to my initial research plan, I planned to interview dying patients, their carers, and health professionals, and to carry out observation in a palliative care centre in Bangladesh. After several months of revisions suggested by the ethics committee, I finally received the approval letter on 4 March 2020. However, I could not savour the joy of getting the approval for even one week as the coronavirus situation was worsening around the world, including the UK, EU countries, and the US. The total number of Covid-19 cases was 87 in the UK on 4 March. However, the situation did not seem too serious at that time. International flights were not yet postponed, so I planned and arranged my trip to Bangladesh so that I could soon start my fieldwork, with an intended timeline of fieldwork from April to October. I was all set for my trip. By mid-March, all kinds of fieldwork were suspended in almost all universities of the UK, including the University of Sussex and the University of Brighton. Covid-19 cases were increasing at an unprecedented rate and infections began to emerge in Bangladesh too. Just a week earlier, I had been all set for my fieldwork, but by late March I found myself in an uncertain situation regarding what would happen to my fieldwork. Consequently, I decided that it was best at such a crucial time to return to my family in Bangladesh.Covid-19 affected my fieldwork method significantly, which I describe in the following section.

New strategy responding to Covid-19

Covid-19 not only disrupted my field trip but also had an impact on my initial method of data collection. Primarily, I had planned for face-to-face interviews and observation of the palliative care clinic, which was approved by the ethics committee on 4 March 2020. Later, fieldwork of such types was suspended by the university due to 'social distancing' guidelines and a general 'stay at home' strategy being implemented around the world. These strategies were used to minimize coronavirus transmission. Both of my main methods of data collection became impossible due to these strategies. In addition, the end-of-life care situation in Bangladesh and around the world became one of the most talked-about issues due to the pandemic.

At this time, I had to pause my work. After I arrived in Bangladesh for repatriation and to stay with my family through the pandemic, I was in self-quarantine for 14 days as per the official instruction of the government of Bangladesh. I started to think about what was to be done about my fieldwork. I was also reflecting on Covid-19 and end-of-lifecare around the world, and engaged with the many articles appearing at that time, such as: 'How Covid-19 challenges our notions of a good death' (Borgstrom, E., 2020)**;'Five things coronavirus can teach us about life and death';** and 'Coronavirus is showing us how we've failed to manage the logistics of death', and many others. Beside reflecting on the pandemic situation, I started to outline the topic guide I planned to use for the interviews.

I was also cautiously following the BSMS guidelines as well as the guidelines of the University of Brighton and the University of Sussex regarding the fieldwork. The BSMS RGEC sent an email to all researchers on 20 March 2020 regarding updated instructions for ongoing research projects and fieldwork activities. The committee provided guidelines for students and researchers who had previously received ethical approval from the RGEC for research projects that involved face-to-face interactions with research participants (such as one-to-one interviews or focus groups**):** all face-to-face research activities with participants were suspended.

The committee then suggested that researchers should change their methods of data collection and submit an amended application to the RGEC. The committee would then grant expedited approval for amendments that met the following criterion: amendments to projects where the sole change would be to halt in-person research interactions and to now conduct these interactions online (e.g. using Skype, online questionnaires or other university-approved online systems). Following these instructions, I applied for the changes and another ethical approval. Then I started my fieldwork with video/audio interviews. After a few months, when the situation began to return to normal, I had to apply again so that I could start my observation and in-person interviews. There were many disruptions which I had to overcome in order to finish my fieldwork. In the following sections I describe my initial data collection methods: observation and in-depth interviews.

Additionally, I described a detail about Covid-19 in Chapter Eight. Chapter eight describes how the onset of Covid-19 affected notions around death and dying in Bangladesh and how palliative care services were affected. In Chapter eight, where I reflect on the impact of Covid-19, I argue that Covid-19 was an experience that left a mark on Bangladesh and illustrate how notions of a good death were affected by it. It reflects on a good death during the pandemic. The notions of what constitutes a good death were jeopardized in the context of Covid-19. In Bangladesh, family members were unable to perform religious rituals after the death of their relatives. Patients died without care from their beloved family members in the final moments of their lives. Funeral practices were sometimes observed by a group of volunteers who were not the relatives or family members of the dead person. Not only Bangladesh, but also countries with the best arrangements for a good death faced severe challenges: for example, the involvement of family members with their dying relatives in the final moments was threatened, families had to bid a final goodbye to their close relatives via an online video call, providers were deprived of giving the ‘magic touch’ to their patients before death to ensure their comfort. Not only death, but also everything we had assumed to be immune to uncertainties and vulnerabilities was under threat.

Field sites

I carried out my fieldwork in three settings located in Narayanganj and Dhaka (the capital of Bangladesh). The three settings are: the Centre for Palliative Care (CPC), Compassionate Korail and Compassionate Narayanganj. The CPC is the governing centre for the two community settings.

The CPC is the designated department of palliative care at Bangabandhu Sheikh Mujib Medical University (BSMMU). BSMMU, which is the only medical university in the country, recognized palliative care as one of its key objectives and began to provide some key services in 2007. The CPC was formally established in 2011, which was a remarkable breakthrough among the few palliative care initiatives in Bangladesh. In 2011, 15 inpatient beds were created in the centre. Now (2022), there are a total of 23 beds: 9 male, 9 female and 5 child beds are available. The centre is situated in Block E of the university. It is designated to the fourth and fifth floor of a six-storey building. This is the only government-initiated palliative care programme in the country. Before the establishment of the centre in 2011, palliative care was a branch of the anaesthetic department of the BSMMU. There was an outpatient centre, which was used for patient consultations, but there were no admissions. The CPC was established within 4 years with the overall infrastructural support of the university and the pioneering effort of Professor Nasir. The CPC launched its palliative care with 15 inpatient beds for admission, which increased to 23 beds in 2020. Besides the centre's infrastructural development, the BSMMU also introduced an MD in Palliative Medicine (postgraduate course) in 2016. Each year several doctors join this course in order to pursue their degree in palliative medicine. Despite several initiatives from the BSMMU, physicians' knowledge of palliative care is not of a high standard according to a recent study. The study concluded that despite having average or above knowledge about palliative care, the physicians' prevailing misconceptions act as a barrier to recognizing the need among the target populations (Biswas et al., 2021). Despite there being a few other palliative care initiatives besides the CPC, most of these are concentrated in Dhaka city. Although there are several palliative care initiatives in Dhaka, most people are unaware regarding when a patient needs to be taken care of in a palliative care centre or why palliative care is important at a crucial point of a patient's dying trajectory. As the palliative care arrangements are established in an institutional setting, access is difficult for people who cannot afford to visit the centre because of their low economic status; because, in addition, most households prefer their dying relatives to die at home, the CPC initiated two community-led projects to add to the permanent centre located at the university. These are: Compassionate Korail and Compassionate Narayanganj. Compassionate Korail is run with the collaboration of the Worldwide Hospice Palliative Care Alliance (WHPCA); Compassionate Narayanganj is funded by UK Aid and involves collaboration between BSMMU, the WHPCA and the Narayanganj City Corporation (NCC) to ensure the availability of palliative care services in Narayanganj.

The Compassionate Korail project office is in Korail slum. Korail is one of the largest slums in Bangladesh and is located under wards (administrative unit) 19 and 20 of Dhaka City Corporation, adjacent to Gulshan-Banani Lake. The slum borders Gulshan and Banani, two of Dhaka's most affluent neighbourhoods. However, the majority of Korail's inhabitants live below the poverty line and work in extremely low-income jobs. Most of the people who live in Korail have moved to the city from some of the poorest parts of Bangladesh. Korail covers approximately 100 acres and is home to approximately 86,200–115,000 residents (Sinthia, 2020). The project has been supporting older people with serious illness, frailty and unmet care needs in Korail through a compassionate community approach. The Compassionate Narayanganj project is in Narayanganj, a city 16 km southeast of Dhaka. Compassionate Narayanganj engages with terminal patients from all socio-economic backgrounds in the city. Both projects have been running since April 2018.

Although the CPC manages palliative care in all the three settings, there are a few operational differences in terms of the nature of the work of healthcare providers at the CPC and at the community projects in Korail and Narayanganj. In addition to the doctors and nurses, there are two additional types of providers in the community settings: palliative care assistants (PCAs) and project coordinators. PCAs ensure home care by visiting patients' homes, while project coordinators ensure the delivery of monthly food packages to needy families registered with the project. Besides operational differences, there are differences in terms of the social setting of the three settings. Therefore, a vivid description of the three field sites – the CPC and the two community settings – is provided in order to set the scene for the findings chapters. The following is a brief ethnographic description of the stakeholders (providers, patients and family caregivers) interacting and participating in the palliative care programme managed by the CPC. The description is given according to my observation of the field sites during my fieldwork.

Centre for Palliative Care (CPC)

The CPC is the operational hub or centre of the palliative care programme I did my research on. As mentioned earlier, the centre is situated in the country's only medical university, which is the BSMMU. It is a government-run medical establishment at the heart of Dhaka city. It is important to consider whether a health facility is government run or privately owned, in order to understand who visits which type of health facilities across the country. Government-run facilities have cheaper admission fees, cheaper pathological test fees and surgical operations are performed at little cost. Privately owned facilities, however, charge more compared with the government-run health facilities. In this situation, patients who are from a lower, lower-middle, or middle-income background tend to visit government-run hospitals or other health facilities.

During my fieldwork I encountered patients and families from different economic backgrounds in the CPC. I saw families carrying luggage for a longer stay in Dhaka city roaming around the premises of the CPC. Family members often came, all together, to Dhaka from a distant district to stay beside their dying relative in their final days. Most such families did not have any place to stay or any relatives in Dhaka. When their relatives were admitted at the centre, they would stay at the centre on a roster basis. They would try to find some other places to stay, whether with close or distant relatives, for the days to come so that they could manage to take care of their patients at the CPC. They would look for people from the same village area or the district they came from. Their sufferings would increase if they needed to stay for longer periods of time. The duration of their stay depended on the financial backup they had. They faced difficulties mostly because of their vulnerable financial situation and not having close relatives in Dhaka and, most importantly, not having proper knowledge about the prognosis of their relatives. Before coming to the CPC, families would look for any available curative options for their relatives. I even came to know that families would search for the best treatment options despite the cost being beyond their means.

There were also patients from well-off economic backgrounds. Most of them stayed in Dhaka, and their relatives also tended to live around them in Dhaka. They also came from other districts as well. Whenever their patients were referred to the CPC and they came to know about the prognosis after the visit, they became confused about what to do with the patient. Family members would discuss among themselves whether they should try to visit other countries such as India or Thailand, or go to other developed countries for their relative’s further treatment. I found that it was a common tendency among those family members who thought they could bear the costs of treatment in those countries. After several discussions with the providers in the CPC and their previous doctors, and discussions among themselves, they would usually decide that it was futile to do that, and would stay in the CPC and not make such an attempt.

I should mention why the patients’ economic backgrounds are significant, regarding their visit to the CPC. As the phenomenon of palliative care is very recent in Bangladesh, most families are not aware of what palliative care is before visiting the CPC. Therefore, they were mentally prepared to try any curative option available for their relative who was suffering from a chronic disease. Every family I encountered in the CPC mentioned that their relative had been referred by their previous consulting physician from another hospital. Before coming to the CPC, family members and other relatives would gather around their dying relative to support them, providing them both mental and financial support. Relatives would try to contribute by providing financial assistance or by participating in the care work during their admission. After coming to the CPC, by the time they came to know that their relative may die soon, family members and other supporting relatives were already in a place to support their dying relatives anyway.

Participants

In this section I present the details of the participants I interviewed and observed in the field. I will then move on to describe some of the sites and informants I found significant for my fieldwork.

Healthcare providers

I interviewed four categories of healthcare providers in my fieldwork. There were six doctors, two nurses, three PCAs and two project coordinators. Not all of them were medically trained professionals, therefore, I refer to them collectively as healthcare providers. The doctors and nurses were medically trained and experienced. The PCAs and project coordinators were not medical professionals.

Doctors

There were twenty doctors appointed in the CPC; three others were appointed in the community projects (two in Narayanganj and one in Korail), so the total number was 23. I recruited six doctors for my fieldwork interviews. I set a criterion in my ethics application regarding the doctors that only those who had been working for at least one year would be eligible to take part in the interviews. Apart from this selection, I also chose one newly appointed doctor in order to understand her perspective.

I interviewed six doctors in total. Most had no specialization in palliative care such as an MD in Palliative Medicine. During the establishment of the CPC in 2013, those who had experience in an intensive care unit (ICU) or had worked in an anaesthetic department got priority in recruitment. A retired professor, Dr Nasir, coordinated the establishment of the CPC from the very start. I interviewed him in order to gain the best knowledge about the palliative care situation in Bangladesh. Besides him, there were many doctors who had worked from the start of the CPC to the present, from among whom I interviewed two doctors. I interviewed one student who was on the MD in Palliative Medicine course and was also attached to the CPC. He was one of the first batch of students on the MD in Palliative Medicine. Associate Professor Dr Azam oversees the administrative and research wing in the CPC. My interview with Dr Azam helped to inform me about recent developments at the centre.

Palliative care assistants

Palliative care assistants (PCAs) for the two community palliative care projects were recruited from the community neighbourhoods and given a six-week course on basic palliative care. Their ages range from 16 to 25 years; most of them are students in either college or university.

The PCAs visit the patients' homes on a weekly basis. They provide all kinds of patient management services, including taking blood pressure, managing medicines, helping to change the colostomy bag for patients with intestinal cancer, maintaining the personal hygiene of the patients and checking the insulin level of patients who have diabetes. Besides all these tasks, the most important thing they do is to pass time with the patients. According to the PCAs both they and the patients enjoy passing time with each other. Ruhi, a PCA in Compassionate Narayanganj, told me:

> Sometimes the dying patients request me to stay longer. They want to talk and share rather than receive any medicine. I also love talking to them. Recently, I have been taking care of 10 patients. Three of them call me ‘daughter’ out of their affection for me.

According to Doctor Rajan: “PCAs are a bridge between medical professionals and the caregivers.” I explain their roles further in the findings chapters. There are several reasons why patients and caregivers feel closer to the PCAs, as they live in the same community as one another; regarding Korail, the PCAs and the patients share many commonalities in terms of socio-economic conditions, sharing access to facilities in the slum community, and generally sharing the constant feeling of vulnerability in an informal settlement for lower-income households. Whenever a patient feels severe pain or another complication, patients call their PCA. If the patient is unable to call due to their illness, they request their family caregivers to call the PCA. Patients really value having a PCA’s presence during a moment of crisis. I focus on the dynamics of this special relationship between the PCAs and patients during the research interviews and observation.

Nurses

Most nurses are recruited to the CPC because of their past experience in an ICU. After joining the CPC, they receive a training course in basic palliative care. Some of the nurses have visited overseas countries to receive further training. I interviewed two nurses: one was based at the CPC and the other was based in a community setting. I focused on the role played by the nurses at the sites during my interviews. Besides their role, I have also highlighted their experiences before a patient death. During my fieldwork, nurses mostly talked about the role of communication in palliative care.

Patients and family caregivers

I describe the family caregivers and patients in the following section. Below, two tables outline the family caregivers and patients, together with their location, age, gender and the relationship of patients with the caregivers (Table 4.1). In Table 4.2, the location, age, gender, and patients’ disease is given.

Table 4.1

Total	**8**
Caregiver’s location	
CPC	3
Korail	3
Narayanganj	2
Caregiver’s Age	
20-30	1
30-40	4
40-50	3
Relationship with Patients	
Son	1
Daughter	4
Mother	3
Gender	
Male	1
Female	7

The table shows that of eight of the total family caregivers I interviewed, three were from CPC, three were from Korail and the remaining two were from Narayanganj. There were several caregivers involved in each setting for each patient. Therefore, it was difficult to select the key family caregiver from the patient’s family. I set several criteria to select them, in consultation with the providers and from my ethnographic observations. The criteria included who spends most time with the patient, who the patients called for help, who fed the patient, who talked to the providers in emergency consultations. However, it was not easy to find out who was the key caregiver because of the division of roles amongst family members. In some instances, there were several people who were doing these jobs, and for other patients, only one person was caregiving. Therefore, the criteria were not the same for everyone. The problem could have been solved if I selected them based on their interest to take part in the interview, but that did not guarantee I was interviewing the key persons as there were caregivers who wanted to take part in the interview who were not actually key caregivers. Therefore, after identifying the key family caregivers for each patient I interviewed, I asked them whether they want to be interviewed or not. Finally, I recruited those key caregivers who showed interest to participate in the interview. The age range of caregivers from Table 4.1 shows four between 30-40 and three between 50-60. This helps to explain the relationship of caregivers with the patients. Caregivers between 20-40 years are the most active age group, and are mostly children. Amongst the eight caregivers, five of them were the children of the patients. In terms of the gender distribution of the caregivers, only one was male, yet this distribution resembles what I observed during my fieldwork; most of the caregivers were female (mother or daughter) in all the settings.

Table 4.2 gives a background of the family caregivers and patients I interviewed.

Total	**9**
Patient's location	
CPC	3
Korail	4
Narayanganj	2
Patient's Age	
20-30	3
30-40	1
40-50	2
60-70	3
Gender	

Male	5
Female	4
Disease	
Cancer	4
Cardiac related & Others	5

I interviewed nine patients during my fieldwork. Amongst them, three were from the CPC centre and the remaining six were from the community centres; two from Narayanganj and four from Korail. Interviewing them was the most challenging part of the fieldwork, mostly due to their terminal illness - for which I was mentally prepared before starting my fieldwork.

Recruitment of family caregivers and patients

I interviewed caregivers after conducting several interviews with providers. It helped me to understand more about family caregivers from the perspective of the providers. I prepared an updated topic guide for the family caregivers after interviewing providers. Below I outline the interview process and conceptual and methodological challenges of doing qualitative research with families in palliative care.

The caregivers' interviews lasted around one hour to one and half hours. During the interview, I did not get the opportunity to talk to the caregivers alone. In the CPC, they always stayed beside their dying relative and were surrounded by other family members. In the community settings, there were always other family members surrounding them, mostly because of the limited household space. Sometimes, all the family members responded all together in replying to my questions to the key caregiver. The interviewee also consulted with the other family members responding to some of my questions. Although I had a topic guide for the interviews, I did not strictly follow it during the interviews due to the flexible nature of caregivers' participation.

In response to my queries about the history of their relative's terminal illness, caregivers shared their story following a distinct narrative. It entailed the narrative of the disease, how things deteriorated, when they came to know about the terminal condition, their initial response, what challenges they faced in managing treatment and care, and how they were dealing with it. At the very beginning of the interview, they summarized how and what was happening with their relatives. I did not intervene in those moments so that they could remain spontaneous. fter I completed the interviews with caregivers, I achieved an understanding of the different kinds of patients, which helped me update the topic guide for the patients' interviews.

I recruited each patient after several consultations with the providers (doctors and nurses) in all settings. Based on their suggestions, several criteria were set to recruit patients, which were different for the centre and the community settings.

I recruited patients after three verification steps to make sure they could talk to me in an interview: first, to find out about the patients from the duty nurses, second, to check my understanding with the duty doctors, and finally to receive an assurance from the higher-management-level in the centre. Finally, I selected three patients from the centre. According to the doctors, they were in the final six months of their lives. Even though they were in their final days, they were about to be discharged home. As they were experiencing less pain than other patients, providers discharged them so they could pass their final moments at home. However, even though they were selected it did not mean they were recruited. After being made aware of their condition and whether they could be interviewed, I asked permission from their family caregivers, as I wanted to know whether they were content with me interviewing their relative. After I received verbal assurance from family caregivers, I approached the patients with the participant information sheet and consent form. Once the patient agreed to talk to me, I started the interview.

I followed a different strategy to recruit patients from the community centres, as they are not set in a formal clinical setting like CPC. As I started my fieldwork with ethnographic observation, I came to know about most of the patients at this point, when significant rapport building took place. I also asked for help from the Palliative Care Assistants (PCAs). As PCAs frequently visit the patients, they have a unique relationship with the patients. They helped me understand the patients' condition, both their recent physical conditions, medication they were receiving and the most recent physical breakdown they had experienced, and how family caregivers managed caring in often quite challenging conditions. As most of the patients were from a lower-economic background in the community settings, there were several issues which the providers considered while caring for a patient. This includes how many members are in the family, who are the earning members, what is their income, who is the primary caregiver, and what challenges they face in caring. After getting to know about patients' condition from the PCAs, I made a potential list of twenty patients. I checked the lists with all the providers in the community settings. Finally, I selected six patients for my interviews. I preferred patients who were physically able to talk to me for at least an hour. Amongst the six patients, four were from Korail and the other two were from Narayanganj.

Interviews with providers ranged from 1 hour to 2.5 hours. Patients' interviews ranged from 30 minutes to 1.5 hours. Sometimes, I paused for breaks, for example when patients were experiencing pain, when they were looking for help from providers or their family caregivers, when they broke into tears while telling their stories about the disease and challenges they got into, and when they stopped talking for a while remembering special moments in their lives. I gave pause in those moments so that they could resettle themselves. Further discussion on how I talked to patients about death is in the final section of this chapter. Although I had a topic guide (Appendix, p. 241) prepared for the patients' interview, I could not follow that exactly. As there was no formal arrangement to conduct an interview with the patients, I always had to start it in an informal condition; for example, patients were resting on the ward or in their home. During the interview, patients were commonly surrounded by their family members at home, and providers in the CPC. In the community settings, I conducted most of the interviews at the patient's home, although three patients visited the community palliative care office for the interview.

Data analysis

Qualitative analysis encompasses three coinciding parts for a systematic enquiry: data reduction, data display and conclusion drawing. Data reduction means the analytic choices researchers make; data display suggests organizing and compressing the choices for further analysis; finally, conclusions drawn from the data need to be tested against the data (Miles & Huberman, 1994). Although analysis entails systematic enquiry, qualitative research calls for flexibility (Bazeley, 2013). In the present study, I linked the research objectives and research questions in order to keep a balance between systematic enquiry and flexibility. Therefore, the data in this study focused on the participants' understanding of a good death, how palliative care is delivered in the palliative care settings and how the notions operative in those settings compare with the notions in global settings.

In relation to these, the data analysis of the present study paid attention to the healthcare providers, the patients and the family caregivers. In terms of the providers, I focused on how the providers want to deliver palliative care in the settings, how providers interact with the patients and their family caregivers, what they think about palliative care in the settings, what challenges they face and how they adapt to those challenges. In terms of the patients, I focused on their knowledge of palliative care, what they expect from the settings, what they understood of a good death and what their experience in the settings was. In terms of the family caregivers, I highlighted how they came to know about palliative care, what was their understanding of a good death in terms of their dying relatives and what did they expect from the palliative care settings.

Data organization

During the fieldwork I recorded the interviews on a digital recording device. For observation, I used notebooks and memos. As the interviews were recorded in Bengali, I had to first transcribe them from Bengali. After the initial coding from the interviews and observation notes, I categorized the themes.

Triangulation

Because I collected data through in-depth interviews and ethnographic observation, there was a need for the data to be validated. Triangulation is a validation strategy for the kinds of data and different methods of data collection used in the study. Triangulation is identified with three outcomes: convergence, inconsistency and contradiction (Mathison, 1988). I checked the data from the interviews with the data found in the observation.

Regarding convergence, both types of data complemented each other in the study. For example, during the interviews, I learnt about how the providers hold a family meeting to inform the family caregivers about their relatives' terminal prognosis. During my observation, I attended such family meetings, which helped complement the data from the in-depth interviews.

In some instances, there were inconsistencies between what the participants thought about palliative care and what they were doing. For example, during an interview, a family member told me that palliative care was a blessing for her relative in their final days. However, I found the same person trying to find further interventions, in the belief that her relative could be cured.

As the study sought to compare palliative care in the research settings with global practice and ideas, different methods of data collection helped me to identify any gaps between ideas and practice. For example, the providers mentioned their anticipation of standard palliative care in the research settings. However, there were inconsistencies in practice. This helped me to understand the scenario of what was happening in the palliative care settings. Based on the triangulation of data, I categorized the themes of the study.

Thematic analysis

Thematic analysis provides a rich and complex account of data. Therefore, sometimes, it is constituted as a method in its own right (Braun & Clarke, 2006). It is also regarded as just a tool in other methodological traditions, rather than the method itself (Ryan & Bernard, 2000). In the present study, rather than being either a method or a tool, themes can be best described as integrating relational patterns explored in the data (Bazeley, 2013).

After I categorized the data according to the participants, first I designed the initial code based on the primary topic guide. I then constructed a pattern of themes while I was working through the data. For each pattern, I highlighted exemplary quotes and expressions across each of the participant's data. After I identified that there were repetitions and patterned relationships, I constructed thematic connections.

Regarding the providers' understanding, according to their narratives in the interviews and the notes from my observation they described how they provide palliative care in the settings. I categorized the specific focus of each of the providers. For the doctors, their focus was on the administration of opioids and the challenges of communication with dying patients and family caregivers. For the nurses, their focus was on how they assist the doctors and how they communicate with the patients and family caregivers. For the PCAs, their main focus was on the relationship they develop with the patients. For the project coordinators, their focus was on the delivery of social support to the patients' families in the community settings. The commonality among the providers was the delivery of total care in the settings. I analysed the theme of ‘total care’ in Chapter five in the present study.

I found that one of the providers’ key jobs after they first encounter the patients and family caregivers, is to inform the family about what palliative care is and how they will deliver care to the patients. As this is a significant step in the palliative care settings, I analysed it under the theme of ‘awareness of dying’ in Chapter six.

In Chapter seven, I analysed how the patients and families perceive the understanding of care in the final days of the patients. I categorized their understanding of care as the theme of ‘a good death’ in Chapter seven.

Several levels were followed during the analysis of the findings. The first level of analysis looked at how participants, patients, their family caregivers and providers were contributing in the palliative care services in the settings.

First, I discuss about care providers. During the analysis of the activities of the care providers, I focused the discussion on those points where it was clear whether they were designing the services of the palliative care center setting a standard like the western practices. Whether there are any kind of challenges to be faced in providing services according to that standard. I have focused on whether they have to rely on local/spatial practices to meet those challenges.

On the second side, I paid attention to what kind of role the relatives of the patient are playing. Although relatives of the patient play an important role in all parts of the world, the kind of role they play in the Global South or more specifically in the countries of South Asia including Bangladesh is much more involving. There are several instances where their role becomes more dominant than the patient's role, either during the patient's illness or during care of the dying patient.

Third, from the patients' point of view, I saw what kind of mentality they nurtured in the days before death. That is, what exactly does he expect from the CPC, from the PCAs, from his family. During the findings I looked at the ways in which a Bangladeshi patient nurtures a different mentality compared to a Western patient. What prevails in his pursuit? What is reflected in one's wishes and dislikes etc.

Since most research on palliative care is done in developed countries in the West, the emphasis is on the characteristics of palliative care in the West, as opposed to the characteristics observed in Bangladesh. Within the broad and expansive world of palliative care, I have prioritized the component of good death. For example, the provider's point of view takes precedence over formal care when looking at how care is delivered informally through normal social relationships in the community. How the patient's relatives play a more influential role than the patient and finally how a Bangladeshi patient's wish is granted, how the family is preoccupied with only their own wish in the last days. That is, the focus was on the family-centric features of The Good Death.

I have done Bangladeshi Good Death Analysis in terms of the above criteria. I have tried to discuss and analyze the deviant cases in the light of this criterion. In other words, I considered negative or deviant cases beyond the normality of the patients, relatives, and care providers of Bangladesh. For example, an example of a negative/deviant case will make it clear on what notion the other cases are selected. Chapter Six contains an example of a patient being abandoned by his family caregiver. A letter was left with it. Looking at other cases, this example is apparently a negative phenomenon. Where it is generally seen that the family plays the most influential role for a patient, the opposite picture appears. Where it is expected that the family will always be on the side of the patient and involved in all aspects of the patient, this case deviates from that.

Rationale for Thick description

I present each of my finding's chapters by following the approach of 'thick description'.

Thick description is described primarily from a level of detail: the ability to create a rich, contextualized description of an event to increase verisimilitude and transferability of the findings (Creswell, 2012; Merriam, 2009). According to Schwandt (2007), 'to thickly describe social action is to begin to interpret it by recording the circumstances, meanings, intentions, strategies, motivations and so on that characterize a particular episode. It is the interpretative characteristic of description rather than detail per se that makes it thick' (p. 296). Ryle (1968) used the term 'thick' as opposed to 'thin', to help illustrate the philosophical complexities of describing human actions. For Ryle, thick description is manifestly a quality of the explication, rather than of the action or text that is explicated. It is not the object that is thick or thin, but only the description of it. Accordingly, thin description can be a detailed one but still leave the action empty of significance (Freeman, 2014). In this regard, Freeman focused on Geertz's (1973) understandings of thick description. Freeman argued how Geertz focused on the centrality of meaning in a thick description. While explaining Geertz's account of thick description, Freeman points towards the fact that thick description designates both the discrete data available for interpretation and a strategy to interpret and represent the data. According to Freeman, what Geertz argued is that ethnographic research is faced with multiplicity of complex conceptual structures, many of them superimposed upon or knotted into one another. This suggests that thick description is not just about a simple matter of gaining enough detail but requires interpretation and translation into a language or means of representing an event. Inspired by Hermeneutics, the philosophy of interpretation and meaning, Geertz focused on the importance of how researchers can make the reader understand how the participants live and act in their daily lives. It is not just a micro world he suggests. Rather, he demonstrates that the work of an anthropologist is one of mediating between an unending web of contextual, historical, semiotic, and affective accounts they must make sense of (Freeman, 2014). Thick description of such suggests the representation of a world in which the participants are existing or participating. Considering the rationales of representing the world of the participants, I choose to focus on thick descriptions of my findings.

I focused on two aspects for choosing thick description. First, I conducted an ethnographic study and second, Bangladesh is an unfamiliar context for most readers in this context. Therefore, I choose to use thick description to explore the multiplicity of ethnographic research and to provide a detailed description of how good death is understood in palliative care service in Bangladesh.

I separated my analysis from my description in each findings chapter. In the description section, I wanted to make sense of what the providers, patients and their family caregivers perceive about good death in a palliative care setting in Bangladesh. I did not describe that in as random manner, rather I designed my description thematically. Themes that were explored in the description were analysed in the final section of each finding chapter. Therefore, the descriptions are both representation of the setting and guide to the analysis. According to Freeman (2014), 'to understand our being, we need to understand understanding, to understand understanding, we need to begin to understand these conditions across contexts and time, not because we can reconstruct any true existence, but because the truth of what matters to us is found in these shared effects of tradition' (p. 832).

Three chapters together explore the following questions. Chapter five demonstrated how providers deliver physical care and non-physical care to the patients. As I have explored, although they prioritize to deliver a global notion of good death, which they must negotiate most of the time with the local values and norms of the family caregivers and patients. Chapter six explores the influential role of family members to decide their relatives final days, instead of the dying patients themselves. How family caregivers of the patients and the providers encounter is explained in the light of the differences of views and expectations between the family caregivers and providers. The chapter vividly shows that family members play more significant role regarding any decisions of a dying patient. Chapter seven focuses on the cultural expectations about end-of-life care perceived between both the family members and their dying relatives.

Sensitivity in the research

Sensitive research is 'studies in which there are potential consequences, either for the participants in the research or the class of individuals represented by it.' (Sieber and Stanley, 1988) Lee (1993) argued this definition was too broad and offered a definition in which the topic under investigation, the situation, as well as any other issues, posed a threat to the individuals involved. Research on death and dying is sensitive in terms of its taboo qualities and sensitivity related with it. The potential risks and complications are explained, in death research, considering the consequences upon psychological condition of the participants, such as dying patients, their family caregivers or bereaved family members. In death research, generalised ideas about sensitivity derive in part from a negative, problem-based view of death and dying (Kellehear, 2009). Often when people talk about death research as sensitive, they do so in general terms rather than stating explicitly what makes it so. The term 'sensitive topic' is frequently used in a common-sense way without being defined (Lee and Renzetti, 1990). When concerns are articulated they tend to centre upon death's emotionality (Cain, 2012; Cook & Bosley, 2007), or the fact that dying participants have limited, 'precious' time (Barnett, 2001) and reduced capacity to consent due to illness (Gysels et al., 2013). Since it is presumed this research is 'sensitive', there is a logical extension that its (human) subjects are essentially ‘vulnerable’. For example, ethics committees are frequently concerned about how researchers will manage and respond to participants’ emotions during interviews (Borgstrom, 2018). It is noteworthy that there has been a range of safeguarding measures established to shield the participants of such research, with a number of gatekeepers including ethics committees, service organisations, professionals, practitioners and occasionally parents or caregivers determining whether such vulnerable groups can participate in research, over the past years or decades (Powell et al., 2018). Ethics tends to be focused on procedural elements, or ‘paper ethics’, rather than real-world research (Robinson, 2020).

In the case of the present research, reflexivity can be understood as a responsible means of negotiating the sensitivity of the topic and vulnerability of the participants (mostly the patients and family members) or as ‘personal responsibility’ (Borgstrom and Ellis, 2021). Here, reflexivity as personal responsibility means the researcher’s careful reflection to determine their actions by untangling the complications due to the vulnerability of participants and sensitivity of the topic in the field setting, or self-management of their potentiality of harming the participants through meticulous contemplation. In the following, I describe complications of reflexivity and how I talked about death with patients and their family caregivers.

Being a Bangladeshi

Being a Bangladeshi, I have had the advantage of not going through the difficulties of learning and familiarizing myself with a different culture. Although I was aware of the advantage, I realized it more forcefully after I met one of my PhD colleagues who was learning a foreign language for her fieldwork. Besides learning the language, she was reading books and articles on how to live in the setting of her research. After seeing this, I realized that I did not have to go through such difficult training before my fieldwork. I did not have to think about the language, nor did I have to experience the additional challenges of familiarizing myself with a different culture for the purpose of the fieldwork. Any researcher doing anthropological work in a different culture has to go through such adjustments.

During my observation, my presence in the palliative care settings was not unfamiliar to the participants. As the palliative care settings were always crowded with providers, patients and their family caregivers, my presence was not like an ‘exotic’ presence to them. If there had been a researcher from a western, or African or Latin country, it would have produced a very different atmosphere.

As I am familiar with the healthcare system of Bangladesh, it was not difficult for me to understand what was happening in the palliative care settings. Here I mention several examples of different situations in the palliative care settings. When a critically ill patient comes to hospital, he or she is always accompanied by a lot of relatives in Bangladesh. A researcher who is unfamiliar with such a situation might be curious to understand the reason for such a crowd. At the CPC, family caregivers talk to the duty nurses or the duty doctors without any formal appointment.

Family caregivers typically bring cooked food for the dying patients at the CPC. I often saw them bringing the favourite food items of their dying relatives. For example, they would bring chicken curry (locally it is called *deshimurgirsalun*. *Deshi murgi* means the chicken is of a local breed and not produced in a poultry farm. It is regarded as a tasty dish in Bangladesh. *Salun* means ‘curry’. Relatives would also bring aubergine fry, *khichuri* (a special rice mixed with lentils), biriyani, fish curry (known locally as *maacherjhol*.*Maach* means ‘fish’, *jhol* means ‘curry’), and many other dishes. I could relate to their love and affection regarding food. I can still remember the stories I heard from my mother about her father’s last days in hospital. My maternal grandfather died of cancer. He used to love the food cooked by my mother. My mother had a speciality of mixing coriander leaves with fish or meat (coriander leaves that grow in Bangladesh have a unique and very beautiful smell). He used to like the smell of the leaves in the meal. There was a blind patient beside my grandfather. Whenever my mother brought food, the blind patient used to say to my grandfather, “I can tell whose food has arrived. Sayed’s daughter has brought food with a beautiful fragrance of coriander.” (My grandfather’s name was Sayed.)

Whenever my mother reminisces about her father, she talks about the dishes with coriander leaves she used to cook. She told me that our grandfather had his favourite meals in the final days of his life.

During informal conversation with the providers, I came to know that many patients wanted to have their favourite dishes in their final days at the CPC. I was not surprised by this as I am very familiar with the importance of food in the life of a Bangladeshi.

When the providers informed the family caregivers about their relative’s terminal prognosis, I would see many relatives surrounding the providers together. When a patient died, I would see lots of relatives and friends of the patient come to see the patient’s body at the CPC. Sometimes, relatives would cry out loud in the presence of providers, other patients and their caregivers. Their emotions would go beyond the usual atmosphere at the CPC. As I am a Bangladeshi, these sorts of happenings were familiar to me during my fieldwork. I can imagine that it would take a long time for someone from outside the culture to be familiarized with the things I described.

However, despite the ease of familiarity gained by doing fieldwork in one’s own society, there are risks as well. I experienced the risk that participants would tend to make assumptions about me. During the conversations, sometimes patients and family caregivers would assume that I knew everything that they were feeling or thinking. When I was interviewing a family caregiver who was the elder son of a dying father, in reply to my question about what he considered to be a good death for his father, he said, “‘You know what a father expects before his death.”

I tried to ask the question again differently, but his reply to me was the same. I experienced such situations several times, even with the patients. In addition, it was difficult for me to mention the word ‘death’ to the patients and their family.

Chapter Five- The role of the healthcare providers in ensuring good death

This study aims to explore ‘good death’ in relation to the palliative care services provided in palliative care centres. I have arranged my findings over three chapters. The present chapter shows how providers, both formal healthcare providers and informal palliative care assistants deliver physical care and non-physical care. Despite the challenges of structural limitations for opioid unavailability in Bangladesh, non-physical care can still be delivered utilizing the strength of community relationships through the informal caregivers in the country. Chapter Six shows how the healthcare providers communicate about the terminal prognoses of the dying patients to the patients themselves and their family members, which leads to an analysis of awareness contexts of dying in a Bangladeshi context. Chapter Seven considers what the family members of the dying patients understand about end-of-life care, highlighting the localized understanding of good death in Bangladesh, beyond the definition of palliative care. In sum, the present chapter shows what the providers intend to deliver to the patients and family members with the limitations and strengths in the settings. Chapter Six shows how family members become the influential decision makers for the patients, instead of the patients themselves or the healthcare providers. Chapter Seven demonstrates why family members are such influential stakeholders during the patients’ end of life in Bangladesh.

The thesis argues that despite the common goals in end-of-life care emphasized in The Economist's Quality of Death Index (2015), there is room for embracing an alternative approach. The central argument is based on the differences in values (values of good death) and logistics (arrangement to achieve good death) between Western countries and those in the global south. While Western ideals prioritize institutionalized and professionalized palliative care, lower-middle-income countries, like Bangladesh, may hold different values, exemplified by community-based models such as the Kerala model in India. The argument centred around the implicit tension between the values and logistics in Bangladesh and those prioritized in The Economist's ranking. The ranking, dominated by Western ideals, imposes a common pathway for global palliative care provision and influences a 'follow west' mindset among policymakers in Bangladesh. The findings in this chapter offers empirical evidence and contribution that might show how ‘follow west’ mindset might not work to deliver end-of-life care to the increasing numbers of death and dying in the country. Rather than the common path, an alternative pathway might be found.

By looking at how physical care and non-physical care is delivered in the settings, the present chapter found the inconsistencies of logistics in the palliative care centre and the community settings. The research findings underscore the critical impact of opioid unavailability on the provision of physical care in lower-middle-income countries. Moreover, the study delves into the realm of non-physical care and reveals that, despite challenges in physical care, it persists through the application of informal care management within the framework of community-based palliative care models. Additionally, the contribution of this chapter goes further to advance the concept of a compassionate community, offering insights into the potential development and enhancement of this model for effective palliative care implementation.

In this chapter, I examine how healthcare providers deliver palliative care based on the concept of 'total pain', despite inequities in palliative care provisions in the country. The concept of 'total pain', means that pain is not only physical, but also a multi-dimensional interconnectedness of the existential, biographical and spiritual aspects of a dying patient (Clark, 2014). Cicely Saunders' early efforts at the advent of modern hospice and palliative care movement was its articulation of the relationship between physical and mental suffering, social problems and emotional difficulties (Saunders, 1964). Total pain means providers' willingness to acknowledge the spiritual and mental suffering of the patient and to see this in relation to physical problems. This is an approach in which pain is a key to unlocking other problems and as something requiring multiple interventions for its resolution.

Keeping the concept of 'total pain' in the background, I present how care is organized and provided by the healthcare providers in the Centre for Palliative Care (CPC) and its two affiliated community projects, Compassionate Korail, located in Korail, and Compassionate Narayanganj, in Narayanganj. Through analysis of my observations in the field settings and interviews, I found that the providers divide care into physical care and non-physical care. Physical care centres on opioid administration and the management and relief of patients' symptoms. Non-physical care refers to mental, psychological, or spiritual care for the dying patients.

While looking into how palliative care is delivered, this chapter shows two aspects of palliative care in the country. First, regarding physical care, even though CPC is Bangladesh's most wellresourced setting to deliver physical care to dying patients, there are limitations and needs to be addressed that are connected with the global opioid inequality in lower- and middle-income countries. The chapter shows that physical care is compromised in Bangladesh due to the practice of strict protocol instructions for the family members to receive opioids for their dying relatives in the centre. In this regard, I argue that a feminist ethics of care can be approached to ensure international responsibilities for care instead of prescriptive principles suggested by The Economist's Global Quality of Death Index (2015). Ethics of care approach was discussed in regards to ensure vaccine doses around the world during covid-19 pandemic (Robinson, 2021). Instead of prescriptive suggestions, author suggested to expand moral imagination beyond national boundaries. Moreover, practices of responsibility and interdependence with others in existing social relationships should be prioritize while ensuring international responsibilities for care.

Second, despite resource limitations, mental, psychological and spiritual care, or non-physical care can still be delivered with the utilization of compassionate community model (Kerala-based model) in Bangladesh. The study found that a unique and compassionate relationship between the PCAs and Patients develops in the community settings of Korail and Narayanganj. A strong and extensive social support network is prominent in regards to non-physical care, demonstrating the prominence of caring relationships rooted in the community.

Introduction

> The essence of palliative care, 'total care' is very different in Bangladesh from its practice in developed parts of the world. It can be understood from two starkly different examples. Imagine a patient in the UK in her final days, staying in a beautiful, clean ward. There is a green meadow outside the window. She looks at the window the whole day waiting for a relative who is supposed to visit her. There is a chest of drawers beside her and a letter she just received a while ago from her son. Now, imagine a shrunken and cramped home in a slum in Dhaka city. The dying relative is living with her five other family members. She is in her 70s and suffering from lung cancer and experiencing severe pain and breathlessness. Despite the severe condition, she is crying not out of her physical pain. Rather, she is crying for her family members. She is crying thinking what her jobless son will do to live his life. She is thinking to whom her daughter will be married. Last but not least, what will they eat in the next meal?(Dr Nasir, founding chairman of the CPC).

Dr Nasir, during the interview quoted from above, highlighted the stark differences from western contexts that he observed among the slum populations in the community palliative care project. Even though poverty has reduced by half in the country since 2000, 20.5% people are still living below the poverty line (ADB poverty data, 2019). After palliative care was started at the centre in 2011, Dr Nasir and other healthcare providers thought of extending palliative care to marginalized sections of Dhaka city. As a way of delivering palliative care to a poverty-stricken section of the population, Dr Nasir and his team-members at the CPC started a community palliative care project in Korail slum in 2017 called 'Compassionate Korail' or *'Momotamoyee Korail'* Based on this experience they initiated another community project called 'Compassionate Narayanganj' or *'Momotamoyee Korail'*in Narayanganj, a city close to Dhaka, in 2019.Unlike Korail, Narayanganj is vast and people from all levels of society live there. Its area is 33.57 sq. km. and the population is more than 1.7 million. Despite its vastness and the diversity of its population, the CPC focused on providing palliative care to poverty-stricken patients and families. Therefore, Dr Nasir wanted to emphasise the stark differences from western contexts that he observed in both community projects. The picture he described does not convey the broader scenario of palliative care, let alone of other healthcare practices, in Bangladesh. However, it underlines the context in which the providers are practicing and innovating in order to adapt to the wishes and aspirations of their patients and families.

In the following findings section, two aspects of palliative care, physical care and non-physical care are prominent. First, in regard to physical care, even though professional care and specialized resources are essential for ensuring physical care for dying patients, I demonstrate the challenges and complications for the patients receiving it. During fieldwork, I found that patients and family caregivers face difficulties while trying to relieve patients' pain. Although pain relief is one of the key priorities in palliative care, patients and family caregivers face challenges due to the Centre's protocol, which is consistent with the restrictive drug legislation in the country. The protocol is discussed later in the chapter in relation to the opioid crisis in the country which is reflected in the unequal provisions for end-of-life care around the world.

Second, despite the challenges of physical care, an informal social support network is found through the involvement of PCAs in communities for non-physical care. Rather than any professional or specialized care, patients receive non-physical care (mental, psychological, and spiritual care) from PCAs in their community, outside formal institutions such as hospices, hospitals or care homes. PCAs appear more successful in establishing communication with the dying patients than professional doctors and nurses, which helps them deliver non-physical care to the dying patients. PCAs are recruited from the same Korail and Narayanganj communities as the patients. They have no professional training in medicine or nursing. However, they receive a short course in basic palliative care and nursing from the CPC professionals. Their primary role entails identifying terminally ill patients living below the poverty line whose family members struggle to provide for their basic survival and medical care. Following their identification, the PCAs register such patients and families on the project's patient list, with the coordination of other providers. Their job involves visiting the patients at home to help family members take care of their dying relatives. I focus here on their family-like relationship with patients that develops over the months or years of the PCAs' visits. They play an important role for each stakeholder: patients share their personal life stories with them, family members rely on them in an emergency, and coordinators, nurses and doctors receive regular updates from them about the patients and families. I found their role to be unique in providing mental and psychological comfort to the patients and their families.

In addition to this support, social support is arranged and supervised by four non-clinical Project Coordinators in the two community settings. Their role involves supervising the activities of the PCAs, coordinating with the other providers in the communities, liaising with the CPC authorities, managing personnel and donors regarding everything that happens at the settings, and managing distribution of food items to the patients' families. Although they are not directly involved with patients and families, their role is significant in terms of ensuring food support for poverty-stricken families of patients. In the following, I describe how physical care is delivered, followed by non-physical care.

Later, in the discussion, about the complications of physical care, I argue, with the concept of care ethics approach, why international responsibilities of care is significant in regards to resource allocation, such as opioid availability in lower-middle income countries. Instead of looking from national allocations, the inequality of resources can be considered by approaching it from a perspective that reveals that interdependence and responsibility are part of everyday life in a society. However, as the needs of palliative care are severe in Bangladesh in coming decades, palliative care can still be delivered with the informal management of care. At the end of the discussion, I discussed how informal caregivers or PCAs can deliver non-physical care by developing a family-like relationship with the dying patients.

Physical care

> ‘We prioritize treatments that relive pain. It takes a long time for us to make the families understand why we are prioritizing pain relieving mechanisms rather than saving them. We try our best to make them understand the difference between the physical care their dying relatives receive in CPC and the care they would receive in an Intensive Care Unit (ICU) in a hospital’ (Dr Rajan)

Dr Rajan, based in CPC, replied with the quote above when he was asked about the nature of physical care staff provide to dying patients. Their main concern is to relieve pain. Therefore, physical care is dependent on the life-limiting diseases the patients suffer. Most dying patients are admitted to the CPC with diseases such as different types of cancer, Chronic Obstructive Pulmonary Diseases (COPD), advanced lung, kidney and liver diseases, and AIDS. Irrespective of the disease, providers deliver three types of physical care: regular medication, physiotherapy, and pain-relief.

Regular medication includes regular monitoring, ensuring patients receive relevant medicine and carrying out regular tests such as ECG, X-ray, MRI, Echo. Regular medication depends on the patients’ recent physical situation. Depending on their physical vulnerabilities, patients are provided emergency physical interventions if needed.

Physiotherapy is regularly arranged for admitted patients. Here, physiotherapy aims to maximize movement and function as most patients are threatened by aging, injury, or disease (Kumar, 2010), and healthcare professionals in the CPC make arrangements for physiotherapy to optimize patients’ physical and mental wellbeing. The physiotherapy department is in a different location from the centre. CPC nurses take charge of those patients in need of physiotherapy during the whole process of physiotherapy.

Even though it provides regular medication and physiotherapy, CPC specializes in delivering pain relief to dying patients in their final days. The centre ensures an uninterrupted supply of opioids and analgesics for their palliative care needs. Doctors’ expertise of opioids administration is tested during their recruitment to the centre. Due to the uninterrupted supply of opioids and the doctors’ expertise, the Centre is regarded as the most reliable place in

Bangladesh for delivering pain relief by the other healthcare providers from other healthcare centre.

The significance of CPC as the most reliable place to receive opioids in Bangladesh indicates a crucial background. It is linked with the issues of opioid unavailability and its restricted usage in many lower-middle income countries. Although WHO has designated morphine a vital medicine (WHO, 2013), a stark contrast exists in terms of access between the world's richest and poorest countries. A patient dying of cancer or AIDS in one of the poorest 10% of countries has access to approximately 200 mg of oral morphine, or equivalent, while the average in high income countries is 500 times this amount (Kanul et al., 2015). These inequities are intensified in Bangladesh with the execution of two restrictive regulations; the National Drug Policy 1982 and Narcotics Control Act 1990. Both regulations are in place to tackle illegal usage of narcotics in the country. The production of opioids is strictly monitored in the pharmaceutical industries and usage is controlled for patients in the hospitals or in pharmaceutical shops. However, as CPC is specialised in providing pain relief to palliative care patients, opioids are more available here than at any other health centre. Patients admitted to the CPC receive opioids free of charge and rules and regulations are more relaxed than at other hospitals and pharmaceutical shops in the country. Despite it being easier to receive opioids in the CPC, there is still a CPC-developed protocol and bureaucratic regulations in place.

Opioid administration protocol

CPC follows procedures both for the usage of morphine at the Centre and for its distribution to family caregivers for their terminally ill relatives at home. CPC has designed many verification procedures to make the best of the limited availability of morphine and to prevent any misuses, as well as to ensure no law is broken.

Patients admitted to the Centre receive opioids through a process of several steps. After the doctor prescribes opioids, the family caregivers take the prescription signed by the consulting doctor from the nurse. The family caregiver then goes to the CPC's administration office for a seal on the prescription. After two-tier authentication, caregivers go to a directorate office situated in another part of the premises (the administration wing of the BSMMU). After they get

Picture 1: CPC Entrance

Picture 2: CPC Waiting room

office approval, they go to the BSMMU pharmacy to receive the morphine. After checking all the required seals on the prescription, the pharmacists give the opioid to the caregiver.

Patients who are discharged from the Centre or choose to go home to pass their final days typically receive a morphine prescription for seven days. However, while patients from Dhaka receive it for seven days, those living longer distances from the Centre receive it for fourteen days. All dosages continue until the patient dies; therefore, family members continue to come to the CPC, receiving repeat prescriptions after each last dosage is given. Family caregivers are requested to return unused morphine after the patient dies.

Complications due to tight protocol

Family caregivers must follow the protocol described above that is set for the prescription of opioids in order to receive analgesics for their relatives. The following is an example of how the protocol is implemented.

After Dr Azam prescribes an increase in dosage, a duty nurse comes to Rabeya, a cancer patient. Her mother sits beside her and massages her head. After the nurse’s instruction, Rabeya’s mother looks for her nephew, who is sitting in the waiting room of the Centre. He stays there in case he is needed for any necessities, such as collecting analgesics from the pharmacy, buying snacks for Rabeya and other family caregivers in the hospital, or any other small job for which a caregiver always stays at the Centre. First, the nephew receives the prescription of analgesics. It is then authorized by Dr Azam, as he himself has prescribed the dosage. Next, the nephew goes to the BSMMU directorate office to have the prescription signed by an official there. After that, he goes to the BSMMU pharmacy to receive the dosage. After all this, he returns to the palliative care ward and gives the dosage to the duty nurses.

During my observation at the Centre, I heard from the caregivers that although the patients may need opioids instantly, it takes a long time for them to receive them because of the protocols that have to be followed. Although the CPC has the best possible infrastructure for providing analgesics to the dying patients, the tight rules sometimes negatively affect the patients and caregivers. For example, there are times when the rules and regulations prevent the patients receiving prompt pain relief. This happens because of the strict protocols the CPC has designed, but the rules are essential in order to ensure the accountability of the CPC to the university authority and the university's accountability to the Department of Narcotics Control at the governmental level. It is a complicated process in which several stakeholders are involved. Dr Azam reiterates that although the doctors in the CPC play their roles differently, their primary role is to take care of the physical care needs of the patients. Some of the challenging situations caused by the tight protocol are mentioned by the participants during the fieldwork.Mahmud explained his experiences when he was receiving opioids for his father from the CPC.

> 'It is sometimes impossible to accept the rules and regulations for receiving opioids from the Centre. Firstly, it has been a painstaking experience to bring my dying dad in the centre despite the sufferings of pain he was undergoing, along with the other challenges. We came to CPC after our fifth attempt to find the most suitable place for his care. He was already exhausted. After such a terrible experience, following the protocol seems like another extra burden. All I am doing is running from a building to another building. There are so many verifications to prove that I am not taking these opioids for any type of misuse. At first, I felt like I just landed in another trap. But very soon I came to know from the nurses that the regulations are maintained for restrictive regulations in the country. However, I must follow such rules because these are the only options, I have on my hands to give my dad a minimum peace in his final days'.

The protocol has an impact on the patients who are discharged home as these patients can receive opioids from the centre until they die. One of the most common challenges is to not have sufficient opioids in times of severe need when the patient is experiencing extreme pain. This is worse for patients who live outside Dhaka city. Patients who are registered for home care and from other districts outside Dhaka city face several issues. One such issue is that it takes so long to come to Dhaka due to huge traffic jams in the city between 9 am to 6/7 pm during the weekdays. Due to this, patients who are in excessive pain suffer a lot.

> A few days ago, my mother was experiencing extreme pain at midnight. There was no painkiller left at that moment. Narayanganj, our hometown is adjacent to Dhaka. It takes two and half hours to travel between our house and the centre. I started early in the morning. It was difficult getting public transport in the morning. So, I took a CNG (a three-wheel vehicle). As it was the morning, there was no traffic jam and it only took one and half hours to get to the centre. And then it took almost another two hours to complete all the formalities of the protocol. However, it had been four hours since my mother had been experiencing extreme pain. After I collected the opioids from the centre, I reached home two and half hours after I left the centre. More than six and half hours had passed since I left home for the opioids. I will not get another chance to make up for the excessive pain my mother had been suffering during these long hours. Shouldn't this drug be available in local pharmaceutical shops like other drugs? (Ashiq, younger son of a patient)

Another challenge is the condition in the opioid protocol that stipulates the family caregiver collecting it from the centre must be an adult. The regulation has an age criterion to keep children safe from the misuses of opioids. However, there are some patients who had no adult caregiver in the family except their little children. I heard of such a case involving a 13-year-old boy. CPC caregivers were in a complicated situation dealing with him. First, how can such a small child take care of his mother; second, the obligations to comply with the legal conditions in respect of the opioid received.

Nurse Lailatul, in an interview said:

> ‘We faced a real challenge with this 13–14-year-old boy. He is supposed to be busy with his studies and enjoy time in the playground with his friends. But at this age he is taking care of his dying mother, which is one of the hardest jobs for anyone. We taught him how to take care of his mother. He was so devoted to his mother that he didn’t feel a thing while he was taking care of her. He became so expert in taking care of his mother in just two weeks. He used to feed her, bathe her and visit different sections of the centre for different purposes such as approval for opioids, bring food from outside, and take care of his mother. But the main trouble started after his mother was discharged from the centre. Right after discharge they can receive free opioids from the centre. But only an adult caregiver can come to collect opioids from the centre as per the protocol, which made opioid collection difficult for the little caregiver. Key personnel sat down and came up with a solution. We approached one neighbour of the little boy to be his legal guardian and receive opioids on his behalf. for the mother. This worked well at last. But the regulation caused severe difficulties for the little boy as well as for the patient’.

Non-physical care

I now focus on how other components of total care are delivered. This is the non-physical care that includes mental, psychological and spiritual care, vital in palliative care to ensure a good death. The providers can give mental and psychological support by establishing successful communication with patients; however, doctors often experience difficulties in providing this care. Additionally, there are no specialized professionals such as bereavement counsellors or religious personnel in the centre. In the absence of these specialized professionals and with the skill limitations of the doctors in this area, I found that the PCAs develop an effective family-like relationship with the patients that meets the mental and psychological needs of the dying patients. In the following sections, I describe the challenges faced by the doctors in providing non-physical care, and the PCAs' effective communication skills with the patients.

Doctors are specialized professionals in their role in physical care, although they also try to deliver non-physical care. Doctors, nurses, and PCAs all make their best effort in this regard, with communication playing a vital role. Here I portray some of the challenges doctors experience due to the lack of training in communication with patients across their academic careers.

Doctors currently working in CPC are from a curative practice background, trained in an academic curriculum where communication is of very little importance. However, very recently an MD in palliative care, a professional degree for doctors, was initiated in BSMMU, the only institution in Bangladesh to do so. One of the key aspects in this curriculum is the importance of communication with patients at end of life. The first doctor to be awarded this degree in Bangladesh received the qualification in March 2022; there are currently other students undertaking it. As this course is still relatively new, the centre is dominated by doctors with curative practice backgrounds. They complete the MBBS degree (Bachelor of Medicine and Bachelor of Surgery) from a medical college, and then become a registered doctor to work in a hospital or other healthcare settings. Due to the lack of training in communication, most doctors experience difficulties while talking to patients about death and dying, as communication skills were rarely a part of their training during their academic lives and afterwards.

Dr Rajan is such a consulting physician at the CPC now. He joined in 2013 and very soon he realized that communicating with dying patients was the most challenging task. He said:

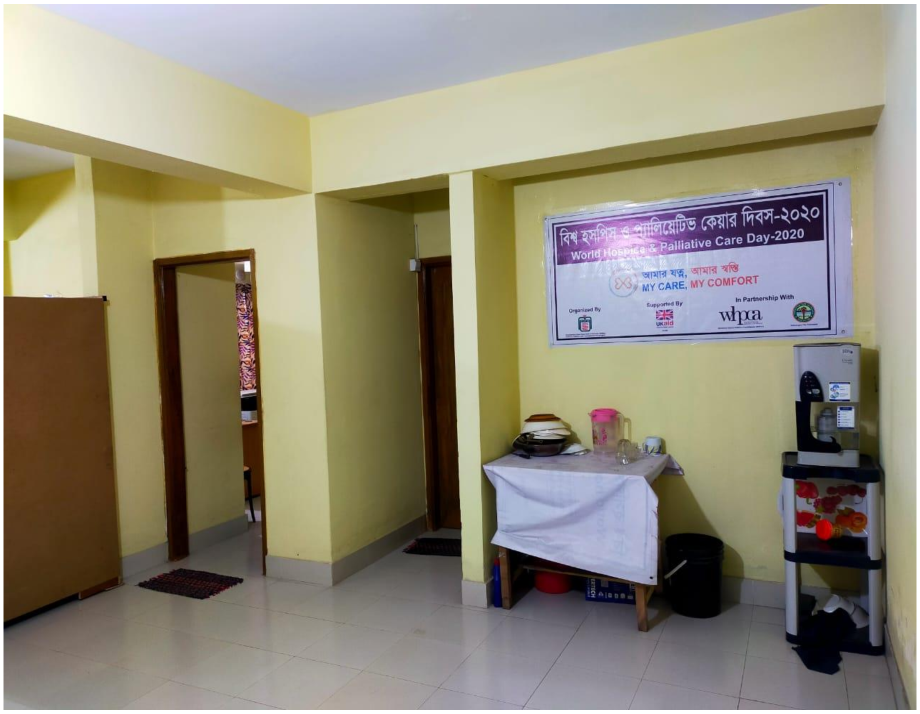
> Before joining here, I rarely listened to patients' stories. Because I wasn't used to it. I was surprised watching Nasir sir [pioneer doctor and ex-director of the CPC] talking to patients for hours. Later I followed him, and I felt different when I started doing that. After I talk to any patient, I know about their whole life, success, frustration, unfulfilled wishes, sadness. Their stories made me very sad. I couldn't comfort myself mentally because of those conversations with patients. Slowly I learned how to communicate with the dying patients. I realised that I am not here to treat, I am here to listen, interact, and provide pain relief. Although I am better adapted now, when I reflect upon my beginner days, I think things were difficult because of the lack of training on communicating with terminally ill patients during our academic life. We learned very little about communication. Mostly we learned how to save a patient, how to insert analgesics in correct ways, but we didn't learn how to talk to the patients. Not at all!

Unlike Dr Rajan, Dr Nurmin reflected differently. She was appointed at the CPC's establishment in 2011. Despite the challenges of communication, Dr Nurmin adapted herself slowly:

> I never thought of working in palliative care when I was student. As there was very little about palliative care in our academic courses, I had no deeper understanding of how palliative care works. I used to cry a lot whenever I encountered any critically ill patient or dying patient during my initial years. Most of my frustrations were due to being unable to communicate with the dying patients. Skills needed to save a patient are different from the skillset to talk to a dying patient. A compassionate mindset is essential for that which I believe I was missing in my initial days. I never stopped trying to get hold of such communication skill. It made me a different person, that's for sure!

The necessities of communication in palliative care are implicit in the above-mentioned quotes of the providers. However, the doctors found they are not the best in communicating with dying patients. Rather, PCAs were found to be better in such communication, despite having no experience in dealing with patients or any medical expertise. My findings suggest that PCAs develop a warm intimacy with patients and sometimes with family caregivers at the end of the patients' life. Below I describe how PCAs are recruited to the CPC before presenting what patients and family caregivers think of their roles and responsibilities, and how the PCAs understand their duties and responsibilities to the dying patients.

Picture 3: Compassionate Korail Office



Picture 4: Compassionate Narayanganj Office

PCAs: Recruitment and Roles

Bangladeshi community palliative care projects are inspired by the Kerala model (Kumar, 2007; Walter, 2017), which is also known as palliative care for lower-income communities. The aim is to appropriate the community network through the assistance of PCAs, who help the families ensure quality end-of-life care for their relatives. Not everything corresponds exactly to the Kerala model applied in Bangladesh settings; for example, volunteers recruited from the community were not paid in Kerala but the PCAs in Bangladesh are paid. They receive a very small amount of money of 10000 BDT ($92) on a monthly basis. The nature of their job is different than the nurses or other professional caregivers. Instead of working in hospitals or health centres, they deliver care in patients' homes in the community. There are 20 PCAs across the two communities. During the course of my fieldwork observation, I had conversations with all of them, and I observed them doing their jobs. Additionally, I conducted extensive interviews with three of them. The following describes findings from the observations and interviews.

Their job entails visiting the patient's house once a week, looking after their medication, finding out whether the patients or families are undergoing further complications, following up about the overall situation and reporting back to the project coordinator. Their essential role is to assist the family members in caring for their dying relatives. The assistance includes finding out whether family carers are providing medicines properly, giving tips about how to carry out basic healthcare tasks (e.g., reading blood pressure, checking sugar levels), looking after the availability of daily essentials, suggesting what to do when the patient is in severe pain and watching for any patient emergency.

PCAs are easily recognisable because of their blue dress. The female PCAs wear a blue *salwar kamij* (a *kamij* is like a type of blouse and *salwar* are a type of trousers). They wear a blue apron above the *kamij*. Some PCAs wear a scarf to cover their head (as part of the *hijab* worn by many Muslims). Male PCAs wear a blue shirt with apron and black trousers. As they live in the projects' local areas, their daily route to the office takes them through the community, and they exchange greetings with the residents they meet on their way. They are recognizable not just because of the blue dress, and because Compassionate Korail is known as a hospital in the community, but also because the slum is a very populous and tight-knit community.

After arriving at their office, they report to their superior, a project coordinator, as part of the office protocol. Afterwards, the coordinator, doctor, nurse, physiotherapist and PCAs hold a meeting together, in which they discuss the plans and goals of the day. Most importantly, the PCAs individually report on their patients' situation to the team; they also provide updates about any new patients that are eligible for registration in the project.

After the meeting, they leave the office premises to go to their patients' houses. This is the most important part of their job. Each PCA is assigned to several patients who require home visits by them. They divide their patients among the five weekdays (Friday and Saturday are weekends in Bangladesh) and visit each family once a week. When they visit their patients, they take a patient register along in order to take notes and make lists of requirements. During my fieldwork, I accompanied PCAs on such visits. Most of the patients' houses are within walking distance of the office, and typically take 5-15 minutes to reach on foot.

The roads and pathways in the slum are full of shops and homes which are very closely connected. Therefore, when anyone walks on the roads, they meet a lot of people. Likewise, on their visit to a patient's house, PCAs meet other residents and people. I observed that there are always some residents who halt PCAs on their way to seek advice about medical problems in their own families. PCAs, in return, suggest they visit the project office to consult the doctor. Sometimes they encounter the family members of their assigned patients while on their way.

I saw family members asking PCAs to visit their relatives outside official visiting hours. Once I witnessed such family members saying to a PCA, "Please make a call to my mother. She feels good talking to you." Residents show warm intimacy and connection with the PCAs. For example, Shamim, a family caregiver of his father conveyed his impression of PCAs as:

> PCAs are our dearest people in the community. Whenever my father [a dying patient] feels bad, I call to Sumi *apa* [people call the PCA s*apa*, meaning sisterlike] to talk to my father. Even though she cannot come at that moment, if she talks over the phone, my father feels good.

'PCAs are important for everyone'

PCAs' roles are equally important for all stakeholders in palliative care provision in the community. I generally found PCAs were well appreciated by patients, family members and the professional healthcare providers. First, for the patients, PCAs are not just a healthcare provider but also a friend. Second, for the family members, PCAs are not just a provider who follows a formal and fixed role; rather, they are flexible in their behaviour and more prone to listen to their needs and problems. Third, for the providers, they are not just an additional pair of hands in a team, but are significant for understanding the real needs and expectations of patients. Regarding this, Doctor Lima said:

> PCAs help to bridge two asymmetric worlds of patients/families and of professional providers. Patients and their families feel comfortable to talk to them. Once they become close with them, patients and their families share their wishes and needs with them and then PCAs convey those to us. That is how we understand better how to design care for them.

In accordance with their regular role, PCAs provide regular updates about the patients to the other team members in the community setting; they do the footwork for the other team members. This includes reporting the physical condition of the patients, relaying any complications faced by patients and their families regarding food items they receive monthly and describing any other wishes or expectations patients want to fulfil before they die.

Based on these reports, the other team members – doctors, nurses and coordinators – update each patient's plan. In this regard, doctors take immediate measures in cases where a patient needs to be examined by them, including referring patients to the centre if they experience excessive pain or other physical suffering. Whenever a PCA thinks that a patient needs immediate nursing care or advice, they contact the duty nurse for the community. Other than physical caregiving information, PCAs provide information about needed food items to the coordinators. The coordinators assess the information to understand whether they need to change any food items or change the amount they provide to the families.

The information provided by the PCAs helps the doctors, nurses and coordinators to accomplish the goals of total care in the community settings. Regarding the importance of their role, Doctor Jiniya, duty doctor of *Compassionate Korail* explained detail about how PCAs make the palliative care delivery easier:

> We highly rely on their update of the patient's physical condition and the other concerns of their families. Their role helps us to realize the goals of community palliative care to provide holistic care to those poor patients getting care at home. They contribute to stepping up the involvement of family members through their volunteering role. It helps us to ensure the food support we provide to the families. They make our work easier by building warm communication with the patients and their families. We have seen that the patients like being

> taken care of by the PCAs. Patients like spending time with them and PCAs come to know their material needs and mental sufferings. That helps other team members to formulate further caregiving plans.

In the following section, I describe why patients enjoy being with the PCAs, which in turn plays a key role in the provision of holistic and compassionate care in the community settings.

Allies of family members

Families find the PCA's role to be beneficial in terms of their staying at the same locality, illustrated by Mowshumi a family carer from Korail:

> My mother is in her final days suffering with several comorbidities. Sometimes she loses her senses and feels nauseous. Whenever it happens, I call Kakoli *apa* [a female PCA] through my mobile phone. If it happens during the day, she brings the doctor of Momotamoyee at our home. It's great that I can contact her easily and she can take some steps as well as the Momotamoyee office being just a walking distance from our house.

Some families appreciate the PCA's caregiving role because key members of the family do not have time to care for their relatives because of their job. As the community project provides for patients from lower-income families, most of the patients that the PCAs visit live in poverty. As discussed in Chapter Four, typically 6-8 family members including a spouse, their children, parents or in-laws will live in two small rooms. In terms of the dying patients' families, the patient is a parent of the husband or the wife in the family. Husbands or wives bring their parents to their house to take care of them in the final days. Although both the husband and wife look after their relatives, it is mostly female family members that take care of them; I consider how these families manage their caregiving role more widely in Chapter Seven. Here, in highlighting the importance of the PCA's role, I focus on the challenges for busy family members with jobs. In such families, the PCA's contribution is immense. Saleha, daughter of terminal patient Nurjahan describes how it is relieving that PCAs visit her house to take care of her mother. Both she and her husband are very busy with their job:

> I work as a maid in four houses. I go to those houses every day. In the same way, my husband is a night guard in an organization. When he returns home, he sleeps the whole day. I try to manage time for my mother [who is a lung carcinoma patient] during my break. After I am finished with one job, I try to look after her food and medicine. But sometimes I cannot come. Sometimes I forget. Sometimes my husband also takes care when he gets up. That's

> not a great way to take care of a terminally ill patient. It's such a relief that PCA Raju visits my mother sometimes. Though he cannot visit her every day, it's great that he comes once or twice a week.

Although most family members experience the PCA's visits very positively, a few family caregivers raised concerns which centred around the belief that it is the sole responsibility of family members to take care of their relatives. Mostly male family members strongly believe that it is their moral obligation to take care of relatives who are elderly and suffering from terminal diseases. In such cases, they feel awkward if their relatives are taken care of by an external carer who is not from the family bloodline. One family caregiver named Tahir, described it in this way:

> I am the only son of my mother. After she had been ill for the last six months, I brought her to my house. Me and my wife try our best to take care of her. Besides, it has been really helpful since we registered her with the Momotamoyee clinic. PCA Sharmin visits her sometimes to take care of the medicine and overall situation. Although her help does a great favour to us, I don't feel entirely good about it. It's nothing to do with the quality of care they provide. Rather, it's more to do with cultural issues. It is not well received in our society if family members need or appoint a carer from outside the family – people will think that the family is not interested in doing the caring work on their own. Moreover, it looks like we are being negligent of her. Our belief is that even though we do not have enough resources and time to take care of our parents, we must manage both despite our limitations.

While discussing this with the PCAs, several told me that they sometimes face difficulties regarding this issue. It was a challenging task for the PCAs to get along with the family members of the patients in the beginning of the community palliative care in Korail and Narayanganj. However, despite these cultural issues, PCAs are generally well received in the patient's families in terms of their efforts to care for the patients.

Beside their caregiving role, the community project initiative involves officials distributing daily essentials (rice, cooking oil, onions, potatoes, lentils) to terminally ill patients' families on low incomes. Eligible families can contact their PCA requesting to be included on the list to receive essential food items monthly. Azad, a family caregiver in *Korail* explained how PCAs help them to receive food items that are allotted for the dying patients:

> I have looked after my father's food and treatment since he was diagnosed with cancer. But it is difficult for a family like ours where I run a family of seven members including my father, my four children and my wife. My wife also works as a maid. Both of us manage the house rent, food, children's education and other necessary things. We literally live hand to

> mouth. Besides, both of our jobs are unstable. We have no savings as well. In this situation, Momotamoyee's food items are blessings for us. Otherwise, life would have been unthinkable. I am thankful to Liza *apa* for helping me to register my father on their list.

A patient's closest friend

During his interview a patient named Abdul Kadir, in his 70s, suffering from stomach carcinoma, talked about the funeral that would take place after he died. He said that wherever his funeral takes place, he cherished the thought that his PCA would be there. According to Bangladeshi cultural beliefs, this is an expression of love towards a person who is really cared about. It is a blessing if the dead person's loved ones are present at their funeral. This patient was referring in this way to his PCA. PCAs become closest friends of the patients in the community. The relationship that develops between them becomes a source of inspiration for them in terms of sharing and caring. Another patient, Hafez, is lonely for most of the day. His son and son's wife are busy with their work almost all day long. The only thing keeping Hafez happy is the company of PCA Rajib. Reflecting on how their intimacy grew, Hafez told me:

> Rajib [a male PCA] comes to me once a week. Now he is more than a family member to me. I talk about my life, my mental sufferings and everything that comes to mind. I found he listens to me enthusiastically which makes me feel great. I feel great because my family members show no interest to talk to me as they are always busy with their work. This is really great for me in this terminal stage of my life.

Patients expressed sheer enthusiasm for talking as it was a relief to talk to their PCAs about their lives. Physical care is very important for the patients but what is more important to them is that someone is talking to them during this stage of their lives. During the conversation, they complain about life, they talk about their childhood, they talk about their agonies and anxieties. A patient named Bodrunnesa pointed out that talking with the PCAs gave him more comfort than the prescribed medicine at the terminal stage of his life:

> Now I am in the final days of my life. Many people think that I am just worried about my physical condition. That is not the case. Mostly I prefer talking to people I love. If someone really cares about me, I would rather tell them to talk to me. That will serve me better than any medicine can do. I like Sharmin [a female PCA] because she talks to me. I love talking to her. That gives me great satisfaction. When I talk to her, I feel I am sharing my mental anxieties with a person who cares about me.

Some patients highlighted the flexibility in PCAs' working hours. Patients could contact their PCAs through their mobile phone outside their official work hours. There is no hard and fast rule for the patients if they want to contact their PCAs. Despite PCAs have certain working hours, they still keep in touch with the patients through their mobile phones. Sometimes patients even request them to meet them outside of their working hours. PCAs responds positively to such requests. PCA Rajib recounted such incidents:

> Patients want to talk with us a lot. Once a week is not enough for them. Therefore, I tell them to call me if they want to talk more. When they call, I meet them at their house and gossip for some time while drinking tea or eating snacks. As I live in the same locality, it's not a huge problem for me to meet them.

While considering their closeness with PCAs, some patients referred to their similarity with them in terms of class position and lifestyle, and being in the same community. Patient Akhlaak told me:

> I feel closer to Raju [a male PCA] because he understands my family sufferings. He understands the sufferings of nine persons living in two small rooms in Korail slum. He understands because he lives in almost the same situation as me. He understands the struggle of my family. Besides the struggles, I share internal matters of my family with him. There are so many things that I cannot share with my family members which I can share with him.

In addition, patients feel very good if someone visits their home out of compassion and care. As the PCAs visit the patients at their home at least once a week, patients feel cared for by them. A patient named Morjina told me:

> PCA Sharmin comes to see me very often. I feel great that there's someone who cares about me. I don't feel left out at the end of my life. Besides, it is known in our culture that if someone comes to see a critically ill patient, it means that person loves you a lot.

With the involvement of PCAs, patients feel attached and connected. The intimacy grows and intensifies because first, through talking, the PCAs give time and attention to patients, and patients can share their thoughts, feelings and sorrows. Second, as the PCAs and patients are from the same community, patients feel more attached to PCAs through their similar community experiences; especially their social and economic conditions such as their living arrangements in the slum or lower-income households and the agonies and frustrations over their unfulfilled wishes. Third, PCAs' patient care is different from the care a patient receives in a healthcare setting. The care and attention the patients receive at home is like from that of a close relative. Because of the home visits, patients can relate culturally to the idea that someone akin to a close relative is visiting them to take care. However, PCAs described the way that the relationship they developed with the patients was not only a relationship of care giving and receiving. They reflected upon the depth of the relationship, which hints towards a different dimension in palliative care.

'Death means the death of a relationship'

While reminiscing about the patients she had taken care of, PCA Kajol mentioned a patient whom she still remembers and misses. Her name was Ruby and she had lung carcinoma. Kajol took care of Ruby for almost a year before her death. Kajol mentioned that she had been a very good friend of Ruby's during the caregiving days. Her residence was just 10 minutes' walk from Kajol's home in the community. Therefore, whenever she could make some time, she visited Ruby. She used to visit her home for scheduled visits and outside her work hours. Whenever Ruby used to feel lonely, she called Kajol and asked her to visit. Ruby, in her 40s, had two children under the age of 10. Her husband had left the house a few years earlier, saying that he was going to search for a good job so that they could live peacefully with the income from his work, but he did not return. Ruby had filed a police report, asking them to search for her husband, but there had been no update. She still firmly believed that her husband would return. She used to share her frustrations and anxieties with Kajol. Kajol still remembered that Ruby called her "an angel from God to give her peace in her final days". The day she died she called Kajol over the phone to come to her home immediately. Kajol ran to her, and found her struggling with severe pain and having difficulty breathing. She told me how she felt when Ruby was dying:

> Ruby wanted me to be beside her when she was dying. She felt good that I was beside her. I couldn't imagine what to do. Although I knew that she would be dying soon it was different and horrible to see that she was dying. I was feeling that I was losing a family member of mine. Before her last breath, she asked me whether I could ensure that two of her children went to school. She also gave me the address of one of her relatives so that I could communicate with them to tell them about her death and taking care of her children.

After Ruby died, Kajol took care of everything she had requested. Kajol firmly believed that Ruby was the only person in this world whom she had loved unconditionally. Kajol felt complete thinking that. She said:

> Every now and then, I know people who are not my family members, but they become like my family after I start taking care of them. Palliative care gave me so many close relatives who are not related to me by blood, but they are related to me by my soul. Whenever they die, I feel like a relationship just died.

'Palliative care gave me spiritual meaning of life'

When I talked to PCA Rasel, he told me why he loves taking care of dying patients. Now in his 20s, Rasel lost his parents as a child after a major fire broke out in Korail slum. Luckily, that day he was in one of his relatives' houses on the other side of the slum. Since age 13 he had joined many voluntary organizations, such as the fire-fighting team and a tree plantation team. But, he felt that joining the palliative care team in the community was more encouraging and virtuous than any other activity he had done before. He said:

> Helping dying patients has a special value in our society. By taking care of dying patients, one can take care of the people who need the care most. Also, by taking care of them, one can also find spiritual accomplishment. In my case, by taking care of them, I feel like I am taking care of my parents.

Rasel also said that he learns a lot about life from the patients he takes care of, most of whom are elderly. When he visits a patient's house, they like to talk to him. He listens to them. They talk about their achievements and failures in life. They also share their life lessons with Rasel. What he loves most is the gratitude of his patients towards him. He later shared with me what one patient had told him – one week before the patient died:

> The care you are providing me is nothing I could expect that I would get at this stage of my life. I feel so lucky about the fact that, instead of having bad times, I am having a good time in my final days. When I talk to you, I feel that there is someone who listens to me. When you talk to me, I think that there's still someone who gives importance to me. I pray to the Almighty so that he accomplishes all your wishes.

Physical care provided by the doctors and the non-physical care delivered by the PCAs are discussed in the following section. Global disparities are at the heart of the discussion. It reflects how total care looks like in a Bangladeshi setting.

The findings show the limitations of care management in a formal settings and strength in an informal setting. As the need for the care of the dying is immediate and there should be at least something at place at present, informal management of care is significant despite the limitations in formal care delivery.

Summary and Discussion

This chapter explores how Bangladeshi providers deliver palliative care to dying patients to ensure a good death. Here, good death consists of two types of care: physical and non-physical. The latter includes mental, psychological, and spiritual care, the components of total care alongside physical care. In western high-income countries these four components are usually delivered by multiple professional teams in specialist palliative care settings such as hospices, and in hospitals and care homes, using advanced skills (Quill and Abernathy, 2013). The present chapter shows how these components of total care are delivered by the Bangladeshi providers; with the involvement of the doctors and the PCAs in both formal and informal settings

Physical care is mainly provided by the doctors in the centre with PCAs delivering non-physical care. For physical care, doctors are experts in consultations about opioids and their usage. Due to restrictive drug regulation acts, opioid delivery is sometimes hampered because of the strict bureaucracy arising from the CPC's opioid usage protocol. Although effective communication is key for delivering both physical and non-physical care, many doctors are not yet properly trained for effective communication with patients at the end of life in Bangladeshi healthcare settings. PCAs are better placed to build warm relationships with patients and their family caregivers. PCAs act as a bridge between doctors and patients, and as close friends of dying patients, developing family-like relationships with them.

The key contribution of this chapter is that it illustrates how total care is delivered in a Bangladeshi setting. Below I discuss how physical care delivery is considered in the context of restrictive local acts for opioid usage, and how international responsibilities for care can be approached with the concept of care ethics. Afterwards, I argues, despite the complications in physical cafre, non-physical care is delivered, focusing on the social support network established by PCAs. I consider physical care in relation to the bigger picture of opioid crisis in lower-middle income countries, with PCAs' role discussed in relation to notions of care ethics (Kittay,

2001) in a compassionate community network, or how a mobilizing social network can support one another in a natural setting, rather than the care provided by professionals. I argue that total care should be adapted locally, alongside universal suggestions or guidelines. Considering the limitations of opioids in the country and the strengths of social support networks, I highlight how palliative care is managed locally in Bangladesh. I also show that, despite the structural limitations in formal palliative care delivery settings, total care can still be delivered through supportive community networks in Bangladesh to meet the immediate needs for the dying. Exploring how total care is managed locally in a lower-middle income setting, I argue that total care is delivered with local adaptations of care management, which are to be considered remarkable, instead of purely formulating a universal framework for ensuring palliative care in coming decades.

Challenges in Physical care: Global disparities in opioid availability

Findings in this chapter highlight physical care delivery that is dependent on two restrictive drug acts in the country; the Narcotics Control Act 1990 and the Bangladesh National Drug Policy 1982. The former regulates the production, distribution, transaction, possession, transportation and cultivation of narcotics in Bangladesh. The Act was passed by the parliament of Bangladesh. It revoked previous laws, including the Opium Act of 1878, the Excise Act of 1909, the Dangerous Drugs Act of 1930, the Opium Smoking Act of 1932 and the Prohibition Rules of 1950. There were later amendments to the Act in 2000, 2002, 2004, 2018 and 2020. Clause 10 (1) (c) prohibits the production of medicine from alcoholic ingredients. Clause 10 (3) states that if a patient must use any medicine that contains alcohol, the patient must have a clearance certificate that is certified by the responsible doctor, specifying the disease and why the patient needs to receive the medication (Narcotics Control Act, 1990). The Second Act – the Bangladesh National Drug Policy 1982 – forbids any combination of analgesics apart from paracetamol and caffeine. Codeine phosphate is prohibited due to fears of addiction (National Drug Policy, 1982). Only four pharmaceutical companies currently have permission to import opioid raw materials, and to manufacture and market opioids. The Narcotics Control Act 1990 makes it extremely difficult for patients and their family caregivers to obtain opioids. The National Drug Policy 1982, makes it difficult for pharmaceutical companies to produce opioids.

Out of the ten pharmacies in Bangladesh approved to stock morphine, nine are in the capital city, Dhaka. Oral morphine tablets first became available in Bangladesh in 2006, when one pharmaceutical company was permitted to manufacture a 15mg sustained release form. Morphine injection and pethidine are also dispensed, but there is no oral immediate-release morphine available. In terms of affordability, one morphine tablet costs around 10 taka (£0.09). The fentanyl patch is imported by multinational companies and costs around 300 taka (£2.70) for a 25 mcg/h patch (Dehghan et al., 2010). Considering the costs are out of reach for extremely poor patients, the CPC provides opioids free of charge. Around 20.5% of the population are living below the poverty line (ADB website report, 2019). Almost 90% of extremely poor families earn less than $23.80 in a month; less than $1 per day (PKSF statistics on poverty, 2020). These two drug control Acts are one aspect of the wider problem of opioid crisis in lower-middle income countries. It is an enormous task to ensure pain relief for dying patients in lower-middle income setting like Bangladesh. The above findings of physical care vividly indicate that the protocols created by the drug regulations act severely prevent patients and family caregivers obtaining opioids. Although CPC ensures availability of opioids, it is extremely difficult due to the bureaucratic process required to ensure that patients consistently receive them.

Such drug act exists not only in Bangladesh but also in many other lower-middle-income countries. Many of those countries are taking initiatives to ease restrictive acts to make opioids more available. India, Nigeria, and Uganda have already taken such steps (Steedman et al., 2014). In Uganda, an amendment to the National Drug Policy and Authority Statute was passed in 2004. The country allowed palliative care nurses and clinical officers—providers in a category of specialized medical assistants - to prescribe morphine. This dramatically affected who could prescribe and receive morphine in Uganda. In India, in February 2014, after years of advocacy from the World Health Organization, and several health watch bodies, the Indian Parliament passed the Narcotic Drugs and Psychotropic Substances (NDPS) Act Amendment Bill, which simplified the legal regulations on opioids. Previously, multiple licenses were required for agencies to procure morphine. Under the 2014 amendment, only one license is required from the

State Drugs Controller, which should make morphine much more available and accessible. However, opioid consumption is still very low in those countries (Steedman et al., 2014; Jayawardana et al., 2021). The opioid crisis is one of the reasons for why there are still acute inequities in palliative care.

Inequities of opioid crisis in lower-middle income countries is so pervasive that its availability cannot be guaranteed by amending restrictive acts in such countries alone. Rather, international initiatives should be at the forefront in this regard. Before considering these international responsibilities, I first consider how Bangladesh, a lower-middle income country experiences death inequality, in terms of not having the required opioid availability due to the crisis.

In relieving total pain or in giving total care, patients' pain relief is a significant aspect of palliative care in any context. Opioids are essential for the pain relief for dying patients in both high-income and lower-middle income countries. Its availability ensures a major part of physical care delivered to the patients. A gross inequity exists between higher and lower-middle income countries in regards to access to pain control. High-income countries account for nearly 92% of medical morphine consumed in the world but contain only 17% of the total population. In contrast, lower-middle-income countries, representing the remaining 83% of the world's population, account for a mere 8% of the total morphine consumption (INCB, 2011). Only 0.03% of the total morphine-equivalent opioids are distributed worldwide annually; during 2010-2013 an average of 298.5 metric tonnes was supplied annually to lower-middle-income countries (Knaul, 2018). More than 80% of available morphine was directed to high-income countries in regions such as North America and Europe in 2021. These countries consume, on average, 63 times as much morphine as low-income countries, in terms of daily doses per million people (Burki, 2023). Whilst the consumption of opioids for medical purposes is increasing in western high-income countries, especially in North America, Western and Central Europe and Oceania, this is not the same elsewhere (Berterame et al., 2016). A longitudinal study of per capita consumption of analgesics in various countries from 2000-2015 found that inequality in opioid consumption between lower-middle and higher-income countries increased over that period. Despite the dire needs of pain relief for the death and dying, almost 6.5 billion people live in countries with lower consumption of opioids (Scholten et al., 2019). While opioids are available in 77 per cent of high-income countries, in contrast only 15 per cent of low-income countries, 14 per cent of lower-middle income countries and fewer than half of upper-middle income countries have availability of oral morphine, according to a WHO report (Sharkey et al., 2017). The disparity between higher-income and lower-middle income countries is much larger in ‘pain control’ than in any other medical practice. As a result, individuals in lower-middle-income countries die with pain and discomfort (Poudel et al., 2019).

Regarding the impediments in lower and lower-middle income settings, a comparative study surveyed 214 countries to identify the barriers to availability of opioids, analysing associations between impediments and use from 2001-2003. Bangladesh was in 126th position in terms of the national consumption of opioids amongst all countries (Scholten et al., 2019). The situation is worse to date in Bangladesh in terms of the national consumption of opioids. Barriers to opioid access in Bangladesh include: absence of awareness training of medical professionals, risks of addiction, restricted financial resources, issues in sourcing, and cultural attitude (Berterame et al., 2016). Similar findings arose from a survey of Bangladeshi physicians, who have been found to have poor knowledge, a negative attitude, and a lack of training regarding opioids (Khan et al., 2014).

The opioid crisis is a crucial reason for such gross inequities in palliative care between high-income and lower-income countries. To tackle this crisis, international policy recommendations prioritize the lifting of these restrictions on the usage of opioids in all lower-middle income countries. One such recommendation is in the Quality of Death Index, where ‘availability of opioids’ is an indicator in the category of ‘quality of care’ (The Economist Intelligence Unit Quality of Death Index, 2015). ‘Availability of opioids’ is regarded as the most fundamental factor within palliative care for ensuring a good death and attaining good palliative care. This indicator was weighed highest (30 per cent) in the ‘quality of care’ category (which accounts for 9 per cent of the overall index). Here, Bangladesh was ranked 77 out of the 80 countries surveyed (The Economist Intelligence Unit Quality of Death Index, 2015).

Considering the complexities of opioid crisis in lower-middle-income countries, death is globally unequal in terms of the people achieving a ‘good death’. Amid wider discussions on medication in palliative care around the world, the picture of death and dying has been described as ‘unbalanced’ and ‘contradictory’ (Report of the Lancet Commission on the Value of Death, 2022). The report focused on the excessive medication in higher-income countries and the lack of access to basic pain relief in lower-middle income countries:

> The story of dying in the 21st century is a story of paradox. While many people are overtreated in hospitals, with families and communities relegated to the margins, still more remain undertreated, dying of preventable conditions and without access to basic pain relief. The unbalanced and contradictory picture of death and dying today is the basis for this Commission. (Report of the Lancet Commission on the Value of Death, 2022, p.10).

The delivery of palliative care remains inadequate for people living in lower and middle-income countries. The number of people who will die with extreme suffering at the end of life is projected to increase significantly in coming decades. A recent populations-based projection study provides clear evidence for strengthening palliative care for cancer across low- and middle-income countries. It estimates that by 2060, 16.3million people with cancer will die every year with serious health-related suffering, with the most rapid increases in low-income countries (Sleeman et al., 2021).

In the light of the strict opioid protocol followed in the CPC, it is clear that the crisis in lower-middle income countries is a complex problem. Although it is not the objective of the present study to explore global economic inequality, consideration of inequities in palliative care provisions are essential. Recent discussions on inequality indicate that, since globalization, especially since the 1980s, inequality between countries has decreased but inequality within countries has increased (Hung, 2021). This view is echoed in many recent academic discussions (see for example Milanovic, 2016). Inequality is measured on a global scale, meaning global interpersonal inequality has declined as if every individual lives in a big country (Milanovic, 2016). The same conclusion is echoed in World Bank report published in the same year (World Bank, 2016). Repeating Milanovic’s data, the report concludes that global inequality has been narrowing since the 1990s. The narrative of the narrowing of global inequality by the World Bank has been criticised by Hickel (2017) for not addressing inter-country inequities. The narrative implicitly regards the disparate fortunes of poor countries and rich countries as separate and unrelated phenomena, which has the effect of depoliticising the analysis of global inequality. By contrast, Hickel argues that global inequality must be understood as a relational phenomenon, meaning inequalities should be considered between higher-income and lower-income regions, which can bring geopolitics into consideration. Inequalities should be understood as an analysis of the gap between poor regions and rich regions that not only looks at the internal conditions of each country, but also attends to the balance of global power: which states to determine global economic policy in their own interests (Hickel, 2017). Global inequality increased between regions, specially between Global north and the Global south, in this regard.

In relation to the impact of the opioid protocol followed in CPC because of the two restrictive Acts, physical care delivery is deeply related with tackling the opioid crisis around the world, mostly in lower-middle income settings. Calls for easing of Acts do not ensure that the crisis will be resolved. Instead, a recent study on global allocation of covid-19 vaccines shows a viable approach to ensure international responsibilities for care (Robinson, 2021). The covid-19 pandemic explicitly showed the vast inequalities both within and among the world's nation-states, mostly in relation to the allocation of covid-19 vaccines. Moral issues surrounding global injustices related to health equity came forward. A relational ethic of care was prioritized to reveal some serious limitations of the dominant global distributive justice paradigm, especially with ethical consideration of the COVID-19 pandemic, in the study. Global distributive justice approaches provide a set of rational ethical principles that can be exercised universally. The approach is rule-based and rationalist. It follows traditional international theories that expresses a world divided by boundaries, whether as physical borders or limits of jurisdiction and principle (Robinson, 2013). The author argued that, the justice paradigm does not work when it comes to any health inequality between and within boundaries. Rather, ethics of care or care ethics helps us to see the diversity and complexities of ethical questions raised during the COVID-19 pandemic. Care ethicists argues that boundary-based justice system does not reflect the way in which morality actually operates in real lives, where moral judgement is interrelated and interconnected between and within groups. Distribution of vaccines are not just an issue about equity between countries or nations but also more complex questions regarding which groups have access or not in a single country as well (Robinson, 2021).

In a similar way, opioid inequity can be addressed with care ethics approach to consider the inequity amongst and within countries or nations or amongst and within groups in a setting. .

Besides ensuring international responsibilities for ensuring opioid equity, the lower-middle income country like Bangladesh can still deliver palliative care with the limitations of physical care. Although there's no specialized professionals such as, psychologist, or chaperon for ensuring non-physical care, informal management of care is still possible with the application of 'compassionate community' model, also called as 'Kerala model'. Informal support is required to deliver an immediate support to the dying. Informal support is required for two reasons. One, despite the opioid limitations, palliative care should be continuously delivered to the burgeoning numbers of dying patients in the country. Two, as palliative care also consists of non-physical care and a natural supportive community is found in Bangladeshi setting, the strength of it can be utilized for the continuation of the service through compassionate community network, in which, an informal support network naturally support each other in the same neighbourhoods.

Non-Physical care: Palliative care through compassionate communities

Specialized or professional services for non-physical care, which are available in many high-income western countries, are not yet available in Bangladesh. Non-physical care is delivered through the compassionate community model, inspired by the Kerala model of palliative care with the involvement of a community social support network or informal support system. The following brief overview of professional services for non-physical care is followed by how the compassionate community model differs from that.

In most developed parts of the world, non-physical care or psychological, mental, and spiritual care is delivered at the end of life in formal healthcare settings and is also known as specialist palliative care (Heath et al., 2000; Carnall, 2000), with the expansion of experts for each component of palliative care. Psychological, mental, and spiritual needs are also delivered by the experts in the same way physical care is handled by an expert physician. Services have become increasingly expert in identifying health and social care needs, and meeting these needs with professional services is known as a service delivery approach to care (Abel et al., 2013) or 'patient-centred care. Patient-centred care is when patients are treated by experts and skilled professionals after being diagnosed with terminal illness and results in increasing specialisation and professionalisation. Palliative care specialists include not only doctors and nurses, but also chaplains, social workers, physiotherapists, occupational therapists, art and music therapists, psychotherapists, complementary therapists, and so on. A fragmented expertise is observed in such care (Abel et al., 2013). Here, a patient is surrounded by multiple professionals at the end of life. A high value is given to individual autonomy, the right to information, freedom of choice and the dignity of a dying patient in the Western context for all countries. Such services are mostly available in western high-income countries, and it is widely acknowledged that hospice and palliative care might become a form of institutionalised ‘good death’ (McNamara et al., 1994; McNamara, 2004). This patient-centred care has been seen as an example of the sequestration of death from social life (Lawton, 1998), meaning a natural community network is not usually involved.

Despite a professionalized care approach largely confined to hospices or hospitals, community involvement for death is at the heart of discussion in recent times, in regards to how death is handled in communities. The concept of Compassionate communities is such an approach to understand how end of life care or palliative care can be delivered in societies, irrespective of whether they are contained in high- or lower-middle income countries. The concept of compassionate community is part of the public health approach to end-of-life care that offers the probability of tackling the inequities of the differences in provision of care in lower-middle income or lower-income countries, for people with incurable cancer and those with non-cancer terminal illnesses. The naturally occurring supportive network surrounding the patient is at the centre for such care. Healthcare professionals can build much stronger partnerships with these supportive networks and transform end-of-life care at home. Further possibilities of support can be developed through communities (Abel, 2018). The concept of Compassionate Community follows the principles of the 1986 Ottawa Charter for Health Promotion and applies them to end of life care, which becomes a community responsibility. ‘Community’ can be an entire city, a school or factory, a slum or a dying person’s own social network. The idea of Compassionate community is primarily drawn from Kellehear’s (2005; 2007) critique of professional services in palliative care in which he advocated for community involvement, rather than a professional approach. Instead of a patient surrounded by multiple professionals in patient-centred care, the dying person and informal carers are at the centre of a social network including not only family, but also friends, neighbours, colleagues, employers, schools, faith community, and so on, with potential to help the person or more likely their carer with practical, social or emotional support in a compassionate community network (Abel et al., 2011; Walter, 2017).

A practical example of the concept of compassionate community that Kellehear posits had been absent until the advent of India’s Kerala model (Kumar, 2007). Although this model was not directly inspired by Kellehear's thinking, it resembles notions of compassionate societies in relation to the use of dying people's existing community social support networks. Kerala provides a large-scale and long-running model of how compassionate community can work at end of life. Local networks of 10-15 volunteers identify patients at end of life in their neighbourhood, organise appropriate care and coordinate with medical services; overall, the Kerala scheme covers a population of over 12 million people (Kumar, 2007). Compassionate communities mobilise local social networks that surround volunteers, as in Kerala; or families mobilising their existing networks. Instead of professionals supporting the dying and the family caregivers, the model focuses on how existing informal social support networks can support the dying person and their family.

In contrast to specialized or professional services for dying patients in high-income countries, in the present research, I show how caring relationships develop between the PCAs and dying patients in an informal social network in the community in *Compassionate Korail* and *Compassionate Narayanganj*. One of the characteristics of this caring relationship is a family-like relationship. In this regard, the caring activity has dimensions such as interdependence and relationality. Here, I argue that non-physical care in this Bangladeshi setting relies upon the relational element between caregivers and care receivers. Instead of a western approach that prioritises patients' independence and autonomy, relationality and interdependence are key in the Bangladeshi patient experience. Societal values and norms already predominant in Bangladeshi culture such as family values, collectivism and neighborhood networks underpin this relationship. The concept of care ethics is essential to understand how an informal support network can be effective in non-physical care delivery in a lower-middle income setting in Bangladesh.

The concept of care ethics echoes understandings of compassionate communities across different phases of life. One characteristic feature of care ethics is its relational ontology. It depicts human beings not primarily in terms of independence, but conceives us as mutually interconnected, vulnerable and dependent, often in asymmetric ways (Pettersen, 2011). Care is a reciprocal relationship based on mutual dependence between two people (Fine and Glendining, 2005). Kittay (2001) suggests that dependency, although having negative connotations, is not an artificial or external social condition. Dependency is experienced in childhood, disability, old age and, in this case, when a person is suffering from an incurable disease. However, western thinking frequently denies the reality of dependency in order to promote individual autonomy. In Bangladesh however, relational autonomy is preferred during the patient’s end-of-life.

Dependency between the PCAs and dying patients is the basis of the unique relationship between them. In the context of end-of-life care, dependency is experienced when a patient is suffering from an incurable disease. It is the foundation of the relationship between PCAs and themselves.

Although care ethics deals with care relationship of various types of care activities, very few works critique palliative care through the concept of care ethics. Liz Lloyd (2004) worked on the tension between the concept of dependence and autonomy. By exploring the complexity of the relationship between ageing and dying, the paper demonstrated a critique of independence and autonomy characterised in the contemporary end-of-life care policies and practices in the UK. Lloyd applied the concept of a feminist ethics of care approach, and argued that the inter-relatedness of human beings and the importance of social context is overlooked in contemporary end-of-life care provisions in the west.

Moreover, both care ethics and compassionate community strongly suggest that human beings are relational beings (Fine and Glendining, 2005). In a natural social setting, people are dependent upon each other for caring support whether it is care in general or care for the dying. Both concepts are based on the idea that human beings are interdependent and have reciprocal requirements and capacities for care. In the same way care ethics demonstrate the connectedness of people in everyday life, compassionate community also calls for support from the natural social network in everyday life. The current study found such notions between PCAs and dying patients. The data shows patients become deeply attached to PCAs. The reasons for attachment are: 1) patients were able to share their feelings with PCAs besides the care activity; 2) they shared a similarity of economic background and life experiences; and 3) care took place in patients’ homes rather than a healthcare institution. These suggest that the relationship formed between them is more like the natural relationship in our daily lives that is based on interdependency, relationalities, and reciprocity, than a patient-professional relationship (Lloyd, 2004).

In Compassionate Korail, inhabitants are from a lower economic background and share the same housing condition. Their houses are tin-shed, where more than three households live. Each household has two tiny rooms (not more than 150 square feet) with a common toilet for three/four households. Inhabitants experience similar complications in their daily lives, mostly in terms of managing energy crises and other amenities with their limited income. In Compassionate Narayanganj, most of the patients are similarly from a lower socio-economic background and share a commonness of the sufferings they go through every day.

Compassionate community is discussed widely in this chapter to address the inequity issues that exist in Bangladesh. It is an alternative approach to adapt the limitations due to economic inequality in the country. The previous section on opioid provision in Bangladesh in the context of inequality helps us to understand the reasons for physical care challenges in the country; similarly, the concept of compassionate community helps to understand how non-physical care is delivered despite the absence of opioid availability or specialized palliative care in the country. Moreover, the Compassionate community offers an opportunity to address inequities in end-of-life care irrespective of diseases and inequality amongst countries (Abel et al., 2018).

In contrast to expensive and formal care arrangements, Kumar (2007) highlights the compassionate community model to address the limitations in a lower-middle income setting or to utilize social connections in those settings. Typically, this alternative approach draws on the concept and theory of social capital, and the relevance of social connections, together with related norms and trust. Such trust is found between the family-like relationship of patients and the PCAs.

The concept of Compassionate Community is about getting the community involved. Non-physical care delivery beyond the formal palliative care system does not rely on the formal health system in Bangladesh because the infrastructure of the formal health system is expensive and time-consuming to develop in low-middle income countries. It is therefore logical to turn to alternative solutions to the challenges of providing palliative care in the near future, hence the rationale for following the Kerala model. One of the aspects of the Kerala model is that social relations in Kerala seek to utilize the powerful role that normal social relations play during death. Caregivers are therefore recruited from their own communities and neighbourhoods.

Compassionate Korail and Compassionate Narayanganj are two experimental projects that explore whether the Kerala model can be translated in Bangladesh. Despite differences between countries and cultures, Bangladesh and India share some common cultural characteristics. One is the role of family and another is informally developed neighbourhood support systems networks.

As Palliative care as a specialty began only a few decades ago, CPC investigated how family and neighbourhood can be of importance in delivering palliative and end of life care outside of the formal healthcare settings.

PCAs are paid very little as a gesture of showing respect to their willingness to come forward to help the dying. Though PCAs are being paid for the job they are doing as a caregiver, like Kerala, relations are based on mutual trust and social connections that are key for compassionate communities. In this context, the global south, despite its barriers to healthcare access, has more potential to promote and practice free-flowing compassion among community members than the global north (Zaman et al., 2017)

But the philosophy of the PCA service is informal, because they are not professionally trained like other providers and have no specialized qualifications. They are neighbours who have come forward with their own interest and initiative when given the opportunity to help. Even though they are being paid, they are not there just for an income; they are doing a type of community service. Despite the little payment of the PCAs, it is an informal social support system in which neighbours take care of each other.

In such an informal support system, patients mentioned that they feel closer to the PCAs than a professional caregiver. Patients repeatedly mentioned that the reasons for their closeness with PCAs is shared experiences of living in the same community. It can be said in the context of Korail: their daily struggle is almost the same. Most of the people living in Korail receive a low income. Some are small traders, other old men, rickshaw pullers, garment workers, or daily laborers. Many of them eat only once a day. Most of these inhabitants in Korail slum migrated to Dhaka city for various reasons: some have become homeless due to riverbed erosion, some have become homeless due to floods, some have lost their farming land and become helpless. The standard of living of those are far from the standards of modern living in the west or countries from the global north. Only those who go through this same struggle understands the pain and sacrifices made. Therefore, a bonding is forged between the patients and the PCAs, in relation to the similar experiences of the past and shared experiences in the present.

In specialized palliative care, the relationship between the professionals is primarily a relationship between a patient and a professional. Where else, a family-like relationship developed between the PCAs and the patients in compassionate community setting, even though they are not family members. Considering differences between specialized and community services, it is not important whether the patients and the caregivers are from the same neighbourhood, which is an essential element in compassionate community model. Patients' conditions are understood more as terminal illness which can be treated or managed to have a good death in specialized care or institutional care. However, in Bangladesh, dying is perceived as a human condition that has a value in the whole community. PCAs illustrate how a neighbourhood support system can help develop a relationship while delivering non-physical care to dying patients. It is the opposite of the care provided in the healthcare settings. Patients are networked with family members, neighbours, and healthcare professionals in the community network. Dependency upon PCAs is significant here, where it is not of the same essence in specialized palliative care. Naturally occurring support systems from the neighbourhood and dependencies are two connecting elements between the concept of compassionate community and care ethics. Just like the compassionate community model, ethics of care also suggest that caring responsibilities exists in societies outside of the professionals' arrangements take place in healthcare settings. Key to such caring responsibilities is the inevitable dependencies at various stages of human lives. In this respect, death is such a stage that addresses human vulnerabilities and dependencies upon each other.

In the following, I explain compassionate community through the concept of 'Care beyond the dyad' and also discussed power within care relationships.

Compassionate communities: Discussion with care ethics concepts

a)Care beyond the dyad

Care for the dying in a compassionate community setting in Bangladesh calls for wider discussion on how caring roles can be played effectively in a broader set of relationships. In this case, I discuss whether a compassionate community model can be a demonstration of care beyond the dyad or not.

Care is significantly performed amongst the family members, friends, or relatives. But I focus here on the PCAs. Even though they were not family members, friends or relatives of the dying patients in the compassionate community settings, there is a new relationship developed which is interdependent, relational, reciprocal and connected. In contrast to what care ethicists vision that caring relationship should take place beyond the dyad, beyond the closed network, PCAs relationship demonstrate a fragmented version of care beyond the dyad.

Care beyond the dyad, according to Barnes, suggest a care system acknowledges that the care relationship does not only consist of two people, but also the other members of the society. It suggests understanding reciprocity in care without assuming a contractual basis (Barnes, 2012a). Families become involved in caring because of their nested obligations towards the person they are taking care because of their vulnerability, illness or in this case, dying phase of their lives. On the other hand, professional healthcare providers become involved for ensuring services that is expected from them due to the market arrangement of caring services in healthcare settings. Barnes suggest thinking beyond this where there will be no such family obligations or economic obligations. There should not be any nested obligations or nested dependencies in care beyond the dyad.

There are other characteristics define the care beyond the dyad. These are: 1. it suggests multiplicity of care, meaning care should not be unidirectional, it can take place in any direction and care for the care providers is also an important thing to consider. 2. It questions unequal power relation between care givers and care receivers also can be understood as the power of capacity vs vulnerabilities of the patients for their needs. It is critical of the caring relationship of just two people. Rather, it argues how responsibilities for care can be ensured beyond the dyad. 3. Calls for expansion of care who are not physically present in care activity. People who are not directly involved, such as policy makers and other members of society or community also need to nurture care in mass imagination.

According to Barnes,

> ‘To care for unknown others demands a moral imagination that transcends the immediate and concrete stimulus of interpersonal interaction or the recognition of apparent shared interests promoted by communitarian values. It is prompted by recognition of the vulnerability of us all and by an acceptance of responsibility that goes beyond that felt for those within our inner circle’ (Barnes, 2015)

4. Considering time of care as a significant matter, in regards to focus on the starting and end point of need when looking into professional carers work and explore close relationship to look at the impact of previous relationship.

Reflecting upon these characteristics, I discuss whether PCAs involvement in caring the dying patients in a compassionate community model can be a demonstration of care beyond the dyad or not. According to the Compassionate Community model, PCAs are recruited and appointed from the same community of patients. They are not the patient's family members; neither are they professional care workers. Inspired by the Kerala model in India, the objectives of the Compassionate Community model is to educate people about the palliative care and train volunteers from the households of the community. The model has two major aims. First, to manage end-of-life care in a lower-middle income setting in terms of managing the care expenses by the community itself, not by the market or state. Second, to utilize the strength of community support network in a society where compassion flows smoothly than many societies.

The following characteristics are described on the relationship between the PCAs and dying patients in the compassionate communities of Korail and Narayanganj. Firstly, PCAs involvement is not prioritised for being family members, friends or relatives. Rather, their involvement is prioritised for utilizing the supportive neighbourhood network exist in the community they live. Secondly, PCAs are not involved in the caring activity that elicits any nested obligations and responsibilities found amongst family, friends and relatives. Neither they are involved from any contractual obligations like the professional healthcare providers. However, they receive a little payment as an incentive to educate people in the community about palliative care. They are initially recruited to utilize the social capital exist in the community. Thirdly, the supporting network in Korail and Narayanganj suggest a multi-directional care netwrok. It means caring responsibility is everyone's in the community. For example, in future when there is a dying patient in PCAs family, other person from a different family can play a role as PCA. Therefore, an interdependent network is encouraged considering the potential of supporting network exist in the neighbourhood.

In relation to the above characteristics, it is found that, in compassionate community model in Korail and Narayanganj, to a certain extent the model demonstrates the notions of the 'care beyond the dyad'. However, the model in Korail and Narayanganj does not demonstrate whether the caring network can be developed effectively amongst the strangers or whoever not present in the community. Compassionate community model relies significantly on the immediate social support network people have in the neighbourhood community. But care ethicists argue that, care should transcend the interpersonal and immediate interaction. They propose a universal communitarian value that recognise the vulnerability and dependency upon others in human lives and accept the responsibilities beyond any immediate network or a closed circle of family, friends or relatives. As caring activity is unidirectional, care pose a burden to the providers and have potential for exercising power upon the care receivers by the providers care ethicists suggest to go beyond the dyad or the immediacy of the relationships (Barnes, 2015).

b) Power within care relationships

Regarding the power relation between the PCAs and dying patients, there’s a different dimension found in the study. The data shows that, PCAs perceive obligations towards the dying patients and elderly in the community. This is close to Kittay’s ‘nested dependencies’ and ‘nested obligations’ (Kittay, 1999) that is supposed to be in contrast with care beyond the dyad. In the care beyond the dyad, there should not be any nested obligations or nested dependencies, so that the care givers, whether they are family or friends, do not feel obliged to bear the burden of care activities, according to care ethicists. Even though the PCAs are not family, friends or relatives, their obligations are culturally driven. Although obligations are thought negatively in the care ethics, it is not found as such in this study. Care ethics cannot explain how that works.

In the compassionate community setting, care is being delivered by people who are not closely related but from the same community. Even though they are not closely related, care was delivered with an empathetic relationship between the care givers and the care receivers (PCAs and Patients). While talking about that relationship, patients do not mention about powerlessness, rather it’s the cultural expectation of being taken care by the neighbourhoods, found in the study. On the other hand, PCAs mention about obligation about taking care of a dying patient or an elderly person, that is not only limited amongst the closed network but also amongst the members of the same neighbourhood or the community.

In terms of moral imagination of care by the people who are not actively present in the care activity, Compassionate community model in Korail and Narayanganj creates a dialogic space for thinking about dying care for unknown others. PCAs relationship with the patients shows how terminal phase of patient’s lives create an empathetic and family-like relationship. PCAs start taking care of the patients after being diagnosed with incurable diseases. Patient starts knowing them in their final days. Apart from the caring activity, they become deeply connected to each other. PCAs become connected believing that they are caring a patient who are like the age of their parents or grandparents. They reflect about death and motivate themselves through cultural codes such as, caring obligations towards elderly or dying patients. On the other hand, patients feel attached to them that someone is taking care of them even though they are not family members or friends or relatives. They think they are being valued in the community through the caring activity modelled by compassionate community.

Dependency between the PCAs and the dying patients are basics of the unique relationship between them. In the context of end-of-life care, dependency is experienced when a patient is suffering from an incurable disease. In the present study, PCAs relationship with the dying patients in compassionate community settings exhibit several characteristics. One, the caring relationship is formed between people who are not immediately related, or they didn't know each other before. Two, however, dependency is contested in care ethics because of the power issues related in the dependency of such activity between care giver and care receivers. Three, power within caring relationship is not explored yet because of the cultural and social values embedded in caring for the dying in Bangladesh.

In light of the above, there are potentials for discussion on how compassionate community model-inspired neighbourhood network in Bangladesh can be defined. On one hand, the neighbourhood goes beyond the immediacy of family, friends, and relatives. On the other hand, it does not go beyond the neighbourhood community in a locality in which there are some sorts of commonalities amongst the people living in the community in relation to culture, lifestyle, life history, and socio-economic aspects. In light of the interdependency reciprocity, vulnerabilities in the care ethics, I argue that such notions are found culturally driven in the settings. Despite some aspects of care ethics are revealed in the neighbourhood community in Bangladesh, some are not. Compassionate community model does not fully embrace the meaning of care ethics.

Compassionate community model in Bangladesh does not yet reflect the issues of power within caring relationship or dependencies explained in the care ethics. However, there are further possibilities that power and dependency will be of important considerations in future. Global South are rapidly trying to embrace the features of modernity adopted by the west. There are possibilities that South are proceeding towards an environment in which there is a pressure to be like the west. In relation to this, Zaman et al. (2018) warned of the risks of the impossibilities of free-flowing compassion both in the west and the Global south. As compassion is getting a priority in contemporary end-of-life care discussions, they argued that, structural assessment of societies is essential to consider the role of compassion. Otherwise, there will be unrealistic assumptions about the role of compassion in both settings. There are substantial barriers that deter the practice of spontaneous compassion within formal systems of health and social care in the west which is highly institutionalized and professionalised. On the other hand, although free-flowing compassion is still possible in global south despite the structural limitations in health sector, these countries rapidly embracing the formalized and professionalised healthcare structure like the west. The Economist's quality of death index is such a standard in which there is an assumption that the bottom countries (Bangladesh is the 79th out of 80 in the ranking) should aspire to be at the top by embracing professional palliative care expertise.

Conclusion

The original contribution of the present chapter is found the inconsistencies in regards to how palliative care is delivered in the palliative care centre and the community settings. The research findings underscore the critical impact of opioid unavailability on the provision of physical care in Bangladesh. Moreover, the study delves into the realm of non-physical care and reveals that, despite challenges in physical care, it persists through the application of informal care management within the framework of community-based palliative care models. Additionally, the contribution of this chapter goes further to advance the concept of a compassionate community, offering insights into the potential development and enhancement of this model for effective palliative care implementation.

The chapter shows how responses to the concept of 'total pain' are practiced differently in Bangladesh. In the west, total pain is more about arrangement of multiple professionals to care for the dying. I have shown how physical care through opioids is adapted with several restrictive acts in the country. As the main objective of the thesis is to explore whether different palliative care provisions might be found in Bangladesh, instead of only institutional or specialized palliative care, components of total pain are explored differently with the coordination between formal provisions (CPC) and informal provisions (community project) in this chapter. Regarding physical care or pain relief, the present chapter shows the complexities of opioid issues. In relation to that, the study found that pain relief is a difficult task because of several restrictive regulations in Bangladesh. Opioid inequity between high-income and lower and lower-middle countries is one of the core reasons for such situation. To ensure pain relief, the chapter argues that, besides lifting of restrictive regulations for opioids usage, it is also important to ensure international responsibilities for care. In the same way, the Economist's suggestion is not the only possible way to ensure non-physical care in Bangladesh. Looking at how a compassionate community model works in Bangladeshi settings, the chapter shows an informal network is conducive to care in Bangladesh, despite the absence of a formal health infrastructure. The chapter shows that a different cultural context is present in which relational autonomy is preferred over individual autonomy. It presents evidence for interdependence being expected more than the practice of independence. It demonstrates how end-of-life care can be provided through informal management in the community. It shows how total care can be practiced, beyond formal institutions; in this case, in the community. Despite the community being given a lower weight in the global death ranking index (2015), it illustrates that community approaches can be more effective due to a cultural divide of independence versus interdependence between the west and non-west. Patients expect care in the final days and PCAs feel an obligation to provide that care. It helps develop a unique relationship that is beneficial for the arrangement of total pain in Bangladeshi contexts.

The chapter also contributes significantly to the evolution of the Compassionate Community concept. While this concept has gained popularity in Kerala, India, there has been limited discussion about the evolving relationship between informal caregivers and patients within the community or home setting. The findings presented in this chapter address this gap and offer valuable insights. Several dimensions of the Compassionate Community concept emerge from the research. Firstly, the interdependency and reciprocity observed among Personal Care Assistants (PCAs) and patients draw inspiration from family-centric values. Secondly, despite structural constraints, non-physical care can still be effectively administered by leveraging the natural support networks within communities in the global south. Thirdly, while relationality, interdependency, and reciprocity are extensively discussed in care ethics literature, the Compassionate Community model introduces a unique perspective on these notions within the context of end-of-life care.

The next chapter explores awareness of dying, another dimension of good death. It attempts to understand whether the Bangladeshi scenario is different from the notions implicit in the notions of ‘good death’ followed in the west.

Chapter Six- Patients and Families' Awareness of dying

This chapter explores what happens after the family caregivers and their dying relatives arrive at the CPC. As the family caregivers are not aware of the terminal prognosis of their relatives at this point, I explore how the families and patients come to know about the prognosis from the providers and describe the procedures the providers follow to inform the family members. I also consider how family members play a significant role in their relative's awareness of dying. Finally, I examine how, in contrast to the providers' anticipation of an open awareness of dying on the part of the patient (an attribute of a good death), the way that families and their relatives respond leads to different kinds of awareness in the research settings investigated. Based on interviews with family caregivers and their dying relatives and on observation in the CPC ward, I describe how family members of five patients dealt with awareness of dying. These five patients are examples from the participants to highlight my analysis in this chapter.

By delving into the concept of a good death in Bangladesh, the thesis aims to argue that the values and logistics for attaining palliative care of Bangladesh diverges significantly from that of the top-ranked nations in the death index of The Economist (2015). Through the findings, the thesis provides a critical analysis of the index, which implicitly suggest that a good death is best achieved through formalized care structures that prioritize institutionalization and professional involvement—predominantly observed in Western contexts. The index implicitly endorses the idea that the Western model of palliative care, prevalent in developed nations, should be followed by lower-ranking countries (Zaman et al., 2016). Rather than unquestioningly embracing Western paradigms, the research offers a critical evaluation of Western ideals surrounding end-of-life care. In this regard, the study extends its inquiry into highlighting the importance of contextualizing notions of a good death within the historical, cultural, and socio-economic framework of Bangladesh. The thesis finally suggests that, in rejecting an uncritical evaluation of Western standards, there is an opportunity to unearth and embrace culturally and contextually relevant perspectives on a good death.

The findings of this chapter are: instead of the dying patients themselves, their family members become the key decision maker at the final days of their lives. Even though the providers in the centre request the family caregivers to convey the terminal illness to their dying relatives to

accommodate a ‘good death’, they try to keep it to themselves in most of the cases. Instead of the patients’ choices and decisions, family is the key role player in the Bangladeshi context. The chapter focuses on the relational and embodied contexts of decision making at the end-of-life of the terminally ill patients by looking at how family intervene in the whole decision-making process at the end of life of their relatives in Bangladesh. Through this, the chapter argues that a different version of good death is revealed in terms of family members concealing information from their relatives and why they conceal it and how they accommodate a good death that is not only dependent on patients choice, control, and agency at the final moments of their lives.

Introduction

I was sitting in the waiting room of the CPC one weekday at mid-day on the fifth day of my observation at the centre.

The male and female wards were just 50 steps away from the waiting room. Suddenly, six people entered the waiting room from the doctors’ room. There was an old lady in a wheelchair with them. They were talking to each other in the middle of the waiting room. There were two men in their 60s, a man in his 40s, two women in their 40s and a youth in his 20s. I saw that the middle-aged man was talking to the others most of the time. I heard him saying: “I don’t think our mother is in a good situation. I really suspect there is something wrong with her because the doctor was suggesting to admit her as soon as possible.”

I understood that the lady in the wheelchair was the patient and she was the mother of the man in his 40s. After a while, a nurse came in and told them that she was going to take the patient to the female ward. The patient was groaning. After the patient had been taken away, one woman in her 40s said:

> Don’t we have any other hospital options than this? Can’t you see how she is crying in pain?

The youth replied:

> We came here mainly because of her pain – this is the best place where her pain can be relieved, that’s what the earlier doctors told us.

One of the older men interrupted the youth, saying:

> It would be better to take my sister to India for better treatment. If Covid wasn't there, we could take her to a very good hospital in Vellore. Then we wouldn't have to roam from one hospital to another in Bangladesh. But alas! We don't have any other option right now.

The other older man replied:

> Let's first hear what the CPC doctors say. Besides, the doctor in the earlier hospital told us that once she is recovered from her pain, we can again start chemotherapy there.

The middle-aged man agreed:

> Yes, let's hear from the doctors here. They told us to prepare for a family meeting. We need to discuss about that. The doctors want to sit with us as soon as possible to plan our mother's treatment. Let us decide who among us will attend the meeting with the doctors.

Both the older men said:

> All of us will be in the meeting. We all need to be in the meeting because we all need to know what's happening. Besides, we will attend on a roster basis to take care of her [the patient] during her stay in this centre. It will be better if we all attend the meeting or whatever the doctors are talking about.

One woman in her 40s then added:

> Let us ask the doctors to arrange that meeting soon so that they can start her treatment quickly. We can start her chemotherapy as soon as she is done here.

Later, I came to know that patient was the mother of two sons and one daughter. The person in his 40s was her elder son, and the youth in his 20s was her younger son. Of the two women in their 40s, one was the daughter of the patient, and the other was her daughter-in-law. Of the two men in their 60s, one was the patient's husband, and the other was her brother. I also came to know that the patient had been diagnosed with cervical cancer the previous year.

I became very curious about two things: first, I wanted to explore how the patients and their family caregivers ended up at the CPC; second, I wanted to understand what a family meeting was and what came out of these meetings. Therefore, in this chapter, I focus on how CPC healthcare providers communicate with family caregivers about a terminal prognosis and palliative care through a family meeting. Additionally, I focus on what the providers anticipate when informing family members about the prognosis and how families and patients respond. To begin, I describe how and why family caregivers end up at the CPC with their dying relatives. I identify the people involved by referring to the patient's relationship with the primary caregiver. For example, if Mahmud's mother is the patient, I describe her as 'Mahmud's mother'.

Section One

Patients and family's entry in palliative care settings

I became very keen to know what made the patients and their family caregivers come to the palliative care setting in CPC. During my observation, I found that family caregivers frequently mentioned previous doctors their relatives had been under the care of before coming to the CPC. After noting this, I asked for details about previous doctors from several caregivers during in-depth interviews and in conversations during observation.

Mahmud's mother

Above, I introduced Mahmud, who is the man in his 40s and the son of a patient. He works for a multinational company as a general manager in Chittagong, a southern city in Bangladesh. His father and mother live with him and his wife in their house, like a joint family. During our conversation, Mahmud described when and how they came to know about his mother's disease. He also told me why he had let his parents stay at his house for the last few years. Several years earlier, Mahmud's parents used to live in their own home in a village. Then, when Mahmud's mother was diagnosed with high blood pressure and diabetes, a few years ago, Mahmud asked his parents to live with him and his wife in Chittagong, so that he could take care of them if they became ill.

Suddenly, Mahmud's mother had begun suffering from severe back pain, which had continued for a year. Her pain was daily getting more out of control and she became scared when she found blood in her urine one day. She shared this information with Sofia, her daughter-in-law, who told Mahmud. At first, they discussed the matter with a relative who was a doctor in a government hospital. He suggested they should consult a general physician at a renowned hospital in Chittagong, and he gave the name of a doctor, whom they quickly consulted.

The doctor suggested many tests. After several months of such tests, when Mahmud, his mother and Sofia went to the doctor, he asked that only Mahmud come into his room. Mahmud's mother and Sofia waited in a nearby waiting room. Mahmud narrated the history of his mother's disease: "The doctor was in a very serious mood while talking to me. He told me that my mother was suffering from a terrible disease." Mahmud learned that his mother had cervical cancer. "I couldn't talk or think about anything else for several minutes in front of the doctor because two of my relatives died of cancer without proper treatment. After some time, the doctor told me that although the cancer had been spreading fast, if we started treatment soon there was a chance that my mother would be cured."

I asked Mahmud whether he had informed his mother about her disease. Mahmud replied: "I wanted to inform her but my father and some other relatives told me not to tell her. They thought that my mother would be mentally upset hearing the news of the cancer." Mahmud explained that he and some other family members had brought his mother to a renowned hospital in Dhaka city: "After four months of chemotherapy my mother's physical situation was suddenly deteriorating again. She was in continuous pain every day and night." Mahmud consulted with the doctor to find out what was happening to his mother. The doctor told him that the chemotherapy was not working due to his mother being in severe pain. Mahmud asked the doctor whether it was possible to cure his mother or not. The doctor did not reply to his question. Rather, the doctor recommended that Mahmud's mother be taken to the CPC. Before her discharge, the doctor provided a referral note for the doctors at the CPC. The doctor also told Mahmud that when the patient was relieved from pain, they would try to resume the chemotherapy. This was a false hope given by the doctor, which Mahmud only came to understand after going to the CPC. However, in that moment, Mahmud became more hopeful after hearing about the possibility of further chemotherapy and quickly brought his mother to the CPC.

Sazzad's uncle

I met Sazzad in the waiting room on one of my observation days. I asked him what was he doing at the CPC, and found out that his paternal uncle (*chacha*) was suffering from lung cancer and had been admitted to the CPC. He came from Dinajpur, one of the districts most remote from

Dhaka city, situated at the north-west border of Bangladesh. Sazzad was the sole carer for his uncle. Sazzad's aunt, his uncle's wife, had died a few years earlier. Sazzad's uncle had two sons, who both lived and worked in Saudi Arabia. They were unable to travel to Bangladesh due to the Covid-19 pandemic. Both knew about their father's situation and Sazzad was calling his cousins via video calls every day. In addition, they were sending money to Sazzad whenever it was needed for the continuation of their father's treatment.

I asked Sazzad whether he had had to undergo any referral process. He replied that he had been looking for places where cancer was treated. For suggestions, he had talked to a friend from his village who worked as a ward boy in a hospital in Dhaka. His friend had suggested that he go to the CPC for cancer care. When I asked him more details, Sazzad said:

> I had no option other than to trust my village friend's suggestion. As I was the only person to take care of my uncle, I was in charge of making sure of good treatment for him. I was like a son to him at that moment. My cousins were relying upon me for my uncle's good treatment. On the other hand, I had no connection with any doctors or experts in Dhaka city. Therefore, I communicated with my friend from the village who had been working in a hospital for the last six years, I trusted his suggestion.

Sazzad also added that, "He [the ward boy] told me that the CPC treats cancer patients very well." With this assurance, he brought his uncle to the CPC.

Fauzia's father

Fauzia is a 33-year-old woman. I talked to her during my observation and found out that she was her father's caregiver during his stay at the CPC. Her father was admitted to the CPC in December 2020. She was her father's oldest child and handled all the negotiations with the doctors and her relatives regarding his treatment. She had been working as a public health expert in a Scandinavian organization since September 2020 and was not staying in Bangladesh when her father became ill. She flew to Bangladesh after her father was admitted to a diabetic hospital. Her father was suffering from liver cirrhosis along with several comorbidities from diabetes and cardiac complications. When I asked her why her family members had brought her father to the CPC, she explained:

> Things were happening too fast with my father. We [family members] were busy with doctors at two different hospitals before coming to the CPC. We took him to a renowned diabetic hospital in Dhaka city. There, the doctors figured out something after looking at a

> CT scan report. They understood that a huge mass was present in the right side of his stomach that had not been identified by tests. Then they referred us to a renowned cancer hospital in the city. We went there and again, after some tests, doctors in the cancer hospital were indifferent about his treatment. They told us that father was undergoing a lot of complications due to urination blockage and his stomach swelling with water. They told us that the CPC was the best place to get rid of the complications. They told us that the CPC also provided good care for cancer patients. We were at a loss and did not have enough time to think as father was in a terrible condition due to the complications. Therefore, we came to the CPC as soon as possible.

Sharifa’s daughter

Another day, during my observation, I saw Sharifa, an older lady in her 50s who was taking care of a patient in her 30s on the CPC’s female ward. I talked to the older lady and found out that the patient was her daughter. The daughter was weeping continuously due to her pain and breathlessness. I talked to Sharifa and asked her about her daughter’s disease:

> We are from Lakshmipur (a city in Bangladesh). My daughter lives with in-laws in that city. But her husband’s work is not in Bangladesh now, he is working in a firm in Abu Dhabi, a Middle Eastern country. My daughter was quite fine two years before. Two years ago, she got a tumour on her breasts. The doctors at a hospital in Lakshmipur removed the tumour by surgery at that time. Things were working well after the surgery. Suddenly, she had breathlessness and the doctors told us that she had water in her lungs.

She described how, after her daughter’s physical condition deteriorated, the family had decided to bring her to Dhaka. She mentioned that her elder son lives in Dhaka with his family and works in a pharmaceutical company as a senior medical representative. With her elder son living in Dhaka, there was no problem managing her daughter’s treatment, so she brought her daughter to Dhaka along with her other two children. In the meantime, the patient’s brother had arranged everything at the CPC for his sister to be admitted. When I asked the mother how her son came to know about the CPC, she said, “He has good networks with doctors and important people involved in healthcare facilities. Maybe he knew about the CPC from doctors or other people that are in his workplace. My son managed everything.” She anticipates that her daughter will recover in the CPC.

Ayesha’s mother

On the day I first saw Ayesha in the female ward, she was talking to a little boy. I could not hear what she was saying to him. Ayesha’s mother was the patient and was sleeping at that time. I began talking to Ayesha to understand how she had ended up in the CPC with her mother. For the last couple of months her mother had been suffering from abdominal pain. At first, the family members took it lightly. When the pain became severe, they went to a hospital in Dhaka. After several tests, the doctor told them that she was suffering from rectal cancer and it was spreading fast. They asked how she could be cured. The doctor did not say anything clearly, but told them that there were many hospitals in Dhaka which provided good care for cancer patients, and provided them with a list.

However, wherever they went, the hospital authorities acted strangely and would not agree to take their mother for treatment. They would not say why they would not treat her. Ayesha then told me:

> Whenever the rejection was happening, we got suspicious about our mother’s condition. We were guessing that maybe she will not be cured. However, we weren’t sure and were still looking for some place where her pain could be relieved.

In the end, very frustrated, they went to the CPC. At last, they found a place where their mother could be taken care of, at least for the time being. Ayesha also stated that they had had no idea about what the CPC specialized in.

An abandoned patient

Alongside these narratives of how the patients arrived at the CPC, I heard a different type of incident from Ruhi, one of the nurses. During an informal conversation, she talked about a patient. In the following, I narrate the incident as I heard it from Ruhi:

One morning there was a patient in a wheelchair in the CPC waiting room. The patient was asleep. There was a saline bag with him, connected through a syringe in his hand. All the providers were alarmed to see a patient in the waiting room. They could not find out how he had been brought there, and there were no family caregivers and no acquaintances with him. The duty doctor talked with the guard at the centre, but he had not seen who had left the patient as he had been busy in the washroom in the morning. After a while, the director told the nurses to take the patient to the ward. There was a clip file in the wheelchair, tucked away in a corner. The director went through the file and found out that the patient had had a stroke a few days earlier. The director looked for details of any relatives in the documents, but failed to find anything.

What was even more interesting was that there was a letter along with the patient's file. Ruhi recalled what was written in that letter during our conversation:

> Dear Doctors,
>
> I don't want to reveal my identity nor that of the patient. The patient is my father. He cannot talk, nor could he move for the last one year. He has been suffering from many diseases for the last few months. I kept him with my family since he was very sick. I tried to take care of my father, but I realized that my situation is helpless. I visited many hospitals to treat my father, but I received negative responses everywhere. Some doctors suggested that I should admit him in their hospitals, but the expenses were too high and there was no assurance that he would be cured fully. I am a clerk in a company where my salary is around 10,000 taka [around £88.50] per month. That's why I didn't keep him in the hospital. I also have three children in my family along with my wife. I am the only earning member of my family. Recently, I came to know that I would be fired in the next month from my office. In this situation, I had no idea how I could manage everything including my father's treatment. I gave a lot of thought to what to do. I have no relatives who can take care of my father. I was looking for a home for the elderly, but I realized that his disease would not be treated there. Then I heard that your centre takes care of terminal patients. I didn't think twice and decided to bring him to your centre. I could have come to you in the proper way, but I am not able to provide continuous care for my father. I believe that my father will be treated well here till he dies. Pardon me please.
>
> Thankfully yours,
>
> Failed son of a good father

Later, the providers discussed the matter with Dr Azam, the senior authority at the centre. They admitted the patient after an initial check-up. Dr Azam appointed a nurse especially for the patient as he did not have any family caregivers. The patient was suffering badly, and his situation deteriorated: he died in the CPC after almost a month. Later I talked with providers about the incident. They said that this kind of incident happens sometimes but is not frequent.

The events and conversations described above reflect that, in general, the caregivers have no clear idea about the CPC before arriving. I asked Dr Azam about this during my interview with him. He told me:

> Most of the patients come to the CPC through doctors' referrals from other hospitals. The family members who first arrive with the patient show us the referral note from the previous doctor, then we prioritize the patients based on the severity of their condition or disease. We

> admit most of the patients who come to us through referrals because of the severity of their pain and other complications. Although the family is aware of the patient's apparent situation, most of them do not understand the real reasons why the previous doctors referred the patients to us [at the CPC]. That's why they try to push us to relieve the pain of the patients or to treat their other complications. We do provide those treatments, but we also make arrangements to talk to the family members openly, to discuss the patient's condition and inform them of the goals of the CPC. By arrangements, I am talking about the family meeting. We look forward to the family meeting to resolve all the confusion.

The family meeting is known as the first protocol of communication between the providers and the caregivers. Whether the patients and their families came to the CPC through referral or other routes, all go through this protocol. In the following section, I describe one typical family meeting I observed.

Section Two

The family meeting

After the family caregivers and their dying relative arrive at the centre, the providers schedule a family meeting to inform them about the terminal prognosis. It is common practice in Bangladeshi hospitals and healthcare centres that the providers first talk with the family caregivers to discuss their relative's condition. The CPC providers anticipate that at the family meeting they will be able to talk about the terminal prognosis and arrange palliative care at the centre. I describe below the family meeting between CPC staff and Mahmud's family.

Mahmud, the elder son of a patient with cervical cancer, was anxiously talking with his relatives about preparations for the family meeting. Although they had thought that they had come to the CPC to rid their relative of her physical pain and other issues, they had started to suspect the worst. "Whenever doctors say that we need to talk in a meeting, that means there's a possibility of bad news for my mother," Mahmud's younger brother said. Mahmud ignored his brother's worries. Rather, he requested all the family members to be present at the meeting. He also asked a nurse to tell the doctor that the family would be ready for a family meeting that afternoon.

The family meeting was supposed to take place at 3:30pm. Mahmud, his younger brother, wife, sister, father and uncle all arrived at the meeting room. Before the doctors entered, a nurse arrived. She asked Mahmud whether they could bring their mother into the meeting. He appeared awkward on hearing this request from the nurse. He explained that the family members did not want their mother to be involved in any events related to the management of her treatment. He stated clearly: “We are all here on behalf of our mother. It is our sole responsibility to bear the mental sufferings for her. Instead of joining in this meeting, it is better that she takes rest in the ward.”

Two doctors – Dr Azam and Dr Jahan – and one nurse, Lamia, were due to attend the meeting. Dr Azam’s presence was essential at a family meeting with regard to establishing fruitful communication with the family caregivers. Dr Jahan had joined the CPC one year earlier and was one of the first batch of students from the MD in palliative medicine at BSMMU. He had consulted regularly with palliative care patients as part of his degree.

The meeting was late to start. By 4:00 p.m. the caregivers were becoming impatient. After a while, nurse Lamia entered the meeting room followed by Dr Jahan. Mahmud asked Dr Jahan, “Where is the *boro daktar* [‘senior doctor’]? Isn’t he coming?” Dr Jahan assured him that Dr Azam was coming. In the meantime, Mahmud’s father asked the doctor, “What’s this about? Any bad news?” Dr Jahan replied: “You will know once my senior joins the meeting, please remain patient.”

Mahmud and the other family members whispered to each other anxiously. Suddenly, Mahmud’s younger brother started crying. Dr Jahan went beside him and stroked the younger brother’s head with his hands. Dr Jahan asked him not to cry. “Whatever happens, we will do the best for your mother. That’s what we are here for. We are here not only for your mother – we are also here for you as well. Please be calm and don’t cry.” Everyone in the family started weeping after watching the youth crying silently.

Dr Azam entered the room at that moment. Everyone in the room became alert. Dr Azam sat down on a secretary’s chair and Dr Jahan took a normal chair. Before starting the meeting, Dr Azam apologized for being almost 40 minutes late. Then he asked Dr Jahan and Nurse Lamia for an update on the patient’s condition. Both described her current state. Then, Dr Azam looked at the family members to talk to them. I sat in the corner of the meeting room, observing. Dr Azam and Mahmud’s family caregivers began a conversation:

Dr Azam: I can understand what you are going through right now. As the patient is in severe pain, we are trying our best to take away her physical pain. We have already started giving her morphine on a daily basis.

Mahmud: Sir, is anything serious happening to our mother?

Dr Azam: What do you know about her condition?

Mahmud: What else can we know other than what you inform us of?

Dr Azam: I am asking about the previous hospital and doctors. What did they tell you about your mother?

Before Mahmud spoke, the younger brother was trying to say something. But his father stopped him and requested him not to talk at that moment.

Mahmud: The doctors in the previous hospital told us that mother’s condition was becoming worse due to the chemotherapy. It was becoming impossible for her to handle the chemotherapy because of her severe pain and other complications. We asked the doctors what that meant.

Dr Azam: What did they say after that?

Mahmud: Unfortunately, they said nothing further. They replied to us in a vague manner. Then we asked directly whether it was possible to cure her. They told us that it was possible, but not at that moment. I felt frustrated with them because they had told us that her recovery was possible. That was why we hadn’t tried to go to India for her treatment. After seeing that I was upset, they referred us here to get rid of her pain and other problems. They also told us to visit them again when our mother felt better.

Mahmud’s father: I don’t trust them anymore. Their behaviour was suspicious. I don’t think they told us the truth.

Mahmud: Sir, what’s happening actually? And why are we here [at the CPC]? Is it about her pain or something else?

Dr Azam: Ok, here’s the thing. I want to explain what our centre does and does not do. But I need all of your support in this. First, I will explain about the patient’s condition. Then I will explain what we can do for her, and finally, if you agree with us, then together we will design a plan.

Hearing that, the daughter and daughter-in-law, started crying. Nurse Lamia went to them and tried to calm them. Dr Azam asked all of them to listen to him.

Dr Azam: The sad thing is that ‘our mother’ is in the last stage of her life. There is no cure for her.

I realized that Dr Azam was referring to the patient as his mother, as the family did. After hearing that, almost everyone in the room began crying. Nurse Lamia was crying while consoling the daughter and daughter-in-law. No one talked for almost five minutes. The family members were hugging each other while crying. Mahmud stopped crying first and asked the others to stop crying.

Mahmud: Sir, the truth is, we guessed this was coming. That’s why we were so irritated with the previous doctors. We asked them several times whether they had any treatment for her or whether we should take her to India. They told us they could treat our mother. We stopped looking for other options because of what they told us. Now I really don’t understand who is to blame. Is it their fault or ours?

Dr Azam: Keep trust upon the Almighty. Whatever God does is good for humankind. Now the patient is in our hands. We can take care of her.

Mahmud: What can you do at this stage? There’s nothing to do. Isn’t it so?

Dr Azam: Yes. There is no cure for the patient but this centre treats those patients who are in the final days of their lives or who are suffering from incurable diseases. We can minimize the patients’ physical sufferings and also try to keep the patients mentally happy and sound during their final days.

Mahmud: So, what do we have to do?

Dr Azam: It is not like the curative practice you have seen before in other hospitals. It is called palliative care or simply you can call it ‘end-of-life care’. Both of us, the providers and the family, are part of this treatment. We need to know what the patient wants or what are their preferences in these last days. Therefore, the first thing we have to do together is to tell the patient about her prognosis.

After hearing this from the doctor, Mahmud said “No.” The others also joined him in saying ‘no’. Mahmud and his father told the providers that they did not want to tell the patient about her condition, but that they wanted to keep it a secret from her. At this, Dr Jahan began talking.

Dr Jahan: There are various procedures at the centre. As Dr Azam-sir mentioned before, end-of-life care is possible when the providers, caregivers and the patients work together. The patient needs to know about her condition if you want to make her final days peaceful and comforting.

Mahmud and his family deliberated between themselves. After some time, Mahmud said: “We need to think about it. We are worried about the consequences for her mental state when she hears about it.” Dr Azam asked them to reach a decision as soon as possible, saying that the patient may suffer because of any delay. The meeting then ended.

For the providers, the family meeting is significant for several reasons. First, they try to make sure that patients know about their terminal prognosis so that care can be arranged for their final days and patients can decide what they want at this time. Second, even though they anticipate informing patients, they cannot do this because they first need to tell the family members. If the family agrees, then the patient can be informed. It is also culturally appropriate that the providers do not inform the patient directly about the prognosis unless they are requested to do so by the family members. Therefore, the providers request the family members to inform their dying relatives. In the following section, I consider the providers’ reflections regarding the role of the family in the family meeting.

Providers’ reflections on the family meeting

During my observation, I observed the providers discussing with each other what happened in family meetings. Later, during interviews and further observation, I asked them about the role of family meetings and what the providers thought about them.

Dr Azam conducts most of the family meetings, so I asked him about the different aspects of these. He explained that they are essential as caregivers have often been misinformed regarding the purpose of their visit to the CPC: “Some of the caregivers come to us to have their relative’s cancer treated, some of them come for pain relief so that the patient’s treatment [chemotherapy] can resume later, some of them have absolutely no idea. Besides all this, our main concern is whether the caregivers of the patients, or the patients themselves, are aware of the fact that this is the patient’s terminal phase of their lives”.

When they break the bad news

Dr Azam explained that the family meeting helps providers resolve any previous miscommunication and, most importantly, to break the bad news of the impending death of the patient. When I asked whether this was challenging, Dr Rajan said: “It is obviously a challenging task. But this is an important task for us. We resolve the miscommunication the caregivers received from their previous doctors.”

Later, I asked Dr Rajan about his perception of the communication gap between the doctors that had been previously consulted and the families.

Risat: Why do the CPC providers take the responsibility to break the bad news?

Rajan: We cannot blame the previous doctors for not telling the family about the death. It is not easy for them to tell the patients’ families about death and what palliative care or end-of-life care is. People do not like to hear about death when they are searching for effective curative options. Besides, they have no knowledge of palliative care in the country. In this situation, as the previous doctors are not trained in palliative practices, they just refer their patients to us. And we do the rest of the work. Communication is a key component in palliative care and we are good at this.

Risat: Are there any other reasons besides this?

Rajan: Yes. It also opens up one important scope for us. The sooner the families are aware of the patient’s prognosis, the sooner we can design our care plan for them.

Rajan also explained that as the families and patients have little knowledge about palliative care, the family meetings work as guiding meetings for the family members.

What the providers say about end-of-life care

Dr Natasha had served at the CPC since its establishment. During her interview with me, she talked mostly about the challenges in her initial years at the centre:

> It was a really challenging task to tell people about death and end-of-life care. It was challenging for the centre and also for me. I can remember one family that came to us after being referred from a cancer hospital. When I explained to them about end-of-life care, the family members ignored it at first. Then I told them that end-of-life care is not about curing the disease. Here, we treat those patients who have no treatment. We try to get rid of any physical suffering of the patient. Besides, we provide mental support to the patients and their families in the final days of their lives.

She also explained that she told the families about the difference between end-of-life care and curative care:

> The caregiver's role is significant in end-of-life care. Here, the providers, caregivers and the patients are in the same team together for the betterment of the patient. As the family members are the closest to the patient, they know most about the patient's wishes and expectations.

Lamia, a nurse at the CPC, during her interview, told me that one of the best approaches was to talk with the relatives about their own deaths to come. She explained:

> It is best because otherwise they do not realize the importance of the knowledge of the prognosis on behalf of the patient. We describe everything about end-of-life care so that they understand the importance of the patient's knowledge of their disease. One day I asked one family caregiver whether he would want to pass the last days of his life fulfilling his wishes. I also asked him what if he died suddenly without telling his family about any future plans for his family. The future plans can be about financial matters or something related to family history.

After saying these things to the caregivers, Lamia said, they would calm down and slowly change their attitude. She explained that family dynamics are different depending on the different family contexts. "After the initial family meeting, we sit with the family several times to try to convince them to tell the patient about their prognosis" she added.

In contrast to what the providers anticipate, family members can respond very differently, reflected in the following section.

Section Three

The families' responses after the family meeting

The section contains what the family caregivers decide to do after the family meeting with the providers. The following case studies are used to show how they reach the decision for telling or not telling their dying relatives about the terminal illness. It shows the decision-making role of the family members for their dying relatives.

Mahmud's mother

During a conversation, Mahmud told me that after the family meeting, when the family finally knew that their mother was in her final days, they had regretted not taking their mother to India for treatment after her initial cancer diagnosis, which, they believed, would have been better for her. He added that even if treatment in India had failed, at least they could have felt that they had tried their best to save their mother.

Later, Mahmud explained to me how their thoughts had gradually changed. When I asked him what he thought about the options available for his mother at the CPC, he said:

> I had never heard of palliative care or whatever they call it before coming to the CPC. The fact is, I cannot save my mother by palliative care. I had several meetings with doctors after the first meeting. The doctors explained to me why it is important for the patient (my mother) to know that her days are numbered. Personally, I can understand what the doctors mean but I am not the only one who makes decisions for my mother.

Replying to my asking why they could not tell his mother about her prognosis, he said: "It's not only my decision. My father and the other older relatives prefer not to inform my mother. They firmly believe that her mental state would be terrible once she knows about her prognosis. The doctors told us that if she knows about her condition, it will be good for her because she is now living with the false hope of being cured. She can pass her final days well if she knows about her prognosis". Mahmud realized that as palliative care was the only option available for them, they could at least accept that for their mother. Once the other family members gave the matter some thought they all decided that they would inform her about her situation.

However, later Mahmud mentioned to me that his family were struggling with another issue: who would convey the news to her? They became anxious about this. Later I heard them discussing the issue with each other:

Mahmud: Who can tell her about her condition? I can’t do it. Dad, I think you can tell her.

Sofia: Mahmud is right, Dad. As time is running out, we need to do it quickly. The doctor also told us that if her pain is minimized, we can take her home. I think it’s better to take her home so that she can pass time with her grandchildren and all of us.

Mahmud’s father: Don’t you think it’s better for her to hear this from the doctors? The CPC doctors are very good and amicable. Your mother was telling me yesterday that the CPC doctors’ and nurses’ behaviour is very good. She feels very good when they visit her. What do you think?

Mahmud: Yes, it’s a good idea but it would be better if one of us stays with the doctor while conveying this to mother. Otherwise, she will feel lonely.

Mahmud’s father: Sure, I will be with the doctor then.

During my observation, I followed how Mahmud and his family members reached the decision to inform their mother about her situation. Finally, they asked Dr Natasha to talk to their mother. I was present in the ward when Dr Natasha told the patient her prognosis. Mahmud’s father and Mahmud were both present. Mahmud’s father stroked her hair softly and Mahmud held her hands at that moment.

Dr Natasha: *Ma* [she was addressing her as ‘mom’], you have suffered a lot from your disease. It will be good for you if you pass your days as you wish rather than staying in the hospital. Your son, your husband – both have tried their level best to cure your disease. But, there’s no proper treatment available at this stage. Mahmud’s mother murmured to them. She tried to catch Natasha’s hands. Natasha moved closer to her. Mahmud’s mother started weeping. Natasha, Mahmud and Mahmud’s father were all crying.

Ayesha’s mother

Ayesha’s family members decided not to receive any care from the centre for their dying mother, even though they had several family meetings with the providers. Ayesha confirmed that the providers had told the family members about the patient’s prognosis. Despite the providers’ many requests, the family did not tell the patient about the prognosis, and a few days later they left the centre. I talked to Ayesha before they left:

Ayesha: In the family meeting, the doctors told us that our mother is going to die very soon. We suspected that before but we were not sure about it. Although we know about it now, I don't know how to tell this to her because every time I go beside her, she always cries and tells me that "I want to be like before, I want to live for at least 10 years." She still thinks that there are treatments for her disease. That's why we cannot tell her at this stage that she is going to die soon.

Risat: Is there any reason she gives for wanting to survive for another 10 years?

Ayesha: It's because of her youngest son, our youngest brother. He is a 15-year-old child. My mother is worried about him as he is not an adult to lead his own life. One day she told me, "All my children are well established except my youngest son. He is still a child. There's no one to look after him. If his father was alive, I could die without any regrets, knowing that at least he has his father to take care of him." I and my other brother try to console her saying that we will take care of him whatever happens to her. But she doesn't feel good. She says, "For a child's upbringing, parents are a must. How can I live in peace in my afterlife if one of my sons is unhappy in this world?"

Ayesha mentioned that the whole family thought it unwise to tell her about her impending death. Therefore, they did not want to continue to receive services from the centre. Once their mother was relieved of her pain, they would take her to their home in the village and the family would take care of her in her final days. The very next day, they left the centre and went to their home in the village.

Before I returned to the UK, I called Ayesha to say goodbye and convey my thanks for her support in my fieldwork. I found out that her mother had died a few weeks earlier. I felt very sorry hearing this and expressed my condolences to her. When I was about to end the call, she kept talking and I continued talking to her. She cried over the phone and talked about her youngest brother. She told me that her mother had made them promise to look after him. Her mother had told them, "If you want to make me happy in my afterlife, please look after your youngest brother. If you don't, I will suffer a lot." Ayesha also told me that her mother's final days were really happy. Ayesha cooked her mother's favourite meal for her every day. Many relatives came to see her mother and she had chatted with them for many hours. They kept her impending death a secret from her until she died.

Sazzad's uncle and Fauzia's father

Both of these patients' families were reluctant to inform their relative about their terminal prognosis. Sazzad told me that even though he understood that his uncle would not survive for long, he could not take the decision on his own to tell his uncle that he would soon die. Sazzad's cousins (the patient's sons) still thought that their father should not be informed about his terminal prognosis. Even though Sazzad decided to accept treatment for his uncle from the centre, he did not agree to inform his uncle about his death. He decided to keep his uncle at the centre until his pain was relieved.

Fauzia told me that when she found out about her father's terminal prognosis in the family meeting, she was furious. During an informal conversation, I asked her why she did not agree to tell her father about the terminal prognosis. She said:

> I know about palliative care. I know what it means. But I cannot agree to the fact that I have to tell my father that he will die soon. My father is a very dignified man and he will be hurt when he realizes that we have stopped trying our best to save him. Once we accept the fact that he will die soon, it's like we have stopped trying. As a daughter, it is my duty to make every effort to save my father, till the last moment.

Rather than informing her father, Fauzia and her family members decided to stay at the CPC until his pain was relieved. Both Sazzad's uncle and Fauzia's father are kept in the centre to show their dying relatives that they are trying their best to do something. Keeping in a healthcare centre, to the family members, is a sign of taking best care possible for their relatives.

Sharifa's daughter

Sharifa and the other members of her family did not tell the patient about her terminal prognosis. Sharifa and others decided to keep her daughter in the centre hoping for a miraculous recovery. I asked Sharifa why they still hoped her daughter would be cured. She said: "We still believe in almighty Allah. Definitely there will be some miracle and my daughter will be saved. My daughter is still young. She is the most innocent girl and she cannot die soon.Even while her daughter was receiving care from the CPC, the family were still planning which hospitals they would take her to after she was discharged from there.

Abandoned patient

Nurse Ruhi told me later what had happened with the abandoned patient. The director of the CPC had decided that they would take care of the patient, who had been left by his son. The providers took care of him until his death. There was no family meeting for the patient but he was informed directly about his terminal prognosis by the providers. He died almost one month after his admission to the CPC.

The above-mentioned findings show how the dying patients final days arrangements are managed in the palliative care centre. Instead of what is expected that the patients themselves decide on their own about their final days of their lives, the findings show that family caregivers are influential decision-maker. Instead of the good death in the western context that is, if the patients themselves decide for their final days, a different version of good death is revealed in Bangladeshi context. The concept of ‘awareness of dying’ is different with the influential role of family members, the chapter revealed.

Summary and Discussion

The chapter shows that, rather than patient-centric awareness of dying, a family-centric awareness of dying is found in Bangladeshi contexts. Even though open awareness of dying of patients is expected by providers as an ideal scenario to ensure a good death, my findings suggest the family plays a key role in regards to the disclosure of a terminal condition. The role of family is significant during any key decisions of a person’s life in Bangladesh, such as, which career should they choose, when and whom they should marry, during any sickness etc. Likewise, family becomes more important at the end of life of their relatives in the country Family decisions are more important than the personal care of the self that is mostly practiced in the west. Finally, my findings help us understand that notions of good death are not only limited to singular narrative developed in the west. In the following discussion , I used ‘western’ or ‘west’ to signify the narratives of good death that are practiced across Western Europe and North America.

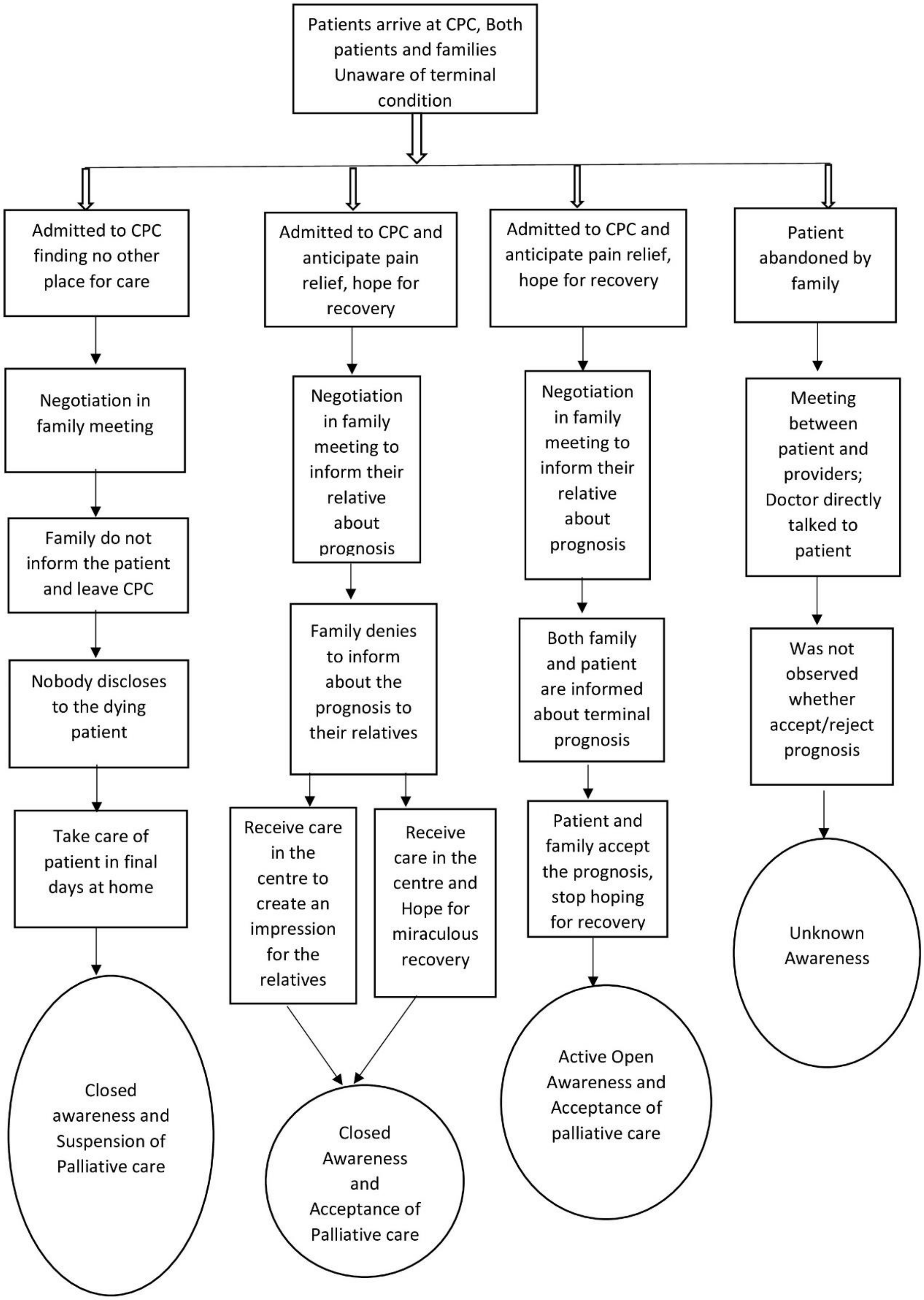
In the present chapter, findings were divided into three sections. Section one describes how and why different families bring their patients to the palliative care centre. As the family members and patients do not know about the terminal condition, providers in the Centre for Palliative Care (CPC) arrange family meetings aiming to inform family members about the terminal condition of their relative and convince them to disclose that to their relative. Such a family meeting is described in section two. Finally, the responses and the decisions of the family members are described in the section three, which shows how family members plan for their relative’s final days.

As patients’ awareness of dying is an important component of good death, the chapter shows how differently awareness contexts are shaped and managed with the involvement of family members in a Bangladeshi context. This chapter explores who makes the decisions about what is to be done at the end of life of dying patients and how they are made in the context of delivering end-of-life care to them. In the west, priority falls to the dying patients themselves in terms of making decisions about their final days (Clark, 2002; Goldsteen et al., 2006). In western countries, there are underlying assumptions about good death that, if patients take decisions on their own after being made aware about their terminal condition, it is possible to have a good death, otherwise not (Clark, 2002; Goldsteen et al., 2006). It means that the patient in the western setting has agency and autonomy, and can exercise control and choice at the end-of-life. However, in the present study, decision-making centres on the active involvement of family members in decision-making, rather than the patients. Several other notions of good death are found in non-western settings or countries (Riley 1983, Seale 1998), such as dependency upon family members, collective decision making of the family members in the final days of their relatives’ life, in opposition to agency, control, and autonomy. These non-western notions are also found in Bangladesh. Despite such non-western notions or practices, western notions of good death are reflected or preferred in the categories comprising the Quality of Good Death Index (The Economist, 2015) or in the ideals of palliative care services from the countries of the western world. In the following, a brief summary of the results is described, followed by critique of Glaser and Strauss’s and Timmermans’ work on awareness contexts that are based on western settings. Finally, I present a brief analysis on why Bangladeshi awareness contexts are different than the suggested ideal awareness contexts for delivering good death. In the final part of the chapter, by taking the argument further, I argue that a patient-centric awareness of dying is notably contextualized in the west, not necessarily in other settings. Instead, a family-centric awareness of dying is found in Bangladesh that includes family members, close relatives or otherwise which can expand the meaning of good death in non-western settings.

Brief summary of findings

Considering the works of Glaser and Strauss (1965) and Timmermans (1994), the findings of the chapter are discussed to contextualise how awareness of the terminal condition is shaped. Four different categories of awareness context are found. The following awareness contexts are not only defined by the awareness of dying of patients, but also shaped by the conditions whether they receive palliative care provided in the centre or not. The first awareness context highlights how families do not always tell the truth to their dying relative. Instead of staying in a healthcare centre, they prefer to let their relatives stay at home in their final days. Besides not informing about the terminal illness to their dying relatives, the family members to not receive palliative care from the centre. Instead, they take their dying relatives to home The second awareness context shows that family members do not inform their relatives about the terminal condition, but decide to continue with the intervention suggested by the providers in the centre. But there are differences between two types of families, based on why they are keeping their dying relatives in the centre. There are families who accept that their relatives are informed about the terminal conditions and they also decide to receive palliative care Finally, there are also unknown awareness context that are not defined because of the exceptional situation of the patients.

Figure 1: Awareness contexts in the CPC



I call the first awareness context as ‘Closed awareness and suspension of palliative care’, Following characteristics are found in this context: family members do not inform their relatives about their terminal condition. After knowing their relatives will die soon, they choose to take them home to accomplish beautiful final days with the closest people. By not telling their relatives, the family believe that it will be good for their relatives’ mental condition. Family members take them home to make sure that they die in a normal routine or beautiful day in their lives, spending time with other family members, eating favourite meals, playing with their grandkids, sitting in the same chair they used to sit in on the balcony, saying proper goodbyes to their family members in their beloved home. Ayesha’s mother’s case is an example of this awareness context.

The second awareness is, ‘Closed awareness and acceptance of palliative care’Although the family members do not inform their relatives about the terminal condition, they decide to continue with palliative care in the centre during the final days. Rather than make arrangements for home, family members prefer that care is provided in a healthcare centre in this context. There are several characteristics in this awareness context. One, dying relatives are not informed about their terminal condition. Two, family members choose to receive care for their relative from the providers of palliative care centre until their death. Three, family members decide to keep their relatives in the centre. Here, two types of families are found. One, Families decide to keep in the centre to make an impression to their relatives that they are kept in the centre for recovery. The centre is like a space of effort to them, meaning they are doing something for their relatives. This false impression is significant for both the family members and their dying relatives because families feel obliged to take care their relatives in a good healthcare arrangement. On the other hand, relative patient also expects to see that family members are trying best to take care of them This is described in detail in Chapter Seven. Fauzia’s father and Sazzad’s uncle are examples of this awareness context. Two, in some instances, families decide to keep their patients not to create of false impression of taking care. Instead, family members really expect for a miraculous recovery of their dying relatives. Besides receiving care from the palliative care centre, the reason for their stay in the centre is to wait for a miracle. The case of Sharifa’s daughter is an example of this. The third awareness context is ‘Active open awareness and acceptance of palliative care is the only one found in this study where family members disclose the terminal prognosis to their dying relative. A core characteristic here is that the patient was in excessive pain. After trying every option elsewhere, the patients' family has nowhere to go except the CPC, with, all key family members reaching an understanding that its futile to think about other curative options for their dying relative. Mahmud's mother's situation is an example of this awareness context. In the fourth, that is, 'Unknown awareness', there are instances in the centre when it's hard to define which awareness contexts they are in. There is a case who were abandoned in the centre with a letter tucked in wheel chair of the patient. In that case, there was no family members. The awareness context is undefined or unknown.

These awareness contexts bring several issues to the forefront: individual decision of patients versus collective decision of families, patient's agency versus family involvement, individual autonomy versus relationality, patient's control versus dependency on family, and independence of patients versus interdependence with families. It demonstrates that the notions of 'good death' are not only limited to the practice of patient-centric awareness of dying that elicits individual autonomy, independence, and choice. On the contrary, it shows that good death also embraces family-centric awareness of dying that brings the notions of relationality, dependencies, and interdependence at the end-of-life of a dying patient. Cultural differences between the west and non-west become the focus of the following section.

Critique of patient-centric Awareness Contexts

Cultural differences in this chapter are revealed through the concept of awareness contexts. Initially, awareness contexts developed from Glaser and Strauss's (1965, 1968) powerful investigations in the 1960s, after intensive fieldwork for six years combining observations and interviews at six hospitals in the United States. It revealed how patient care was affected by the awareness level of the dying process. However, as the modern discipline of palliative care was established in the 1970s, the practice of talking openly about dying was encouraged as an improvement of the patients' dying experience (Field, 1996). According to modern palliative care practices in the west, it is important for a patient to be aware of their terminal conditions if they are to ensure a 'good death'. Such is reflected in an article published by Richards et al (2013)

> ‘In the UK, Field’s (1989) landmark study of nurses’ experiences of caring for dying patients demonstrated that attitudes to disclosure of terminal prognosis had changed by the 1980s, with ‘open awareness’ regarded as a necessary component of humane care. Much has been written in the literature, before and since, about the cultural and historical processes at work in both the UK and the USA, which have forged a link between awareness and attainment of the ‘good death’ ideal.
>
> (p. 2654-2655, Richards et al., 2013)

Awareness of dying became significant so that the patient themselves can make decisions for themselves, thus exercising agency in the final days of their lives. It is assumed that patients can decide on their own about their end-of-life care after being made aware of terminal illness. In the following, a brief background of the awareness contexts and their relationship with ‘good death’ in palliative care is given.

In the 1960s, Glaser and Strauss introduced four awareness contexts: closed awareness, suspicion awareness, mutual pretence, and open awareness. Closed awareness is when the terminal patient does not know about their impending death, despite the providers having the necessary information (Glaser & Strauss, 1965). The providers try to maintain this context to protect the patient from bad news. In the suspicion awareness context, the patient gets suspicious, for example when they experience severe pain or certain other physical symptoms due to chronic illnesses, but do not know about the terminal prognosis. Mutual pretence is an awareness condition where both the patient and the providers know that the patient is dying but pretend otherwise. Open awareness is when both the providers and the patient know the patient is dying and accept their actions and the context. Open awareness has been the trend in healthcare settings in terms of patients right to information and plan for their treatment afterwards, as Seale (1997) notes:

> ‘Awareness of dying enables life planning to proceed, and offers the hope of a degree of control over the manner and timing of death. Relatives can be called to the sick bed, practical and emotional affairs can be set in order, loss can be anticipated and grieving begun by both dying people and those close to them. Plans can be made for the negotiation of a dying career, involving choices about sources of care and the place of death.’
>
> (Seale, 1997, p. 477)

Open awareness has been regarded as an important attribute of a good death and is regarded as a significant aspect within palliative care in the western countries:

> ‘A preference for open awareness of dying is now well established in terminal care settings and amongst the general population in the U.K. (Charlton et al., 1995; Seale, 1991; Thomsen et al., 1993), U.S.A. (Blackhall et al., 1995; Carey and Posovac, 1980; Good et al., 1990; Novack et al., 1979) and other Anglophone countries (Chartton et al., 1995; Adams et al., 1978; Holland et al., 1987). It has been argued (Seale, 1995a) that the desire for open awareness of dying is related to a dominant ethos of individualism, translating, for example, into vigorous consumerist movements in health care settings’ (Seale, 1997, p. 477)

Providers aim for open awareness of patients who are in the terminal stages of their lives, meaning that the providers prefer to convey news about the terminal condition to patients and their caregivers. It has been suggested that if an ‘open awareness’ is achieved by the patient, appropriate planning and decision making can occur (Glaser & Strauss, 1965). Examining the development of this concept, awareness of dying and, afterwards, acceptance of death, is seen as one of the key elements of a good death in western anglophone societies (Clark, 2002; Goldsteen et al., 2006; Houska & Loucka, 2019). Providers such as doctors’ and nurses’ openness about communicating with dying patients and their families after the 1970s was partly inspired by the modern hospice movement (Seale, 1991).

The modern hospice movement is acknowledged for the change of attitude to talk openly about death and illness, mentioned by the notable death scholar and psychologist Kubler-Ross (Seale, 1991). The significance of the modern hospice movement lies in changes in attitudes and openness towards illness and death, regarded as key elements of the growing hospice movement in the 1960s (Kubler-Ross, 1969). Awareness of dying enabled the patient to plan the end of their life and gave the hope of a degree of control over the manner and timing of death. Relatives could be called to the sick bed, practical and emotional affairs could be set in order, loss could be anticipated, and grieving begun by both dying people and those close to them. Plans could be made for the negotiation of a death, involving choices about sources of care and the place of death (Parsons & Lidz, 1967). Hospice care provided these kinds of support to patients who acknowledged death.

Simultaneously, open awareness has been regularly re-evaluated since the time of Glaser and Strauss. Such a re-evaluation was undertaken by Timmermans (1994), who revisited and extended awareness theory. He argued that Glaser and Strauss’s theory emphasized the rational negotiations of family carers and patients with providers, rather than the family and patient’s emotional considerations. Therefore, he re-evaluated the structural conditions in accordance with an age of open awareness, where withholding medical information from patients and carers was not the norm anymore. He also argued that in a contemporary medical setting, where open awareness exists, theories of awareness contexts must reflect how patients internalize their prognosis. He categorised three types of open awareness:

1) Suspended open awareness: patients and families understand the information but choose to ignore it. In this context, communication between the carers and the providers comes to a halt. It is a temporary or transitory condition. The consequences of the disclosure are not completely realized yet by the patients and their families. In the context of suspended open awareness, the patient or family member obstruct the information about the terminal condition. They remain in a state of disbelief as if the disclosure never happened (Timmermans, 1994).

2) Uncertain open awareness: patients and families discard the unpleasant aspects of a diagnosis and focus on positive possibilities. It is called uncertain because physicians report not revealing all information to patients and the families in their best interests. How physicians maintain uncertainty can be explained in three strategies (Taylor, 1989): First, when they disclose a terminal condition, they acknowledge that there is uncertainty about diagnosis. Second, physicians conceal the prognosis from families and patients. Third, physicians repress prognosis information. The core reason for this uncertainty is linked with hope. People literally live by hope (Field, 1992). When there is no hope, patients become isolated, abandoned or socially dead (Sudnow, 1967).

3) Active open awareness: patients and families fully accept the probability of death. Patients and their families understand the full implications of the disclosure. Patients have no hope for recovery. They are inclined to religious thought or reflection on their own lives, bid farewell to family members and settle financial affairs.

Seale makes clear how palliative care or end-of-life care and openness of dying were being institutionalized together to treat dying patients at their end of lives:

> ‘A great deal has been written about what and how to tell the terminally ill about their condition. There has been, in general, a move towards openness in what is advocated for and by doctors over the past thirty years….There is an increasing interest in training courses that help professionals develop their counselling skills in this area.’ (Seale, 1991, p. 943)

Timmermans explained open awareness in more detail. He argued that open awareness depends more on the emotional strength of the patient and their family members than on the willingness of the provider. Although there are many barriers to open awareness, it is encouraged in palliative care to improve the dying experience of the patient. It is an important component of the good death. This value of open awareness is assimilated in the idea of a good death (Seale, 1991), which has become very important in institutional palliative care. But, at a societal level, open awareness appears to accord with dominant Anglophone cultural values, emphasizing responsible care of the self and preparation for death as an extension of the highly individualized project of identity construction (Giddens, 1991).

However, despite mention of family members, Timmermans and others rarely explored how deeply awareness contexts are shaped when the patient's choice and control are not preferred at the end-of-life. The role of family members here are preferred more in decision making and their involvement is significant in ensuring good death. A family-centric approach is found in many such settings, mostly in non-western countries. Bangladesh is also a country where families' involvement is preferred more than the patient's agency at the end-of-life. In contrast to the care of the self in the West, family plays a more important role in Bangladesh. Family decisions at the time of illness appear more important than individual patient's decisions. Therefore, family members are first informed by the providers about their relatives' terminal condition in the centre.

Although patient-centric awareness of dying is prioritized in western literature and end-of-life care policies for achieving good death, family's role and awareness of dying is discussed in various geographical settings. The present chapter argues for a family-centric awareness of dying where patients' awareness is not the only way to achieve good death. As Glaser and Strauss's work and Timmermans' work hints towards a patient-centric awareness of dying, the present chapter is a critique of such patient-centric awareness of dying. The following discussion is a critique of individual autonomy, choice, or control of dying patients that are desirable for the end-of-life care in the west. Besides showing how the family-centric awareness of dying found in the study are different than Timmermans, the following discussion on family and awareness contexts further brings forward the notions of relationality and interdependence.

Family and awareness contexts

Family has always had a central place in the dying process, and particularly in palliative care settings. Family dynamics strongly influence everything at end-of-life, including whether family members want their relatives kept under the supervision of providers in their final days and how they strongly influence the decisions about which place should be preferred as the final resting place for their dying relatives. The ways in which families handle dying relatives reflect wider cultural practices in and around kinship and collectivist versus individualist culture (Riley 1983, Seale 1998). It is important to understand the implications of how cultural forces are immersed in the shaping of dying as a social and relational process (Seale 1998, Howarth 2007, Kellehear 2008). Dying and palliation is more of a collective experience than an individual experience, being immersed in complex agendas, needs, desires and interpersonal dynamics (Seale 1998, Kellehear 2008, Stajduhar et al. 2010). Tensions between individual wishes and family principles suggest that the character of end-of-life care is rooted in family expectations and cultural ideas around responsibility towards dying relatives (Broom and Cavenagh, 2010, 2011). Families also go through significant burdens in end-of-life care contexts (Harding and Higginson 2003, Grande et al. 2009).

Even though a focused patient-centric good death prevails in western contexts, family dynamics shape the awareness of dying in end-of-life care. A recent study shows how standardisation of an individualist approach in end-of-life-care decision-making dissolve the diverse cultural sensibilities and expressions that shape trajectories of care at the final days of life amongst ageing Chinese migrants' community in Adelaide, South Australia (Zivkovic, 2021). In contrast to autonomous decision-making about the withdrawal of care in Advance Care Planning (ACP), most participants emphasised the decisions of the family. This highlights the active role of relatives as opposed to self-determining individuals. Zivkovic reconfigures Goffman's face-work (Zivkovic, 2021, p.2) beyond the singularity of the bounded and rational individual to examine the multiple and relational ontologies of face across shifting filial relationships between the dying patients and their relatives in diverse cultural landscapes. Tracing the many ways in which this relationality is constituted, the paper attends to the multiplicity of reality in practice (Mol, 2002), revealing how face at the end of life is perceived as the face of a family, instead of an individual. In doing so, it foregrounds relational ontologies that exist within (and indeed across) cultures, but which are obscured in the neoliberal politics of self-management and individualism ascribed in the ACP. In contrast to the bounded self that is prescribed in advance decision-making about ageing and the end of life, intergenerational familism produces different versions of face and filial piety that change and diversify with time and circumstance, but which cannot be reduced or tethered to individual autonomy. Zivkovic argued that, in contrast to neoliberal approaches to ACDs, care at the end of life cannot be universalised or standardised according to principals of autonomy and self-determination. On the contrary, care performed, and decisions made towards life's end are always relational, nuanced, and entangled with a multitude of intersecting material and socio-cultural constraints and circumstances. Family decisions are more significant than the individual patients at the end of life, looking at the concept of 'face'. Rather than any individual connotations, meaning of face is perceived collectively amongst the family members of the patient, rather than its individual or patient-centred or autonomous meaning inferred in Goffman's work.

Another qualitative study argues against the western notions about dying individual's own decision. The study was conducted in the north of England found that the awareness of patients approaching end of life does not always follow the pathways preferred by institutional palliative care. Even though the priority is to inform the patients of their end-of-life and make their own decisions in their final days, it is found that the patients do not always want it that way (Richards et al., 2013). The study was conducted with patients with fatal diseases who could benefit from palliative care. The ethnic identity of patients was not given. After these patients were made aware of their terminal prognosis, they had options to refer themselves to specialist palliative care, that would enable them to use 'time left' in a conscious way to 'achieve their personal goals' in their final days (The et al. 2000, p.1381). Despite such culturally informed assumptions about a desire for self-determination (Department of Health 2008, Nursing and Midwifery Council 2008, General Medical Council 2010), leading to the promotion of an 'open' awareness context as a person approaches their death, the study shows that it varies and fluctuates (Richards et al., 2013). Despite endorsing an ideal of 'open awareness' with patients in these hospitals, the authors found that patients do not always conform to the autonomy paradigm of a self-directed life followed by a self-directed death. Moreover, the cultural value placed on preparedness before death has a limited reach, due to the complexity of the social interactions and subjectivities which determine the context where a person becomes aware that they are approaching death. Contrary to the professed ideal of ‘open’ awareness, some participants were only partially aware and others wholly unaware that they were likely to be approaching the end-of-life. Those identified as unaware were over 85 years. Participants displayed a reluctance to acquire knowledge which would require them to face the imminence of death. Philosophy and policy aside, people do not always conform to the autonomy paradigm of a self-directed life followed by a self-directed death even in this western setting.

There have been tragic consequences on family relations when patients were prevented from knowing the truth about their terminal illness (Marzano, 2009). The study was based on 30 in-depth interviews with the relatives of late-stage cancer patients in Italy, part of a broader ethnographic study on dying of cancer. Both healthcare professionals and the relatives work as a team to ensure that the dying patients are not informed of their terminal days. Family members help maintain non-disclosure to help the healthcare professionals to achieve their institutional goals.

The above studies from Australia, England and Italy shows that the ideals of open awareness for good death are not always followed even in the high-income countries or in the western countries. As family members are found to be influential decision makers or mediators, a relational and family-centric decision-making is present alongside the patient-centric decision-making that is implicit in western notions of good death. These studies help to understand that the ‘ideal type’ scenario around open awareness is only a singular narrative of good death in palliative care. Family-centric awareness of dying exists beyond that singular narrative in which family members are prominent in deciding whether their relatives will be informed or not. Besides these studies, there is other evidence that the patient-centric awareness of dying is not evenly followed in the west. At an individual level, some older people (Gott et al. 2008) and hospice patients (Payne et al. 1996, Lawton 2000) stated they would prefer a sudden death rather than being made aware of an imminent death, highlighting the limitations of the perception of the link between awareness of dying and the achievement of good death. Despite this evidence, emphasis is given only on the individual responsibility that narrows the scope of decision making and detracts from relational embodied contexts of care (Zivkovic, 2021). Therefore, open awareness is understood mostly from the perspective of terminal patients, not how family caregivers might play a significant role. Despite family members being important stakeholders, their role is understood as secondary in most studies of awareness contexts. Such studies narrow the scope of decision making to the dying individual, not extend its meaning to collectives or the involvement of family members. Considering my findings and evidence from the west considered here, I argue that the individual and collective approaches to decision making at end of life are not mutually exclusive.

Despite various instances, family-centric values at the end-of life are not the mainstream trend in the west as in the non-western countries; significantly in the countries of the global south. Bangladesh is such a country where family values or traditions together with collective values are more important than individual or personal autonomy (Zaman, 2005). The present research demonstrates that by looking at the how awareness of dying is not defined by individual patients. Rather, it is wholly managed by the family members of the patients. Even though the palliative care staff wanted patients to exercise open awareness, that has not been possible or achieved because of family members' intervention.

The four awareness contexts, Closed awareness and suspension of palliative care, Closed awareness and acceptance of palliative care, Active open awareness and acceptance of palliative care and Unknown awareness in Bangladesh suggest that, even though open awareness of dying is expected by providers as an ideal scenario to ensure a good death, the family plays the key role in regards to the disclosure of a terminal condition. Moreover, the situations show how family participates in that mediating role. Family decisions are more important than the personal care of the self that is mostly practiced in the west. Family caregivers play an active role here.

The actions of the family members are inspired by the cultural values and beliefs prominent in Bangladesh in end-of-life care The influential role of family members and their indispensability in caring for dying relatives are essential at end of life. The sense of family bonding is so pervasive in Bangladeshi culture that a family-like relationship is also developed between PCAs and the dying patients, described in the previous chapter. Patients are dependent upon PCAs. In a similar manner, an essential and dependent relationship between family members and their dying relatives is found in this chapter. Family members take the major decisions and also carry out caring responsibilities at the most vulnerable moments in the final days of their relatives.

The striking feature of end-of-life care is that the individual decision making is not prioritized in Bangladesh. Although the individualistic notions are prioritized in the end-of-life care policies or guidelines, these are nuanced even in the western countries. It is the family members' decision making that is practiced in Bangladesh. Such importance of family or kinship ties and responsibilities are prominent in the Indian philosophy of spirituality. Indabas (2018) outlines three concepts that are key in shaping the understanding of spirituality at the end of life, namely: the concept of the human person, the purpose of human life, and the understanding of death. It is not the rational and thinking agent who is at the centre in Indian philosophy. Rather, personhood is tied with responsibilities, duty, soul, divinity (Indabas, 2017). About the concept of human person in Indian philosophy, he stated:

> The concept of the human person is based on the understanding that the human soul is from the divine and is of the same substance as its divine source. It is not the individual's capacity as a "thinking being" or a "rational being" that gives the human person his/her existence. It is an extension of the divine, a gift of God. The purpose of life is the ultimate liberation from the māya of this world and to be united with the divine. In the words of Rabindranath Tagore, "Death is not extinguishing the light; it is only putting out the lamp because the dawn has come." (p. 339, Indabas, 2017)

Even though patients' awareness of dying is an essential aspect of good death in palliative care, that is redefined in the Bangladeshi context. The core components of the three contexts are mostly about the involvement of family members in their relatives' final days. Although being aware of their death in their final days is regarded as having control and exercising choice at one's end of life, these things are predominantly western. The scenario is not found here. The present study found it incompatible in a Bangladeshi context. There are several characteristics can be explained from the four awareness contexts of the present study

a) Family members are the decision makers when it comes to end-of-life care. Not only that, but also it is important that the key family members are present during the critical moments of their relatives' lives.

b) The western literature suggests that the patient can decide their own at their end-of-life. Therefore, being aware of their situation is a key to 'good death'. However, rather than control and exercise of the patients, it is more crucial in Bangladesh that family members take full responsibilities of their dying relatives.

The present study conforms Zivkovic's argument. Despite not focusing on the concept of 'face-work', I reached a similar conclusion about the importance of family members, by looking at the theory of awareness contexts. Like the Chinese migrant communities in Australia, dying patients and their family members in Bangladesh show that end of life decisions and planning are relational, rather than the straightforward expectations of the providers in the study. Despite a similar conclusion, Zivkovic's research doesn't directly expose the inadequacy and indeterminacy of 'open awareness' contexts amongst dying patients and their family caregivers in a palliative care setting as the present study does.

Conclusion

The current chapter critically explores the values associated with a good death. Much of the Western literature posits that individual autonomy is a pivotal element in achieving a good death. The implicit assumption in Western literature is that a crucial aspect of a good death involves informing patients of their terminal illness, enabling them to be conscious of their impending demise. Consequently, palliative care is organized in specialized centers or hospices, aligning with patients' preferences for how they wish to experience their final days. This approach aims to empower individuals in their dying moments, fostering a sense of control and dignity. However, this chapter unveils a more nuanced perspective on autonomy within Bangladeshi settings. Here, the role of the family surpasses that of the individual patients, a nuanced observation has been elaborated in the findings and discussion sections.

The findings in this chapter critically explore the concept of autonomy in end-of-life. The findings contend that, the concept of autonomy should be reevaluated for the death and dying. In challenging the predominant narrative centered on patients' autonomy as the cornerstone of a good death, this chapter contributes to a critical examination of the singular narrative surrounding the concept of autonomy. It suggests that the understanding of a good death is more multifaceted than a strict focus on individual autonomy would imply.

The original contribution of this chapter is that there is not a single narrative of awareness of dying and good death that is only dependent on the patients' themselves. Rather, patient's decision-making and awareness are significantly defined and determined by family members in the Bangladeshi context. It also adds that, awareness of dying in good death and palliative care is not only patient-centered but also family-centric in Bangladesh. Family plays a more influential role here, with family decision-making and participation being more important than the patient's own decisions in their last days of life. The chapter argued the awareness contexts proposed by Glaser and Strauss (1965) and Timmermans (1994). In contrast to Timmermans, the chapter explored four awareness contexts which are heavily reliant on family involvement.

The good death isn't linear, rather it is much more nuanced and multi-layered. Despite the patient-centred awareness of dying in prioritized in policies, good death death is not linear, it is much more nuanced and multi-layered, in Bangladesh, even in the many western settings. Despite there’s a singular narrative in policy, qualitative study and other evidence shows that there is more than one narrative that challenges the specific interpretation of good death. The specific interpretation is good death means patient's choice, patient's agency, patient's own control in those settings. My chapter challenges this specific interpretation by showing that it is not the patient's own control but family intervention and interdependence that is found in the present study. Rather than patient's choice, decision of the whole family is more important. Dependence on family rather than patients’ agency is found. Through these, this chapter establishes a comprehensive conceptualization of the good death that will help think beyond the established specific interpretation of the good death that is mostly established in the west. Finally, I argue that, as the literature review highlights that there is not a singular narrative about good death; the findings of this chapter challenge this specific interpretation of good death.

Chapter Seven- Patients and Families' Understanding of Good death

This chapter explores understandings of a good death among the families and patients I interviewed and observed for this study. I did the observation and interviewed the family caregivers and their dying relatives at the centre: both in the CPC ward and at the community palliative care projects in Korail and Narayanganj. Among the nine patients and eight family caregivers I interviewed, five were from the community settings. The other patients and their caregivers were from the hospital centre of CPC. I divide the findings into three sections in this chapter. First, I describe the family's point of view, and the cultural components signifying how the family perceive 'caring' as an obligation. Afterwards, I narrate what the families do to fulfil these caring obligations. Second, I describe the patient's point of view and the cultural understanding of the expectation of care in their final days. Along with their own expectations, I describe the patient's reflection on unfulfilled responsibilities towards the family, which leads to the third section. The third section explores the difficulties the families face in managing care for their relatives. Most of the participants in the community were from a poor economic background; this section, therefore, explores the narratives of their struggle to continue caring for their relatives. Finally, the chapter shows that the families and their dying relatives nurture a different understanding of care in the final days. How the family manage care and what the dying relatives expect and perceive in their final days are described. I conclude the discussion by focusing on family values and the mutual obligations, roles and responsibilities that shape their understanding of a good death in the research setting.

As the central argument of this thesis contends that, despite the common end-of-life care goals, emphasized in The Economist's Quality of Death Index (2015), there exists room for embracing an alternative approach to end-of-life care, the current chapter aims to explore different understandings of end-of-life care in Bangladesh. As the death index implies that optimal palliative care is best delivered through institutionalized, formalized, or professionalized arrangements, primarily via specialized palliative care settings, such as opioid/professional care in hospices, hospitals, or specialized care homes, the present chapter aims to critically explore palliative care beyond such institutions. Moreover, the thesis establishes its empirical contribution by illustrating how adopting a 'follow west' mindset may not effectively address the growing challenges of end-of-life care in the country. Rather than advocating for a singular approach, the study proposes exploring the possibility of identifying an alternative pathway. In the subsequent sections comprising findings and discussion, this chapter delves into an alternative interpretation of a good death by examining how family values influence end-of-life care. Departing from medicalized or institutionalized perspectives, the ensuing discussion revolves around the pivotal roles of responsibility and obligations in shaping the understanding of a good death.

Introduction

Poribar amader ekmatro vorosha

‘Family is our only hope.’

– Hasna (a cancer patient)

Ei muhurtey maayer shebai amar ekmatro kartabya. Eta amar dhormiyo kartabya

‘Taking care of my dying mother is the most important duty of my life right now. It is my religious duty as well.’

– Fatema (caregiver)

The patient’s quote, above, conveys the centrality of family in caregiving; the caregiver’s quote signifies the mindset of obligations and responsibilities perceived by the family caregivers during the final days of the patient. Keeping in mind the backdrop of poverty, and combining the point of view of the family caregivers and that of their dying relatives, this chapter shows that the cultural notions of caring for the dying signify an understanding of a good death in Bangladesh. Contrary to the notions of a good death found in the west, which are based on individual preferences and wishes, this research found a collective or collaborative understanding of a good death, in which the family, close relatives and neighbourhood are responsible for ensuring the care of their dying relatives. In turn, dying relatives expect care from their family caregivers. They also reflect upon their position in the family considering their roles and unfulfilled responsibilities towards their family. Combining the views of the patients and the families, the chapter shows that the care provided by the families and the thoughts expressed by the patients create notions that can be characterized as the values of a good death. Based on these notions, the families try their best to always provide care in the final days.

Before exploring the findings, I describe the story of one patient from two different points of view: firstly, that of the patient's family caregivers, and secondly, that of the patient herself. The first scene describes how Fatema and her sister manage to care for their dying mother despite their poor economic condition. In the second scene, Fatema's mother reflects about her children and the future of the next generation in the final days of her life. In describing the scene, I portray how the family plays a central role among the family caregivers and their dying relatives.

Scene 1

Fatema's mother now lives in Fatema's two-room household in the Korail slum. She has been taking care of her mother in her house since she knew that her mother may soon die. It all started six months earlier, when her mother was suffering from cardiovascular complications after a heart attack. Fatema and her elder sister took their mother to several hospitals after the heart attack. A doctor suggested that their mother needed bypass surgery, but they were unable to bear the expenses of the surgery. Fatema, her sister, their husbands and some other relatives discussed at length what to do, weighing up the ins and outs of the probable expenses. At that time, they had no savings and all of them were in insecure employment. Therefore, keeping everything in mind, they reached a decision not to have any surgery done. They consulted with the same doctor and asked whether there was any alternative to surgery for their mother. The doctor prescribed a few medicines. He also told them that the patient's condition may worsen at any time. In the meantime, after hearing about the community palliative care in their area, Fatema made an appointment with the palliative care team there and the doctor registered her mother as a category one patient. Category one patients are those who are elderly and may die soon.

However, life is not smooth in the two-room household in the slum. Seven people live in the house: Fatema, her husband, four children and her mother. Fatema's husband is the only earning member in the family. He is a rickshaw puller (a rickshaw is a traditional tricycle vehicle designed to carry passengers in Bangladesh. It is a manual vehicle and a common source of work for poor urban males in many cities of Bangladesh). Fatema had also earlier had a job as a maid in a house, but she left the job so that she could take care of her dying mother and her children. Therefore, it had become very difficult for them to manage the daily necessities; with the little income her husband brought they had to pay their housing rent, their food expenses and the expenses of caring for her mother.

Sometimes they cannot manage the expenses; then, Fatema takes her mother to her sister's house, which is also in the neighbourhood. Fatema and her sister take care of their mother by turn: when her sister cannot manage, Fatema brings her mother back to her own house and continues her care. In reply to my asking how they manage to take care of their mother in such difficult circumstances, both state that they are happy to be able to do so, despite their family's limitations. They also mention that their mother sacrificed a lot to raise them in their childhood. The difficulties they are facing cannot be compared with the extent of their mother's sacrifice, they think. They feel complete and satisfied while taking care of their mother, despite the difficulties.

Scene 2

Fatema's mother has not been able to talk properly since her heart attack. She also cannot move properly and needs constant care to carry on her daily life. During the afternoon, she sits beside the small window to have some sunlight on her face. On one such afternoon, I sit beside her. She looks down at the muddy floor, seeming pensive. As she cannot talk properly, I intend not to disturb her; rather, I ask Fatema whether her mother is always like this. Fatema replies that her mother is always thinking about them (Fatema and her sister). Sometimes, when no one is at home, her mother calls her and says that she feels bad that she could not do something significant for their future. By that, she means that she does not have property or money or wealth that she can leave for her daughters. She tells Fatema that she cannot find any comfort, thinking about her unfulfilled responsibilities. She feels terrible that she will very soon be no more.

These two scenarios, highlighting the family caregiver's mindset about caring and the patient's reflections on their families, touch upon the findings that follow in the next sections. These lead to the discussion of a good death in the concluding section of this chapter.

The family's point of view

In this section, I present about the family point of view about taking care of their dying relatives. First, I present about their beliefs about caring as an obligation and then I explore how they carry out their obligations.

Caring as '*Kartabya*' and '*Dayitto*'

a)

Azad is the primary caregiver for his terminally ill mother. He is a college-going teen and the youngest son in the family. His mother has been suffering from breast cancer for the past two years. Recently, she has been living in her elder son's house in a joint family, with her husband, her younger son, Azad, her elder son and his wife and children. Her situation has been deteriorating since July 2020. She has suffered continuously from bleeding in her affected breasts for the past two months.

After she was registered with the CPC's community palliative care team, PCAs taught Azad to do the dressing and cleaning of the cancer-affected parts of his mother's body. He learnt this very quickly and does the dressing regularly (usually twice a day); he manages this although he is a student and also does a part-time job in a pharmaceutical store. He feels good about the fact that his mother likes the way he takes care of her. He thinks that he is accomplishing his duties as a child for his mother. Azad told me:

> As a son, it is my most important duty (*kartabya*) to take care of my mother. As I am a Muslim, I believe in a Quranic text that says, 'The paradise of the child is under the feet of the mother'. If I can give my mother a little peace with my care, it's good for her and it's also a blessing for me in my afterlife.

When I asked Azad how he feels performing the tasks, he stated that he was accustomed to it these days:

> When I started cleaning my mother twice a day, I felt a bit awkward at first. But after a few days, I started to feel the very opposite of that. It's like I am taking care of my own body.

He also said, "My mother likes the way I do the dressing. She said she feels comfortable when I do it." During the interview, Azad said he will miss this caring activity when his mother is no more.

Before her cancer was diagnosed, the mother used to live in their ancestral home in a village. After her situation worsened, Azad's elder brother brought her to his house so that they could all take care of her together. Taking care of parents in the children's home has become a common practice recently in Bangladesh. After marriage, the son or daughter usually go to live in bigger cities for work and better amenities, while the parents stay living in the ancestral home. If the parents become seriously ill, the children bring them to their house in the city to take care of them. They bring their parents not just to ensure continuous care by the family members, but also because of the better healthcare facilities in the cities.

Azad has another sister, who lives a few kilometres from their house. She also visits her mother regularly and brings cooked food for her. Sometimes, she takes her mother to her own house to stay for 10–15 days. During the interview with Azad, his brother and sister were also present beside him. Sometimes they also took part in the interview with Azad. When asked about caring responsibilities, they said:

> We are happy that we are taking care of our mother. We are doing it together. Although we are unable to provide her the best care, at least we are trying for it. That's our motivation. It is our moral duty to make sure that she is best taken care of in her final days. It is a responsibility impressed into our mind since childhood. We saw that our parents were taking care of our grandparents.

The following is a description of Shamima, who, similarly to Azad and his siblings, is a daughter-in-law taking care of her mother-in-law

b)

Shamima is the caregiver of her mother-in-law, who had a stroke one year earlier. When I visited her home, a two-room house in the middle of the Korail slum, she was busy with a baby in her lap. Both rooms in the house are very small. Shamima and her husband live in one room and her mother-in-law, the patient, lives in the other room. They have a kitchen, which is attached to their rooms. The toilet is beside their house and is shared with other neighbours. “We are four family members. Me, my husband and two children,” she says. I was a bit surprised that she didn’t mention her mother-in-law. After asking where her other child is, she smilingly mentions her mother-in-law. “My mother-in-law is my other child; I take care of her like I take care of my 1-year-old baby girl.”

She explains that she does everything for her mother-in-law, and that this is like raising a child. From feeding and cleaning to medication, she does almost everything for her. She says that she scolds her sometimes when she does not listen to her (if her mother-in-law does not eat, she will scold her to make her eat).

After the stroke, she became incapable of fully understanding what she has to do regarding her daily activities. That’s why Shamima keeps a close eye on her always. She cannot talk properly so she uses her body language to communicate with Shamima. It is only Shamima that takes care of her mother-in-law the whole day because her husband works in an office every day. He is a clerk in a private organization.

After her husband registered his mother with the community palliative care project, they decided to put all their effort into taking care of her as she was approaching frailty and death.

“I have been taking care of her since last year. Now I don’t get tired of taking care of her. Although I become tired sometimes, I will miss this part of my life. I will miss her badly, because both she and my child are the centre of my life.”

Despite Shamima being the daughter-in-law, not the biological daughter, she feels that the care is her responsibility too since she is the wife of her son. Shamima’s husband is the only child of her mother-in-law. Her father-in-law died five years earlier. Since then, her mother-in-law has been living with her only son.

Despite becoming exhausted sometimes, she motivates herself by realizing that she had been unable to take care of her own parents as both died when she was very young. Therefore, she feels good that she can take care of another parent-like person in the family. “I used to feel like I was the unluckiest person in the world as I lost my parents when I was very little. She (mother-in-law) is filling this gap in my life.”

Like Azad and Shamima, other family caregivers talked about the responsibility of taking care of their terminally ill parents or, in some cases, about taking care of their terminally ill children. For most of them, caregiving is not made easy just because they feel motivated about their caring responsibilities. It is an even tougher journey for the families who are from a lower-income background in the community palliative care area. They manage and seek support (economic, social, spiritual) in many ways. The situation is not as complicated for the better-off families; nevertheless, finding support from close relatives or the neighbourhood is a common practice in Bangladeshi culture. Such support is significant when a family member becomes terminally ill. In the following section, I describe such supporting ways.

Means of support to carry out '*Kartabya*' and '*Dayitto*'

In conducting the interviews, I found that when the participants began speaking, they spontaneously followed a narrative structure. They would start by narrating the story of the diagnosis of the disease, their visits to hospital, their relative's admission to the hospital, referral to the CPC, being informed about the terminal prognosis and the way the family dealt with the situation. In order to keep the spontaneity of their narrative I did not follow my pre-designed topic guide. Their narratives evolved around these themes: how the families handled the critical moments; what difficulties they faced; how they managed or overcame those difficulties; psychological breakdown; and how they were continuing to manage care. In the following sections, I mostly describe the support the families received and the compromises they made with their lifestyle to ensure care for their dying relatives.

Support from close relatives

Once their relative was diagnosed with a life-limiting disease, the family members would first contact their close relatives for support. By close relatives, I mean cousins, uncles, aunts and members from the in-laws' family. When the family members were unable to meet the expenditure by themselves, they would seek financial help from close relatives who were well-off. Other than the financial issues, close relatives tended to provide support for caring duties and the actual labour needed to ensure the patient's wellbeing. In the following sections, I describe two families who received help from their close relatives.

a)

Sajib, the caregiver for his mother, shared how support from his relatives helps them to manage their family. His mother has stage four breast cancer and he and his wife both take care of her. As he is the only earning member of the family, he was having difficulties taking care of his mother in addition to running the family. He is a tea-vendor in the slum. His income is hardly 7000 taka (£61) per month.

With the diagnosis and the continuing treatment, he was already in a miserable financial situation. One day his mother told him about some of their close relatives. Surprisingly, he had not met them before, although he knew that he had a few relatives in the capital and in their village. Among them, his mother had three cousin-brothers whose social position was quite comfortable. They were a doctor, a college teacher and a businessman. There was also a cousin-sister, married to a politician who was an *upazila* chairman (*upazila* is a subdistrict-level administrative unit in Bangladesh. The *upazila* chairman is the highest political authority at this level). Sajib went to her house to seek financial help. He was excited to meet them as well as nervous as he was not sure how they would react to his request. Among them, his mother had the address of just two of the relatives. She told Sajib that if he met them, he could then get information about the others from them.

First, he went to the cousin-sister's (Sajib's aunt's) house in the village. This was a new experience for him as he had never thought that he had such an influential relative. He had to pass through security protocols to enter his aunt's house. (As this was a chairman's house, there were guards and maids in the house.) His aunt was unable to recognise him at first. After asking a lot of questions about his mother and other information about acquaintances, she understood who Sajib was and greeted him warmly. She became upset when she heard the news of Sajib's mother's cancer. Regarding financial help, she told him that she would try her best to support him. In addition, she helped him by contacting the other relatives his mother had told him about. His aunt introduced him to them over her mobile phone. Now, Sajib is able to contact his relatives every month when he needs money for his mother.

b)

Rima, a lung cancer patient, had been admitted to the female ward at the centre. Her mother and mother-in-law are sitting beside her. Whenever she feels pain, her mother sits beside her and gives her a soft massage. Her mother takes care of her cleaning and feeding in the ward. Her mother-in-law sits on the other side of the bed; she is counting a *tasbih* (a set or string of 99 prayer beads used by Muslims as a counting aid in reciting their prayers) and blowing gently on Rima's face. It is a gesture of showering religious blessings.

Outside in the waiting room are her elder brother and several cousins. She came to Dhaka from a remote district. When she was diagnosed with cancer in the district city, her family members went with her. Her mother-in-law, brother-in-law, her two children, her mother and her aunt: all have come to Dhaka to take care of her. Each of them play a role by doing something for her.

Rima's brother handles the finances and coordinates with other family members about Rima's care and managing the family's arrangements. He works as a manager in a readymade garments factory in Dhaka. Rima's husband also coordinates with her brother. Unfortunately, Rima's husband is not beside Rima as he is now in a Middle Eastern country, where he is employed as a construction worker. He is not able to visit Bangladesh because he fears that he could lose his job if he takes leave in the uncertain circumstances due to Covid-19. Rima's brother requested him not to come so that his earnings could be used for Rima's treatment expenditure.

Regarding the other close relatives, Rima's brother coordinates with everyone to plan how they can all play a role in taking care of Rima. He has discussed with all the family members regarding their shifts at the CPC looking after Rima. It is a common practice in Bangladesh for at least one or two family members to stay at hospital while their relatives are admitted. They stay awake in the waiting room in case of any emergency. Each of the relatives plays a role for Rima. Her mother is the one who stays longest in the ward with her. From feeding to cleaning, Rima's mother is a constant presence beside Rima's bed. Rima also feels better when her mother is beside her. Rima's mother comes to the ward every morning and leaves before evening when another family member arrives. Before leaving, she asks Rima what she would like to eat the next day, so that she can bring her favourite meals. Rima’s sister-in-law comes once every two days and stays for two to three hours at the ward. She brings Rima’s two children with her when she visits, so Rima eagerly awaits her arrival. When her children ask her when she will be well again, she does not reply; rather, she becomes silent and hides her tears. Her brother-in-law deals with the necessary work at the CPC during the day. Doctors and nurses communicate with the family members at the centre to inform them of what tests need to be done or what medications they need. The brother-in-law and other cousins stay during the day to attend to such work.

It seems a patient needs a whole army of caregivers when they are diagnosed with a terminal disease. To ensure that a relative is taken care of by everyone in the family, those closest do not travel to remote destinations, but stay close by. It does not matter whether the family members are old or young, the family make their presence effective beside the bedside of their dying relative.

Rima’s brother explains it this way:

> We are giving our best to Rima. When we found out about her terminal condition, we decided that we would all stay together wherever she will be. Although it is not easy for me to manage everything, we are waiting for her pain to be relieved so that she can return to Noakhali and pass her final days in her home.

Rima’s story is that of a family whose financial condition is stable in comparison with that of other families in the area of community palliative care. In Rima’s case, the support of close relatives is more about providing the necessary support (physical, mental spiritual) during her admission. In the following section, I describe the situations of families requiring mostly financial support.

Support from the neighbourhood

On a regular day at the CPC, having reached there at around 10 in the morning, I began my observation on the female ward, where I saw five patients had been admitted that day. One of them was Hasna, who was in her 30s. She was a cancer patient. Her mother (Rahima), her aunt and her husband were the family caregivers for her on the ward. I was observing them and other patients and families, as on any other day of my fieldwork. Rahima was feeding Hasna *jau bhaat* (soft rice made specially for patients). In the middle of this, Rahima received a call. I could hear her replies. She was feeding Hasna with her hands while talking through the mobile phone, keeping it pressed to her ear with her shoulder. The phone conversation was about the money needed for Hasna's care. When she hung up the phone, she said to Hasna: "Don't be without hope, my loving daughter. I will manage whatever money I need for your care." Later, I approached Rahima and asked for an interview.

During the interview, Rahima told me that Hasna was married, and she had three children, aged between three and ten years. Her husband was a carpenter who worked as a daily labourer in a carpenter shop owned by another man. His daily income varied according to the work the shop received: 300–400 taka on a good day and 100–150 taka on a bad day. He had to cover the expenditure for Hasna's treatment with this small amount of income. Hasna's husband, her mother and her aunt divided the care into day and night shifts, so that Hasna's husband's work was not disrupted. After finishing his work, the husband would go to the CPC and Rahima would go to Hasna's house to take care of the children.

However, they were not able to manage with the little income they received from the carpenter shop. Therefore, they asked for help from their relatives and from the neighbourhood. They received a little help from relatives. A little later, a friend of Hasna's husband suggested to him that he could ask for help from the school their children attended. The husband went to his children's school and asked for charity from the head of the school and, unexpectedly, the response from the school was huge. Hearing of Hasna's severe ill health, the head of the school made an emotional appeal to all the students, their parents and the teachers at the school. The school and the students' families donated almost 300,000 taka (around £2640) for Hasna's treatment. However, they stopped collecting money for a cure after they came to know about the terminal prognosis given by the centre.

The section has portrayed how families manage to take care of their dying relatives in their final days amid structural challenges, including the lack of any formal social and economic security. As there is no centralized healthcare insurance for all and no significant healthcare packages for the disadvantaged, the family is the connecting hub for all kinds of effort and for the management of care at the end of their dying relatives' lives. Therefore, families put effort into collecting charity from neighbours, and, when necessary, move to Dhaka so that they can play a significant role in their relative’s care; they also make compromises in their lifestyles. The scenario of families expending such effort illustrates how end-of-life care in a low-income setting is the very opposite of that found in a high-income country. It is opposite in the sense that the difference lies in the degree of the family’s involvement in a dying relative’s final days. This brings us back to the discussion about the family’s influence upon the life of the relatives on their deathbed in Chapter six, which explored the different awareness of dying contexts of dying relatives. That is, the providers need first to consider the family’s preference regarding informing patients about their terminal prognosis – they need confirmation from the family members first. Continuing the attempt in Chapter six to argue that the family’s decision making on behalf of their dying relatives calls into question the relationship between open awareness and the autonomy of patients, this chapter extends the search to explore why and how the family plays multifarious roles in their dying relatives’ lives. In arguing this, the thesis looks to reconsider notions of autonomy in the context of the lives of dying patients in Bangladesh. Therefore, the involvement of the family in aspects of the awareness of dying and in managing the overall care of their relatives at the end of their life extends the discussion on the deep-rooted cultural factors that play a role in the family and their relatives’ lives. However, within this chapter, the present section has also revealed that structural limitations are a key reason why the family is involved in financing, managing and coordinating the care of their relatives. Nevertheless, during my data analysis, while I was going through the transcriptions of family members’ and patients’ interviews, I found that the notions of giving and receiving care displayed connotations of spirituality and religiosity in the narratives. Besides spirituality and religiosity, they also touched upon the notions of responsibility, duty, obligation and expectation. In taking care of their relatives, family members do not do so just to help their vulnerable relatives: they are also playing a greater role in conformance with family obligations or religious responsibilities; these are sources of inspiration that are culturally ingrained in people’s lives in Bangladesh. In addition, relatives also nurture expectations and wishes about receiving care in the terminal stage of their lives. In the following section, I present findings which explain the aspect of mutual exchange in the notions of caring among both families and relatives.

The patient's point of view

In this section I present the patient's perspective on the care they have received since they were diagnosed with a terminal disease. It is related to the previous section regarding the understanding of the centrality of the family, adding the perspective of the patients themselves to that of the family members. In the previous section, I demonstrated how the families of dying patients arrange terminal care on their own despite having an unfavourable family situation. More importantly, I explored how the family negotiate between the motivation for caring as part of their responsibility and their economic realities. In this section I present what the patients expect from their family and what they think about the struggles of their family members regarding their terminal care. In addition, I present their thoughts on death which are more about how it affects their family members than about any individual wishes.

Expectation of care

The patients I interviewed expressed their expectations regarding receiving care from their family. Although the expectations varied according to age, gender and class position, in general, patients submitted their agency to their family members. It is almost a taken-for-granted notion in Bangladeshi society that whenever one becomes a patient, the family comes to the forefront to take the necessary action, whatever the patient as an individual thinks or does. During his interview, Dr Nasir, founding chairman of the CPC, put it like this:

> Whenever someone becomes a patient, whatever their age is, they become a child to their family members. It is an in-built cultural code in Bangladeshi society that the family act collectively when a member becomes a patient. The patient unknowingly accepts the fact and expects it unintentionally.

In this section I describe the patients' expectations in this regard.

Fayez, an epilepsy patient with multiple other health complications, was staying at his elder son's place in Korail slum. Before his health deteriorated he had been staying at his own house in a village. When he had become very unwell, four months earlier, he had called his son with his mobile phone. His elder son had gone to the village and taken his father to his place in Dhaka. I asked Fayez why he had called his elder son. He replied, “In older age, children are our safest shelter. I felt very bad the night I got sick. In that moment, I needed him to take care of my situation.”

There is a Bengali word – *oviman* – which can better explain how parent-patients feel when they are not taken care of by their children. I looked for the English translation of this word: Google translate suggests the meaning of *oviman* to be egotism, an extreme sense of self-respect. But these meanings do not catch the essence of the word. I mention the word to explain the emotive aspects of parents’ expectation of care from their children.

Ambia, a colon cancer patient in Korail was feeling *ovimani* about her children in the first few days of her disease. Although her situation was worsening, her children were not beside her. Her neighbours and a maid in her house helped her to go to a hospital and get further treatment. Ambia was very upset about the fact that her two sons did not take care of her, because of their business. “I cannot think that they avoided me in a critical situation like this. I am shattered because I was never negligent about their care when they were children. It really hurts to see that they didn’t care about what I was going through.” A few days later her elder son came to see her in the hospital. She was adamant that she would not talk to him, but she could not resist her emotion when he hugged her. From that time, she stayed at her son’s house in Korail.

When the patient is younger, parents, elder siblings and other relatives take care of them. From the very time they receive their diagnosis, these patients are taken care of by elder family members. However, a few such patients feel bad that the family have to go through a lot of difficulty due to their terminal condition. I found various such mental sufferings and anxieties among the patients I interviewed and observed; these are presented in the following section.

Unfulfilled responsibilities towards the family

Patients go through various kinds of mental suffering in their terminal days. I found that the sufferings are mostly related to their inability to fulfil duties and responsibilities to their family. The perception of inability differs from patient to patient according to their age, gender and socio-economic position. Apart from the sufferings related to family affairs, there are several other types of mental suffering patients experience, which I will describe separately. In this section, I focus on the family-related mental suffering, in connection with the idea of the responsibilities a patient perceives in respect of their families during the terminal phase of their life.

I firstly describe an elderly terminal patient. Jalil**,** a carcinoma patient in Korail, told me why family responsibility is the most important element in human life. He had come back to his daughter’s house a few days earlier from the CPC. He had found out about his terminal prognosis in the family meeting and had chosen to go to his daughter’s home to pass his final days. While talking to me, he explained that he had been thinking deeply in recent days about whether he had performed his duty towards his family or not. Sometimes he felt worried thinking about this. He mentioned an Islamic Hadith (a tradition of the Prophet Muhammad) which he had heard from one of his religious mentors a few years previously. He could not recall it exactly, but he explained the theme of the Hadith to me: “Before someone dies, they have to think whether they have fulfilled their duty to their children and wife. People should evaluate their thoughts about death based on their responsibilities, duties and commitments.” Thinking of his own family, he was worried about his daughter. Although his daughter was employed she was not yet married. “It is tragic for a father if he dies without marrying his daughter to a good human being,” Jalil said.

Hasna, a 30-year-old cancer patient, had been thinking about her three children. The eldest was a 10-year-old girl; the other two were boys, aged seven and three. When I interviewed Hasna at the CPC, she spoke about her three children and their future:

> I will be leaving from this world too early. I really can’t accept the fact of my death. Who will take care of my children? They are still very young, and I know how horrible they will feel after losing their mother at such a young age!

Hasna wished to accomplish the building of a new home on their own land; she and her husband were saving money to do so. When she was diagnosed with cancer six months earlier, she and her family members had thought that she would be cured. However, her situation had deteriorated. The providers had informed her mother and husband about her terminal prognosis in the family meeting and later her husband and mother had told Hasna of her situation. A doctor was beside her when she was informed, who reassured her that the CPC would take care not only of her physical symptoms, but also of her mental suffering as well. Hearing that, Hasna asked: “Doctor, how will you take care of my mental situation? I am worried about my children’s future. It’s impossible for you to take care of me without taking care of my children.”

Amir was a tetraplegic patient in his 30s. He was depressed about the fact that he was unable to take care of his family. He talked to me about the role of an elder son in a Bangladeshi family:

> In our society, the elder son is very important. They have a lot of responsibilities towards their parents and siblings. Besides, they need to take care of their own family as well. I am unable to perform any of those duties. My parents and my sisters have been taking care of me for the last 10 years. It makes me very depressed.

He was also worried about the fact that he would not be able to marry because of the infection in the lower part of his body:

> I miss the fact that I cannot have a family of my own. I see my friends getting married and having a good time with their wives and children. And I am on my deathbed. I will die any day. There’s no improvement in my disease – it’s just getting worse.

The difficulties of caregiving

The above findings demonstrate two perspectives on how family members experience caring for terminal patients and how the patients expect care from the families. In this section, I describe how the family is affected by the terminal illness of a member of the family. Whenever a member of the family is diagnosed with a terminal disease, it is not just the patient but the whole family that is affected. However, despite the difficulties, families carry on performing their roles and carrying out their duties to their dying relatives. In the following section, I explore how they do that.

Prioritize care over difficulties

Whether it is in the CPC ward or in a small two-room household in Korail slum, dying relatives remain surrounded by their family members. I describe here a patient’s family from Korail.

Sultana is the patient’s daughter, in her 30s, taking care of her mother on a sunny winter afternoon in December 2020. Her mother is a patient with several comorbidities (hypertension, diabetes, unable to talk, unable to move). She has been staying with Sultana for the past four months in Korail after being informed about her terminal condition. It is Sultana who has decided to bring her mother to stay with her so that she can ensure care for her mother in her final days. However, the arrangements have not been easy for her and have called for a lot of compromises from the other family members.

After Sultana’s mother joined the family, the number of people in the household became nine. The other family members are: Sultana’s husband, her father-in-law, four children and Sultana’s younger brother. All of them live in two small rooms which total approximately 200 square feet in area. Basically, it is a single room that Sultana and her husband have turned into two rooms by attaching a plywood divider in the middle of the room. Sultana, her husband and her four little children live in one room, and her mother, father-in-law and her brother share the other room.

Sultana’s husband and her younger brother are the only earning members of the family. Both are day labourers and their income is very low. Some days they do not find any work due to the precarious nature of their job as day labourers. Sultana’s mother having joined in the family, they are now feeding an extra mouth. Besides, Sultana has to devote time and effort to taking care of her mother. She cleans her body, feeds her three times a day, helps with her medication and keeps her eye on her the whole day. In addition to taking care of her mother, she looks after her four children and her father-in-law. The children’s ages range between five and twelve And they are two boys and two girls. Sultana’s father-in-law is in his 60s. Although he is not suffering from any critical disease, it is also the unwritten job of a housemaker to take care of the elderly.

Amid all these caregiving roles, Sultana makes sure that her mother gets the best care. This is why both she and her husband have decided to make some adaptations in the family expenditure and other aspects: firstly, Sultana left her job as maid when she started taking care of her mother so that she could manage the time to focus on her mother; secondly, they have decided to limit their daily food expenditure to 150 taka. However, Sultana says:

> It is very difficult to buy food items with only 150 taka for nine family members. Therefore, I always buy potatoes and small fishes to keep the expenses in line. Sometimes me and my husband eat less. I also keep *muri* (puffed rice) all the time because it’s cheaper and it keeps us away from hunger.

Besides Sultana leaving her job and putting a cap on food expenditure, she is teaching her 12-year-old daughter how to take care of her grandmother. Recently, the daughter is also helping by going for groceries and doing other household chores. “Although my daughter is very young, there’s nothing wrong in helping family members in a poor situation like us. I feel relieved when she helps me by doing those things,” Sultana says.

Sultana’s family tells a tale of compromises and resilience, which is protecting the mother from the most adverse situation possible in her final days. Despite their extreme poor condition and miserable life in the slum, all the family members are making sacrifices to make sure that their dying relative passes her final days peacefully and receives uninterrupted care. Firstly, Sultana took on the full responsibility of taking care of her mother in her terminal days. After she arrived in the household, Sultana and her husband compromised by Sultana leaving her job, and by limiting expenditure on food, which affects the nutrition they receive. Finally, they are preparing their children at a young age to take on some of the family responsibilities themselves.

One day Sultana was talking with her husband about the family expenses. In the middle of their conversation, they both realized that the expenses were a bit high that month. They argued about it. Suddenly her husband told her that if Sultana’s mother was not there, they would be able to manage the family well. Hearing that, Sultana started crying. During her interview with me, she described the incident. She also said that her mother had heard their conversation as the rooms are very small and there are no doors between her room and her mother’s room. She was upset, thinking about how her mother would have felt about it:

> Sometimes I get tired, emotionally and physically. I can’t keep balancing my mother’s care and family expenses. I pray to God to take me to him before my mother. Sometimes I don’t want to face these hardships. What keeps me alive is that I think about my mother’s sacrifice, about how she raised me despite her volatile situation when I was a child.

The story of a marriage

I described Shamima earlier – she is the primary caregiver of her mother-in-law. Here I talk about Shamima’s marriage. Eighteen months earlier, she and her husband, Rafiq, were neighbours and Shamima lived with her brother and sister-in-law. She was studying in a college.

When Shamima and Rafiq were neighbours they rarely talked to each other. One day, Rafiq had called at Shamima's house in the middle of the night and asked for Shamima's brother to help him. His mother was feeling so sick that she was unable to talk or move. Shamima's brother helped Rafiq to take his mother to a hospital. Later they came to find out that the mother had had a stroke; she was admitted to hospital for a few days. Shamima's family had helped Rafiq a lot at that time. After Rafiq's mother was discharged, Rafiq had approached Shamima's brother with a marriage proposal for Shamima. Rafiq had told Shamima's brother that as his mother was very ill, and there was no one in his family who could look after her, he wanted to marry Shamima so that she could take care of his mother. Shamima's brothers and other relatives had discussed Rafiq's proposal among themselves. A few days later, they had informed Rafiq that they agreed to his proposal. Shamima's brothers had also talked to Rafiq about Shamima's education, ensuring that she could finish her college education after marriage. However, she did not continue her college education further.While relating the story of her marriage, Shamima told me that Rafiq's mother's illness had played a key role in their decision to marry:

> As Rafiq was alone and struggling to care for his mother at that time, he was really looking for a life partner to share his life's responsibilities. It's not that he was just looking for a partner to help to take care of his mother. He is a gentleman and a man with dignity. When my brothers asked me whether I would agree to marry Rafiq, I accepted the proposal because I liked him a lot when we were friends. His mother's illness was a special situation and it pushed him to think about marriage. A responsible son thinks like this and I was amazed to see his care for his mother.

Loan for treatment

Roksana, a patient with lung carcinoma and in her 60s, had gone through several upheavals in her family life. She was living alone in a one-room house in Korail slum. She had earlier lived with her elder son's family before moving to the one-room house because of some issues with her family members regarding her treatment. One year earlier, she had been diagnosed with cancer in a hospital in Dhaka city. The doctor had suggested to her two sons that their mother needed chemotherapy for her treatment. Both sons were junior rank clerks, in two different organizations; their salaries were not more than 15,000 taka each (around £130) per month. They took a loan from a family support scheme institution. After the chemotherapy, Roksana's condition became a little better. She felt very good that her two sons had helped her during the hardest time of her life.

Soon, the situation worsened regarding Roksana's health; regarding the loan scheme, the two sons failed to keep up with the repayments. The situation became difficult for the sons and their families. They began looking for extra work so as to manage the crisis. Roksana's health improved for a couple of months before worsening again. Her elder son was unable to manage both the expense of her treatment and the crisis of the loan instalments together. It became unbearable for him. One day he told his mother about the financial difficulties and told her that to repay the instalments he must reduce other costs, such as the cost of her treatment. After a few days Roksana left her son's house without saying anything. She requested a council leader at Korail slum to rent her a house as she was very sick. The council leader managed to find a one-room house for her, and told Roksana to pay the rent when she was able to. Later, Roksana came to learn about Compassionate Korail and consulted with the doctors and nurses at the centre. She was registered as a category one patient there as she had no caregiver to look after her, and was in a critical condition.

The abandoned patient

In Chapter six, I described the incident of a patient who was abandoned by his son and left in the waiting room at the centre. A note written for the providers was left with him, in which the son wrote that had left his father there because he was unable to deliver continuous care for him. Because of his poverty and being overwhelmed by his responsibilities, he had decided to abandon his father in the waiting room.

Summary and discussion

In Bangladesh, family members play the most significant roles during the final days of a relative's life. This chapter has explored how the family's roles in respect of dying relatives go beyond typical roles such as giving physical care and spending time with them. Also highlighting the dying relative's perception of their impending death and of the care they receive in their final days, this chapter presents the perspectives of both the family caregivers and their relatives on the final days.

This research explores the understanding of a good death held by providers, family caregivers and their dying patients. The first chapter of the thesis demonstrated how the providers organize and deliver palliative care both to the patients at the centre and to the patients in the communities. The providers deliver palliative care to the patients who visit the centre and agree to receive care from the providers at the CPC. The research findings show that when the patients receive palliative care from the CPC providers the family members' involvement is significant; for example, the providers cannot inform the patient about their terminal prognosis without first gaining agreement from the family members. Therefore, one of the important aspects of a good death – awareness of dying – is seen rather differently at the CPC; this is discussed in Chapter six. Following a portrayal of the prominence of the roles and responsibilities played by the family caregivers, the present chapter has presented how the family plays an all-encompassing role for their dying relatives, and has described what the dying relatives also expect from the family, which the study found goes beyond the framework of that palliative care version of a good death as understood at the centre.

The findings reveal that there are certain notions of a good death found among the families of the patients in the palliative care settings in the study, which can, to some extent, be seen as counterparts of the palliative care version of a good death. However, the present chapter does not highlight those families who withdrew their relatives from the CPC or from community interventions. Therefore, the chapter does not discuss such families and whether their relatives achieved a good death or not. It should be noted that families want the best for their relatives whether they withdraw their relatives from the CPC or keep them there.

Regarding the all-encompassing role of the family, this study highlights how end-of-life care is not only about what is delivered at the CPC: it goes beyond the duties of the doctors, nurses and PCAs, and is more than what happens inside the CPC or what is suggested by the providers there and in the community settings. Chapters five and six revealed what happens inside the palliative care centre and community settings in terms of how the doctors play a significant role in administering morphine, prescribing other medications and making suggestions as to how a terminal patient can attain a comfortable state of body and mind in their final days, as discussed in Chapter five. Chapter six illustrated how the families are informed about their relative's terminal prognosis. This chapter has shown what happens inside the family between the family caregivers and their dying relatives. I conclude by arguing that dealing with the terminal illness of a relative is not just about ensuring a painless death, or the open awareness of a dying relative in a palliative care centre. It is also about the motivations of family members and the expectations of dying relatives, as is reflected in this chapter.

The motivations of family caregivers can be explained in terms of cultural notions regarding the roles, obligations and responsibilities practiced in Bangladesh towards dying relatives. In addition to the close family members, the extended family and kinship network become involved when a relative is given a terminal prognosis. As in other affairs of life, the family prioritize notions of roles and responsibilities in terms of taking care of their dying relatives. The findings reveal that these notions are more important for the family caregivers than are the burdensome and stressful aspects of caring activities. This becomes more explicit in terms of the families from lower economic backgrounds found in the community settings. Despite their poor economic situation and hardship, family caregivers from such families take care of their dying relatives in their final days. In doing this, they perceive that they are fulfilling a major responsibility. The motivation provided by cultural norms around roles and responsibility shapes the family caregivers' understanding of a good death.

To add to this, dying relatives' understanding of a good death can be explained by their expectations of care in their final days, revealing what they perceive about their family caregivers in those days. Besides their expectations, they also reflect on their responsibility towards their families. They think about whether they have performed their duty as a father, mother, son or daughter. For example, if the patient is a father, they may reflect on whether they were able to marry their daughter to a good husband, whether their son is employed, whether he has resolved disputes (perhaps regarding land settlements), to make sure his family do not face complexities after his death. If the patient is a mother, they may think about whether their children are happy with their spouses, and whether the children are well established in their positions. If the patient is a younger adult, they may become depressed, thinking about being unable to fulfil their roles and responsibilities for their parents and other family members.

Nevertheless, family caregivers' perspectives on what constitutes a good death can be understood from the combination of their motivation regarding their obligations, and their hardships. The dying relatives' perception can be understood from their expectations and their sense of obligation towards the family caregivers before their death. Rather than considering the aspects of caregiving and care receiving, the understanding that family members and dying relatives hold of a good death is bound up with the idea of obligations as well, as is found among the participants in the study. Based on such findings, I discuss how, like all other aspects of life, death is significantly connected with the values of roles, obligations and responsibilities among the family caregivers and their dying relatives. In the following sections, I discuss the cultural aspects of the importance of family roles at the end of life; this is followed by discussion of the understanding of a good death among the family caregivers and their dying relatives. Despite the intervention of palliative care at the CPC and in the community settings, this study reveals that the family plays a major role in taking care of dying relatives among the participants of the present study. Therefore, I argue, finally, that the future of palliative care in such settings can be reconsidered based on the way both family caregivers and dying relatives understand the notions of a good death, motivated by their sense of obligations, and rooted in their cultural practices and social lives.

Family and kinship at the end of life in Bangladesh

The family's involvement in a relative's illness is a common trend in almost every culture (Frank et al., 1991). There is an acknowledgement of the necessity of the engagement of family members in caring for acute care patients and elderly patients (Kutash & Northtrop, 2007). The role of the family is more significant in the context of palliative and end-of-life care. Family caregivers are considered to be key persons in palliative home care and can be seen as being essential (Brogaard et al., 2011). A systematic review of literature on the caregiving role of families in countries such as the US, Sweden, Australia, Thailand, Norway, Brazil and Taiwan found that the family is still regarded as the greatest source of support for those patients who prefer to be taken care of at home. Although most studies on the family's role in palliative care highlight how their assistance helps the palliative care professionals to achieve a good death, there are few studies which have highlighted the roles of family caregivers.

However, what the findings of this study suggest is that irrespective of the notions of a good death in palliative care, family members play significant roles in caring for their relatives on their own. Not only family members, but also members of the extended family and kinship network also take part in caring for dying relatives. Family members arrange their involvement in different caring activities to make sure that their relatives pass their final days comfortably.

Family involvement can be understood as part of the historical past of Bangladesh. There are ingrained cultural codes behind family involvement in people's lives in Bangladesh. The family is still a crucial unit in society in Bangladesh and plays an influential role in the life of an individual (Zaman, 2005). The family is influential not only in Bangladeshi society but also in many non-western countries. The traditional Bengali notion of *gusthi* describes the basic relationship in society in these settings or countries, where everyday activities are carried out by members of the same clan or group, mostly formed by family lineage (Gluckman, 1962). The Bengali term *gusthi* encapsulates a notion of kinship that guides people's everyday interpersonal relations in Bangladesh. The *gusthi* network does not necessitate a blood connection, but rather consists of closely related and neighbouring households and can thus be very large and complicated (Aziz, 1979). *Gusthi* can be identified with the notion of kinship and is formed among extended families. Although it was an important aspect in agrarian economic activities in the past, *gusthi* is still used to refer to extended family members. However, with rapid economic growth and urbanization, the notion of *gusthi* is being reconsidered in the context of the daily activities of people's lives. With the interventions of state and market in agriculture and other economic activities, it is argued that economic activities are not significantly determined by the *gusthi* network anymore (Makita, 2007). However, in terms of the illness of a member of the family, the notion of kinship, extended families or *gusthi* still matters in Bangladesh. An ethnographic study of a Bangladeshi hospital found that the relatives of patients felt that it was their moral duty to attend to their sick family members during their stay (Zaman, 2005).

Focusing on the present study, the findings reveal that the notion of kinship still plays a role in the behaviours of family members when a relative becomes ill or develops a terminal condition. The close family members of the patient (father, mother or children) seek assistance from the members of their extended family. Such assistance can include financial support, emotional support and caregiving support (giving time to provide physical care at home, helping in the hospital, going to doctor appointments). By focusing on the role of extended families or kinship

– indicated by the term *gusthi* – I argue that the role of the family is extended and strengthened by their support. The present study shows that the family works as a hub of support in the treatment of ill patients.

In the present study what is significant is that whether palliative care is given or not family members and their dying relatives have their own understanding about how the family can make sure that their relatives are able to pass their final days in comfort by playing out their duties and obligations towards them. In addition, relatives also have certain expectations and a sense of their obligations which shapes their activities in their final days and their reflections on how an untroubled death might happen. Despite not having any understanding about a good death in terms of palliative care, families' and dying relatives' notions of a good death evolve around certain cultural practices and values of caregiving and care receiving, which can be compared with and discussed in relation to the palliative care version of a good death.

In the following section, I explain the values of the obligations perceived by family members.

The understanding of a good death held by families

Despite the families having little understanding of the palliative care version of a good death, their role in the final days can be understood as an effort to achieve a death that is 'peaceful', 'comforting' or 'accomplishing'. The words 'peaceful', 'comforting' or 'accomplishing' suggest meanings that are not confined to physical pain relief or mental soundness: these descriptions go beyond the meaning of these notions as generally understood in palliative care. For example, in the context of the palliative care notions of a good death, 'peaceful' and 'comforting' refer to the relief of physical pain. 'Accomplishing' is meant to indicate the fulfilment of the patient's wishes in their final days. It is to be mentioned that the words 'peaceful', 'comforting' were used by the participants themselves. However, in the context of the families in the present study, although their priority is to relieve pain or help to fulfil the wishes of relatives, families evaluate these notions in terms of playing their moral duty and fulfilling their obligations towards their dying relatives. These terms are not just about a service from healthcare providers or enabling relatives to fulfil a particular wish before their death.

When family members talk about the effort they make in taking care of dying relatives, they describe this in the language of moral duty. Unlike the good death understood in palliative care, the family members of relatives describe what this means by referring to their sense of duty and responsibility to ensure their relative's physical and mental comfort in their final days. Regarding their caregiving, they tend to use Bengali words such as *dayitto* and *kartabya* ('duty' and 'responsibility' respectively).

Both *dayitto* and *kartabya* can be better understood through the word *dharma*. According to traditional Indian values, human life can achieve perfection through three goals: *artha* (prosperity), *kama* (desire) and *dharma* (righteous living). By achieving these three, a person can attain *moksha* or *mukti* – the liberation of the soul (Indabas, 2017). In this regard, *dharma* is significant in understanding the dynamics of notions of *dayitto* and *kartabya* among family members towards their dying relatives; *dharma* guides one's responsibility in society: for example, the moral obligation of a father to his children or of a child to his parents.

Family members, in this study, perform their roles out of moral obligation towards their relatives, whether they are parents or children. A sense of moral obligation among families is also found in a study of hospitals in Bangladesh in which the relatives are described as the 'silent saviours' of the patients in terms of their attending to their relatives out of moral obligation (Zaman, 2005). In the hospital they carry out crucial tasks, such as helping with feeding and washing, bringing food and medicine from outside, negotiating with the hospital staff and providing emotional support for the patients in the hospital along with the healthcare providers. In the current study, the moral obligation of family members towards their dying relatives is also explicit. Moral duty is not only related to doing a favour for relatives, but is also bound up with the meaning of death. Moreover, the family's caregiving efforts are not aimed at finding a cure, but at making their relative's final days comforting and untroubled.

Whatever the outcome is, family members prioritize their caregiving efforts despite facing various limitations. For example, if they have financial limitations, they try to minimize them through various means, such as seeking help from their kinship network or neighbourhood. Sometimes they compromise on valued life decisions in order to continue the caregiving, such as an earning family member leaving their job to dedicate time to caring for a relative, or siblings taking on responsibilities when it becomes difficult for the main caregiver. Often it comes down to compromising on lifestyle decisions, such as lower-income households choosing to spend less on food or luxury items. As most of the families were from lower-income households in this study, they had to take these kinds of difficult decisions in order to prioritize caring for their dying relatives.

In this regard, the study also showed how the family members struggle to fulfil their moral obligations despite the resulting hardship due to their limited resources. Despite the high value placed on the moral obligation to care in some cultures, caregivers find it difficult to fulfil their cultural expectations with limited resources. A study on Mexican American caregivers found they experienced severe stress, feelings of being burdened and dissatisfaction, despite clearly fulfilling their role obligations (Jolicoeur & Madden, 2002). In the current study, too, families experienced stress and anxiety in fulfilling their obligations. However, despite the negative impact upon the family situation, families motivate themselves by internalizing the spiritual importance of caring for their dying parents or children in their final days.

The understanding of a good death among dying relatives

The study reveals two aspects to the notion of what constitutes a good death among dying relatives: their expectation of care from their family members and their sense of responsibility towards their family members. Firstly, I discuss the expectation of care, and secondly, the sense of responsibility.

The dying relatives evaluate their final days in terms of how they are taken care of by their family caregivers. In accordance with their age (elderly parent or young adult), dying relatives' expectations and thoughts differ in their final days. For example, in the current study, one elderly patient mentioned that children are the safest shelter when one becomes elderly and vulnerable, or suffer from incurable diseases. When dying relatives do not get the care they expect from their family members, mostly their children, they become frustrated. Based on how their expectation compares with the reality of their experiences, they evaluate how meaningful their final days are. The meaningfulness of their final days can be understood as an aspect of what constitutes a good death.

Regarding the expectation of care from children, a study conducted in a rural setting in Bangladesh found that elderly parents were able to accept their death at the end of their life in accordance with the reality of whether their children were financially and socially capable of taking care of them (Joarder et al., 2014). In this regard, I argue that the elderly parents' understanding of their death is dependent on the role their children play towards them.

The concept of 'filial obligations' may be useful here. There are five dominant theories of what filial obligations are based on: reciprocity, friendship, needs, an implicit promise and special goods the that are derived from being in a parent–child relationship (Stuifbergen et al., 2011). Here, I explain the theories of reciprocity and needs in order to discuss my findings. Regarding the theory of reciprocity, it is assumed that the reason why adult children take care of an elderly parent is because of reciprocity. The theory suggests that children feel obliged to care for their parents as they brought them into the world, nurtured them and helped to build a future for them (Stuifbergen and Delden, 2011). However, the theory of reciprocity has been criticized for not differentiating clearly whether reciprocity is understood as a debt to be returned to parents or as the expression of gratitude for the things they did for the children.

In the context of the current study, an example can be drawn upon by which to understand the theory of reciprocity, whether referring to debt or gratitude or something else. Ambia, an elderly patient and mother who was suffering from colon cancer, expressed frustration when her two sons chose not to provide support in her final days. She used the Bengali word *oviman* to convey her feelings. The English translation of *oviman* suggests egotism, pride, self-respect and so on. None of these translations capture the full meaning in the Bengali language. It is a complex emotion that can arise between people in any close relationship (parent–child, spouses, siblings, close friends). It is found among close relatives who expect or hope for something from the other in the relationship. The one who expects to be cared for – for example, Ambia – does not state clearly what she wants, expects or hopes from the others. If the others do not understand the non-verbal cues given by the one who is expecting, the one whose hopes are unmet will be upset (*ovimani*). In this study, Ambia became upset (*ovimani*) because her children did not understand that she expected care from them. However, she did not expect care because it was seen as returning a 'debt' of gratitude.

Ambia expected care because she was in need of care due to her vulnerabilities. Her need for care can be understood by the theory of filial obligations based on (the parent's) needs. If the parents are vulnerable or dependent, adult children have the responsibility to protect them

(Goodin, 1985). Goodin (1985) also mentioned that for the parents their needs are more for emotional support than for material aspects. However, there are arguments against the idea of needs-based obligations, as they can be fulfilled by a distant friend or an admirer who makes them happy (Kittay, 1999) – they need not necessarily be fulfilled by children (Collingridge & Miller, 1997). In this study, neither Ambia nor Fayez talked about any distant friend or admirer. Both talked about expecting care from their children first.

In the present study, the relatives' expectations of care also suggest that they prefer to stay at their adult children's family home when they become vulnerable or critically ill or are in their final days. In the case of Fayez, he was staying at his elder son's house. In the case of Ambia, neither of her two sons invited her to stay with them when she was experiencing complications in her final days. That is why she became upset, which I described as *ovimani*. Elderly parents living with their children or being supported by them is a major trend in Southeast and South Asia (Yeung et al., 2018). Although there has been a proliferation of nuclear families in these regions, there is no indication that there is any resultant lack in terms of intergenerational support. In almost all the countries of Southeast and South Asia, most elderly persons live with their children, with figures ranging from 60 per cent to a high of 80 per cent of older adults in each country, mentioned in that study (Yeung et al., 2018). Both sons and daughters provide care to ageing parents in Southeast Asian countries (Friedman et al., 2003), while sons are the primary caregivers in South Asia (Barik et al., 2017; Liebig & Rajan, 2003). Despite rapid modernization and changing family structures, this trend can be explained in terms of historical and cultural factors that influence family expectations and norms in the region (Yeung et al., 2018). Dying relatives' expectation of care from family members is explained in terms of the theory of filial obligations based on needs due to vulnerabilities and terminal diseases in their final days.

Besides expectations of care, dying relatives' perception of what constitutes a good death is revealed in their thoughts on the fulfilment of their responsibilities towards family members. Notions of responsibility, known in Bengali as *dayitto* and *kartabya,* which I discussed earlier from the perspective of the family caregivers, can also be helpful in understanding the dying relative's point of view. In the final days of their lives, dying relatives reflect upon their responsibilities towards the family. Such reflections include self-evaluation of what they have done for the family throughout their life, what they could have done better for their family members, and what they can do for the family in their final days to accomplish self-worth. For example, an aged dying father thinks about whether his sons are independent or not, whether he has been able to marry his daughter to a good husband, and whether he could leave some savings or property for his children. An aged dying mother thinks about whether her children are happy or not. A younger dying man (below 40s) thinks of his young children, his wife and his living parents. A younger dying woman (below 40s) thinks of her little children and her husband.

Rather than the attributes of a good death as understood in the context of palliative care, family members' and their dying relatives' perspectives on death are based on their cultural practices and social lives. From the perspective of the family members, caregiving in the final days is motivated mostly by the notions of obligation towards a (dying) family member that are already prevalent in their family lives. In addition, dying relatives' expectations of care from their family members are stimulated by the cultural practice of filial obligations that exist in their daily lives. To add to this, relatives, in their final days, explore their self-worth in relation to others in their family. Rather than being based on notions of choice and autonomy or control over their dying, as is observed in palliative care practices, the findings of this study indicate a contrasting scenario: family members and relatives assess the goodness of death based on their duty or responsibilities in the final days.

Conclusion

As the thesis posits a central argument challenging the prevailing end-of-life care goals underscored in The Economist's Quality of Death Index (2015), the present chapter explore how family values shape end-of-life care, steering away from medicalized or institutionalized perspectives. Despite the index's emphasis on optimal palliative care through institutionalized, formalized, or professionalized settings, this chapter seeks to explore alternative approaches in the family while delivering end-of-life care to any of its members. The original contribution of the chapter is that, rather than adhering to a 'follow west' mindset, the chapter contends that, besides the notions of patients' agency, choice, and control in the west, there are other aspects that shapes end-of-life care such as, responsibility and obligations. Through this contribution, the chapter establishes its empirical contribution of the thesis by exploring different notions of good death. These values or different notions might help design alternative approaches for ensuring end-of-life care in the global south.

Chapter Eight- Covid-19 and Palliative Care in Bangladesh

The previous three chapters focused on the understanding of a good death among the providers, patients and family caregivers at the CPC and its community settings. The observation was carried out after the lockdown due to Covid-19 had been lifted, and the interviews focused more widely on experiences of delivering and receiving palliative care. However, this chapter focuses on the unique effects the pandemic had on the providers, patients, family caregivers and me. During my observation and interviews the pandemic remained as an inevitable presence due to its impact upon everyone's lives. Whenever I observed and interviewed, participants talked about the pandemic. Based on these conversations, I decided to write a chapter reflecting on the effect of Covid-19 upon myself and the participants.

In this chapter, I present how dying patients' daily lives were disrupted by Covid-19. I also describe how the providers adapted to the adverse situation and continued to provide care and social support to the patients and families. Firstly, I describe the difficulties that families underwent at the beginning of Covid-19. These cases indicate a derailment of the perceived understanding of a good death from the family perspective that I analysed in Chapter seven. Secondly, I describe how the CPC initiated adaptations to handle the difficulties faced by their families and patients. The adaptation strategies indicate a local experience of handling terminally ill patients in Bangladesh. The CPC's adaptation also signifies end-of-life care activities in the country amid Covid-19, along with the local challenges. Before describing how palliative care was disrupted in Bangladesh, I firstly portray the background of what happened in Bangladesh at the beginning of the pandemic.

My reflections on the pandemic

As part of the Secondary Annual Progression Review of my PhD, in September 2020, I had to attend a Zoom meeting with the panel members and responsible officials of the doctoral school. One of the panel members started the meeting by saying to me, "You know you are one of the very fortunate researchers who has the opportunity to reflect on the pandemic in your research because of your subject matter of death and dying." His remarks motivated me a lot. I had also felt like that myself since the second week of March 2020, though I mention the word ‘fortunate’ with caution because, as I write this at the beginning of 2022, a total of 5,786,884 people have died and 402,474,763 people have been infected with Covid-19 (https://www.worldometers.info/coronavirus). Researchers forecast that the poorest will be hit hardest by the pandemic’s long economic fallout (Whitehead et al., 2021). As Melinda Gates has said, “This pandemic has magnified every existing inequality in our society – systemic racism, gender inequality and poverty.” The pandemic also affected my life, directly and indirectly, in many ways. Therefore, by ‘fortunate’, I mean as a researcher, as an observer and as a human being: what I am seeing and recording every day can be a great source of knowledge for the next generation, perhaps even for the next pandemic. In the context of the present research, as the subject is related to death and dying, I can clearly state that I have been fortunate because I have been able to reflect upon and analyse what happened during the pandemic in relation to my thesis subject matter. In addition, the thesis can contribute to understanding what happened during the pandemic in Bangladesh.

In order to be more specific about the relevance of my subject matter to the pandemic, I need to refer to previous chapters of the thesis. In Chapter seven I portrayed how family members join together when a relative becomes terminally ill and become fully involved in caregiving for them, arranging the best care possible according to their abilities. They also perform roles beyond acts of caregiving, such as deciding about unfinished business, accomplishing any last wishes, involving their close relatives, or helping their relative to visit their ancestral home for the last time. There is a reunion of the family and kinship network during the terminal days of a relative.

However, from the onset of the pandemic, and the introduction of social distancing to reduce the spread of Covid-19, families were severely affected when a family member was infected or died. They were unable to meet their infected relatives, they could not attend the funerals, could not touch them for the last time before the final disposal of the bodies, whether through burial or cremation. Although the situation affected people worldwide, I focus on the experience of Bangladesh, where the role of the family is significant when a person becomes ill or is in their terminal days. In addition, beliefs and values about the role of the family instantly came under attack. I can still remember what my father said to me on 15 April 2020. We heard a live news bulletin about the first death due to Covid-19 in Bangladesh. My father, with a heavy face, told me before going to bed:

> Death was the last ritual which family used to handle together. Now Covid-19 is taking that away from us. Earlier, the family used to arrange everything during a marriage, before convention centres [the commercial halls where, these days, marriage ceremonies are held] took over. Everything was slipping away from the grip of the family with so called modern times, except death. Now it is also gone!

On that day, this was just my father's fear, it was not yet a reality, but very soon, in the first few months of the pandemic, we saw this become a reality

The pandemic and my fieldwork meet at a crossroad

It was so dramatic the way that my fieldwork plans and the pandemic were walking together. In the first week of March I was all set for my fieldtrip – my flight was booked for 10 April 2020. However, the scenario changed almost overnight and by the second week of March the university had suspended all kinds of in-person fieldtrips whether outside or within the UK. The UK government was still undecided about when to impose a lockdown to curb the virus. Whatever would be the case, it was obvious that there would be a lockdown sometime soon. To me, my flight date of 10 April seemed like a century away, because if there was a lockdown before then, I would not be able to travel to Bangladesh. As the fieldtrip had already been cancelled for an indefinite time, I planned to go to Bangladesh to be with my family. After discussing the situation with my supervisor, I changed my ticket to 20 March. Things were changing so fast; 20 March also seemed uncertain. My family were very happy to know that I would be arriving three weeks earlier than planned. I told them: "Don't be too excited. Things can change any minute. I won't believe it until my plane takes off on 20 March."

The journey

I was so unsure about the journey that I reached the airport six hours before my flight time of 20:25. I was very tense as I realized that if the government imposed any restrictions, I would not be able to go to the airport. (It seems strange now, but that was the state I was in.) When I reached the airport it was a frightening situation. Most people were wearing face masks but I did not have one. I had tried to buy one but had not been able to find any in the pharmacies and superstores in Brighton, although two years later face masks are commonly found in any kind of shop. There were hand sanitizers at many points in the airport. It was all new for me, and for everyone else. I eagerly waited for take-off because I could not wait to be with my family at this dangerous time. However, when I was in the queue to board the plane, an official stopped me after seeing my passport. He told me: “Sir, you have to wait a while. We need to find out whether Bangladesh has restricted flights from the UK.” Hearing that, I became nervous; as far as I knew Bangladesh had restricted flights from the EU, but not from the UK yet. I waited for positive news from the official. After 10 minutes he told me: “Sir, luckily you can fly. Bangladesh is placing restrictions soon but have not done so yet.” At last, I was on board. I was ready to take off to my beloved home – but the suspense did not end there. When I reached Dubai for transit, I met some other Bangladeshi travellers, bound for Dhaka on the same flight. As we chatted, someone came to learn from an online news portal that our flight would be the last flight from Dubai to Dhaka, to be followed by travel restrictions for an indefinite period! We celebrated that at last we would reach our home. As I had no face mask, one of the Bangladeshi *vai* (*vai* is a term used when we meet someone of our own age) handed over some masks to me, saying that he had made these for his fellow Bangladeshi travellers. Conveying my heartfelt thanks to him, I took them and used them during my trip to Dhaka.

After I reached home...

When I landed in Dhaka I had to fill up a form regarding Covid-19. Although the cases of infection were still low, policy makers were worried about the fact that, like me, many people were returning home from European and Middle Eastern countries. Therefore, the authorities collected information about the returnees so that they could track them afterwards in case of infection. After collecting information from the returnees, the authorities stamped a seal on their hands; I also received such a stamp. Once I had finished all the formalities at the airport, I was finally able to go home.

Although in Bangladesh cases of infection were still low in number in comparison with many other countries, policy makers and experts were sure that very soon the situation would become severe. Therefore, the government began planning to impose countrywide restrictions to movement, similar to a lockdown. However, things were becoming complicated countrywide. There was fear and anxiety among the public. Very soon, fear and anxiety turned into stigmatizing behaviour towards infected patients and their families. Some of the steps taken by the government authorities made the atmosphere fearful and terrorized people. For example, in many rural districts, local authorities began marking the wall of an infected patient's house to inform the neighbourhood not to socialize with members of the marked household. Besides the marking on the wall, the authorities also put a red flag on those houses. These types of initiative, in some ways, played a role in creating panic and stigmatizing behaviour among the public.

As in other countries, misinformation – spread mostly through social media – played a role in the chaotic situation in Bangladesh. There were almost 90 million mobile Internet users in the country, according to the Bangladesh Telecommunication Regulatory Commission 2020 report. Misinformation caused immense confusion among the public. For example, there were suggestions from many unknown sources regarding medications. People shared pictures of medicine lists from anonymous sources stating that such medicines could prevent Covid-19. During the first three to four months, a herbal drink became very popular – finding the recipe for it, people tried to drink it every day. Many types of guidance flowed over the Internet at that time. As the government was still undecided about what to do, people became more reliant on these sorts of alternative guidelines. Finally, the government announced a public holiday around the country from 26 March 2020 to contain the spread of the virus. The government declared the closure of all educational institutes (schools, colleges and universities). All public and private offices remained closed from 26 March 2020 to 30 May 2020, except for the emergency services and limited banking services.

However, the confusion, fear and panic did not stop with the announcement. Both the infection and the death rate became higher in the middle of April. When the infection rate became higher, people began to panic. The scenes in the streets and hospitals were horrible. Healthcare and essential workers in PPE (personal protective equipment), ambulance sirens in the community, patients being carried in an atmosphere of emergency: all of these made an impression of horror. Severe panic spread regarding confusion over transmission of the disease from the dead bodies of Covid-19 patients. There had been reports in the news about family members anonymously leaving the dead bodies of relatives in hospital premises to prevent their neighbourhood from finding out that the household had had a Covid-19 patient. These sorts of news reports affected others. The panic of stigmatization and horror about the infection was at its peak during the first two to three months of the pandemic.

In mid-April 2020 I received a phone call from someone who had been a colleague at an organization I had earlier worked for. He informed me that another colleague of ours had committed suicide. No one knew why he had done so. I was shocked on hearing this news. Later, I came to know from his parents that he had been suffering from fever and a cough for a few days. There had been an altercation between him and his family regarding whether he should go to a hospital or not. He was against the idea of going to hospital as the neighbourhood would find out that there was a Covid-19 patient in their area. He later panicked and locked the door of his room. The next morning, when his family tried to call him, there was no response. They broke the door open and saw his body lying on the floor. It was later found that he had taken an overdose of paracetamol to commit suicide.

As the family plays an important role during any illness among family members, news of the negligence of families spread shockwaves at that time. Opinions spread on social media about how the pandemic was preventing families from taking care of relatives in the way they used to in Bangladesh. Previously in case of any illness among family members, relatives would remain beside them to ensure their best care. Because of Covid-19, these situations became difficult. Taking care of and being beside patients became forbidden at that time. One day my father and father-in-law were discussing this. They said:

> We always cherished the idea that our sons and daughters would stay beside us and take care of us in our dying days. Now this will not happen if we get Covid-19. There’s nothing worse in our society than the fact that a person is dying without being taken care of by his or her family members.

As stated above, things were complicated during the first few months of the pandemic in Bangladesh. The government was undecided about whether a lockdown would be effective in such an overpopulous country. In addition, the pandemic revealed the defective reality of the healthcare situation in the country. Although healthcare had improved since Bangladesh became independent in 1971 in terms of life expectancy, the infant mortality rate, the maternal mortality ratio and community healthcare services, there was still inadequacy in terms of the numbers of hospital beds, ICU beds and healthcare professionals in the country. During the first wave of the pandemic, healthcare facilities collapsed due to those inadequacies. Some private hospitals were shut down and others were unable to cope with the rising spike in cases. Although the government hospitals carried on providing services, they were also in danger of collapsing. There were several private hospitals in Dhaka and Chittagong which were very expensive and continued providing services to those who could afford them. Although there were initiatives such as recruiting new doctors, and increasing the number of hospital beds and ICU beds, there were also discussions about the need for policy makers to prioritize renovating the country’s healthcare sector to fight the current and future pandemics.

Besides all these difficulties, there were glimpses of hope as well. At the beginning of the pandemic, there were severe shortages of face masks and hand sanitizers. However, student organizations at different universities took the initiative to produce hand sanitizers charitably. Later, many other university authorities were inspired by these actions and used their laboratories to produce hand sanitizers in bulk. Although the total quantities were not huge, such initiatives motivated others to contribute during the peak of the crisis.

Remarkable changes took place in terms of the funerals of those who died from Covid-19. There was much fear about becoming infected by touching the body of a deceased Covid-19 patient, and families could not come up with a solution. According to Islamic tradition, there are several rituals in which proximity to the dead body is needed: washing the body before burial, touching the body, carrying the body to the graveyard and so on. These rituals were disrupted for many families who lost their relatives due to Covid-19. Several volunteer organizations took the initiative to perform the rituals and funerals for deceased Covid-19 victims. Two such organizations were: Quantam Foundation Bangladesh and Al-Markajul Islami. The organizations set up standard operating procedures to maintain safety at funerals. There were several branches of these organizations in Dhaka and in many other districts and cities. Besides such national initiatives, there were several other initiatives set up by individual or local volunteer organizations in different localities. Team Khorshed was very popular in Narayanganj because of the funeral services they performed during the peak of the pandemic. Khorshed was the name of the person who motivated many youths in his locality to join in the activities.

Besides the fear and the stigma, positive contributions such as these spread hope and shaped the experience of the pandemic in Bangladesh. Next, I focus on the experiences of the family caregivers and providers at the centre. During my interviews with them, they referred to various challenges caused by the pandemic. Based on those conversations, I describe these challenges in the following section.

Challenges faced by families and patients in palliative care settings

Failure to try curative options

I talked to several family caregivers whose relatives were admitted at the centre during my fieldwork. Before coming to the centre, patients had been refused care in hospitals due to the pandemic.

One such patient was Anwar's mother, who had lung cancer. She had been experiencing severe breathlessness and other complications since the end of March 2020. However, Anwar had been unable to take her to a hospital because none of the hospitals were treating any new patients because of the Covid-19 related uncertainties. As a result, he had had to wait for two more months for her condition to be diagnosed, by which time it was July 2020. He had tried every option to find treatment for his mother. He told me:

> If there were no travel restrictions in place, I would go to India or Singapore for my mother's treatment. I had some savings in case of an emergency to pay for her treatment in a foreign country. But I am undone because the world is going through the catastrophe of Covid-19. There are no chances left for me except to wait for things to be normalized.

Kawsar, the husband of and caregiver for Samira, expressed frustration about not being able to obtain the best treatment for his wife. Samira had already been undergoing chemotherapy in a hospital in Vellore, India, since November 2019. She had an appointment there in April 2020 which they had to miss because of travel restrictions. Kawsar later tried visiting different hospitals in Dhaka so that Samira could continue treatment; failing to find a place, he finally found a reference in a government hospital and arranged chemotherapy there. However, Samira had a liver condition which was worsening because of other complications: Kawsar came to know that Samira's situation was not improving and there was nothing the doctors could do – they quickly referred Samira to the CPC.

> I am not sure whether things would have been different if Samira could have continued her treatment in India. I am also not sure what's going to happen next to Samira. What I wanted in the first place was to try every possible option to cure her. Now it's all finished, I guess… When I had the meeting with the doctors at the CPC, they all told me that there was little hope of a cure for Samira. Although I can understand that she is getting the best care possible in her final days, somewhere in my mind I still feel bad about how things went because of Covid-19.

Both Anwar's and Kawsar's quotes indicate that they were trying their best for their relatives. Their priority was to find a cure for their relatives, rather than for them to receive palliative care at the CPC. In Chapter six, I described the situations of families who first tried to obtain curative options and agreed to receive palliative care when they became exhausted after failing in their efforts. In some cases, they ended up accepting palliative care because they had limited resources and had been exhausted by their efforts for their dearest one. In the cases described above, Anwar and Kawsar were unable to access the curative options that would normally have been available. The unprecedented situation due to Covid-19 meant there were few or no options available. The Covid-19 situation, therefore, caused great distress among family caregivers when they were unable to try their best to save their relatives.

Limited access of close family members

In Chapter seven, I described how close family members and relatives join together to help their dying relatives. However, since the pandemic, for some patients, this has not been able to happen. Due to the international travel restrictions and limited movement around the country, the involvement of close family members and other relatives has been less than before.

In Chapter seven, I described the case of Rima, a lung cancer patient, whose husband was unable to visit her because of the pandemic-related international travel restrictions. He was a Bangladeshi migrant worker in Kuwait. The last time he had been able to visit his family was in August 2019. One year later, when his wife was diagnosed with cancer, he tried to visit Bangladesh to see her. However, due to the Covid-19 situation his job was so insecure that if he had taken leave to visit his home country, there was no assurance that he would be able to resume his work after he returned to Kuwait. Therefore, he had to make the difficult decision not to visit Bangladesh. Besides, although international travel was starting to normalize back in August 2020, things were still uncertain at that time, with rules and regulations changing quickly around the world due to the fast-changing Covid-19 situation. In addition, as he was the main earner for the family, he decided not to visit because if he continued working he could provide for the family so that they could bear their living expenses and the cost of treatment and the other family members could provide Rima with the best possible care with his earnings.

When I talked to Rima about not seeing her husband in her terminal days, she told me:

> It is more than shocking that he is not beside me right now. I really want him beside me. But I totally understand that he is doing the best for me. I am so unlucky if I die without seeing my beloved husband in person beside me. However, I believe in the Almighty that something miraculous may happen. Two things can happen: maybe I will be cured or maybe he will come one nice morning beside me like a fairy tale prince.

This was not the only case where a dying patient was unable to be beside their dearest one. There were other instances of the limited involvement of close family members which affected the end-of-life care their dying relatives received.

Badrunnesa, the caregiver for her mother, told me that her mother had been suffering since mid-April 2020, which was the beginning of the lockdown in Bangladesh. Her mother stayed with Badrunnesa and her husband in their house in Dhaka when she became unwell, although she also had relatives in other cities. In spite of the chaotic situation and many challenges, they managed to consult a doctor and got Badrunnesa’s mother admitted to a hospital. Badrunnesa and her husband were shocked when they came to know that she was diagnosed with lung cancer. Although Badrunnesa was updating her two brothers and other close relatives, it seemed almost impossible for them to go to Dhaka to be with her. Despite the difficulties of travelling, Badrunnesa’s brothers and their wives managed to get to Dhaka. During their travel, they were stopped by law enforcing agencies to verify whether their travel was essential. Badrunnesa and her brothers’ plan was to divide the responsibilities among them during their mother’s admission to the hospital. However, this was impossible for them because of Covid-19 rules and regulations – the hospital authorities would not allow more than one family attendant at a time in the hospital. She told me:

> It was too difficult for us to continue taking care of her (mother). We couldn't stay the night in the hospital. We couldn't bring homemade food for her. What was more bothering was the difficulties of movement because of there being a limited number of vehicles on the streets. There was panic in the hospital about Covid-19. As there were no mass testing facilities yet, whenever a patient was newly admitted, we would hear a rumour that the new patient had Covid-19. Whenever a new patient was admitted it played havoc with others' mental wellbeing. We were in a wrecked state due to her critical situation. Covid-19 intensified our mental stress in that situation.

The involvement of close family members and relatives is regarded as an essential element in Bangladesh, which I illustrated in Chapter seven. During the Covid-19 pandemic this was hampered, according to the family caregivers and patients I observed. I found this to be the case during the observation as well on the wards at the centre. Family members would talk a lot during conversations or in the middle of my observation about the ways that Covid-19 brought many obstacles. The overall efforts of family members towards caregiving and the fulfilment of the expectations of dying patients were severely disrupted during the pandemic.

Meanwhile, the situation was different among the research participants in Korail and Narayanganj. The participants I interviewed from these communities were mostly from poor economic households as the project's patient inclusion criteria were aimed at providing palliative care to marginalized sections of society. When I interviewed these participants about Covid-19, although they too faced difficulties that were similar to those experienced by Anwar, Kawsar or Badrunnesa, the particular challenges the community participants faced were related more to economic vulnerabilities. I describe such challenges in the following section.

Economic vulnerabilities during Covid-19

Regarding the families of the patients in Korail and Narayanganj, I observed that they went through different kinds of experiences than those of the caregivers and patients at the centre. Here I describe what some of the participants in the Korail slum and Narayanganj went through since the start of the pandemic.

Ashik was the primary caregiver of his mother, who was a breast cancer patient. He and his two siblings – his elder sister and an elder brother – took care of their mother on a roster basis.

Although she was diagnosed with the disease in 2019 things became worse from May 2020. Ashik's mother was given the option of chemotherapy in the hospital where she was diagnosed. Doctors there told Ashik and his siblings that if his mother did not have surgery or chemotherapy, there was no assurance of a cure. Ashik's brother was the only earning member of the family. He sold food for the birds (especially pigeons) in the local area and business was badly affected during the pandemic. He had to close his shop because there were no sales at that time. Ashik then looked for a job in a local pharmacy because work was still available in pharmacies throughout the pandemic. Ashik's brother took a temporary job in a small restaurant beside their house, from which he received a very poor salary. With these difficulties and the chaotic treatment facilities throughout Bangladesh they struggled with their mother's treatment.

Nadia, the caregiver of her mother, lived in Korail. On the day I interviewed her for my fieldwork, she was organizing her household things to be ready for moving to her husband's village. They were moving because her husband had lost his job after the Covid-19 lockdown started. He had been a street vendor, selling toys in front of schools and in residential areas. However, his income had gone down since the schools had closed and movement had been limited. He realized that it would be difficult to maintain his family if they stayed in Dhaka city. He had discussed the matter with Nadia, who was reluctant at first because of her mother's treatment. Her mother had been cared for by Nadia in her home since she had had a stroke in January 2020. Nadia felt unable to reach a decision in that situation. She went to her brother who was also living in the Korail slum. After talking a while, Nadia's brother reassured her that he would take care of their mother, and she was relieved. However, she told me:

> It's one of the most difficult decisions I had to make. I know he [her brother] will take care of mother properly. But I will be deprived of the opportunity to take care of my mother once I leave the slum. It was a tough call. I had to choose to go to the village due to our meagre income situation since Covid-19 happened.

The participants I talked with in Korail and Narayanganj went through much turmoil because of Covid-19. An exploration of the situation of the patients and their families at the centre and in the two project areas hints at a breakdown of the fabric of society in terms of family members' efforts during the terminal phases of their relatives' lives. Although there were differences between the circumstances of families at the centre and those in the project areas, there was also common ground regarding the compromises family members had to make.

In this section, first I portrayed Kawsar and Anwar lamenting their missed opportunities to go to foreign countries for treatments, which they believed could have saved their relatives. I described Rima's anxieties because her husband was unable to travel to see her from the Middle Eastern country he was working in. Badrunnesa described how taking care of her dying mother became a more difficult job than it had been, due to the restrictions imposed due to Covid-19. Meanwhile, the family caregivers from Korail and Narayanganj talked about the economic difficulties they faced once Covid-19 struck, which affected the care of their relatives tremendously. Although the details of their experiences were different in nature, all were related to the fulfilment of the expectations of family members and patients.

In the following section, I describe how the CPC responded to the challenges presented by Covid-19. I also present the complicated experiences the families and patients went through due to the adaptations made at the centre and in Korail and Narayanganj.

Challenges faced by the providers

Adaptations in operation

"Like everywhere else, we had to make changes to the way we were doing our work at the CPC."

Dr Azam said this to me when I asked him about the changes or adaptations they had to make at the centre during the Covid-19 pandemic. Regarding such adaptations, I talked with three personnel: Dr Azam, who is the director at the CPC centre; Julfiker, who is the project coordinator in Narayanganj; and Kartik, who is the project coordinator in Korail.

Dr Azam gave an overview of the adaptations they had made in the wards at the centre and in the project areas. Julfiker and Kartik described how they assessed the changing needs in the project areas. As soon as Covid-19 hit Bangladesh, at the beginning of March 2020, CPC officials had to prepare new strategies to be able to continue care. There were three aspects of those strategies: those for the patients at the CPC centre, those for the patients in the project areas, and those pertaining to arrangements for the providers.

There was no interruption to services in the wards at the centre, although the services were limited for the first three months after March 2020. As the situation was changing very quickly officials set new guidelines from June 2020. Patients who were admitted to the wards, needed to provide a certificate showing they had tested negative for Covid-19 before their admission. The number of family attendants was strictly limited in the wards. Home visits were suspended, which made the operation of CPC services difficult in Korail and Narayanganj because home visits were the primary form of care in those areas. Palliative Care Assistants (PCAs) did not visit patients’ homes for three months. However, telecommunication services were strengthened and used to monitor each patient.

At this time, there was an exchange of experiences between the CPC and the Kerala palliative care team. From the onset of the pandemic authorities in Kerala had designed guidelines on how to provide palliative care during the pandemic. CPC officials translated the guidelines into Bengali and made some cultural adaptations for the providers of the centre. Dr Azam said:

> What we tried to do was to continue the service at the centre and in the community settings. We adapted in accordance with the new rules and regulations regarding the wearing of masks and Covid-19 testing, to restrict Covid-19 transmission. Despite our efforts, we couldn’t escape infections. Twelve providers were infected with Covid-19. However, there was no death due to Covid-19. Among the patients, two were infected. Besides taking care of the patients, we also prioritized the psychological wellbeing of the providers. It was very important to continue the service because of the reduced number of staff in our centre.

Besides these adaptations, the project coordinators in Korail and Narayanganj went through several challenges. The main earners in the patients’ families were hit by Covid-19 restrictions: since most of the earners had been doing daily income work or temporary work, their income started to drop. Some of them lost their jobs. In that situation, it was difficult for them to run the whole family, let alone taking care of their dying relatives.

After observing the situation in their respective areas, Julfiker and Kartik held several meetings with Dr Azam of the CPC and other key officials of the donor agency. They conveyed about the income situation of the families to them. Finally, the donors agreed to increase the amount of support given for essential food items. The coordinators came up with an innovative idea of how to distribute rations in those areas. They contacted a specified grocery shop in each community area and established an agreement with the shop owner that the patients’ families would receive their essential food items from the shop. The coordinators would pay the dues at the end of the month. Later, Julfiker told me: “That worked like magic – we continued that way for three months. Families were so relieved. Although there was no face-to-face interaction, we could provide medical care over the telephone and basic support through the local network.”

Besides these operational challenges, I came to know about other complications the providers went through.

Provider’s frustration: losing the ‘magic touch’

One day when I was observing in the waiting room at the centre, Lamia, a ward nurse, came to me after her shift. She sat beside me and began talking about how there was a huge difference between the care that was given before the pandemic and what care was like during the pandemic. I asked her to explain. She told me:

> There is a female patient on the ward right now. She is a cervical cancer patient and it is likely that she will die within a week. She has now been in our centre for a week. She feels very close to me and I understand the way she wants to talk to me. Whenever she finds out that I am on my shift, she calls me several times for different sorts of help. What she really wants is to talk to me. Realizing that, I have been having conversations with her for the last two days. But I feel like an alien to her because of the masks. What’s the point of a compassionate conversation if the patient doesn’t see my face? Besides, in such situations, I used to put my hands upon the patient’s forehead but now I cannot put my hands upon them. We call it the ‘magic touch’.

Lamia meant that the ‘magic touch’ was very comforting. Whenever a patient becomes very weak in their final days, they talk with the providers a lot. The providers become closer to their patients in that stage. They talk with them a lot, they put their hands upon them, they even try to fulfil some of their wishes or expectations. Lamia was saying that such intimacies were becoming difficult because of Covid-19 norms. Overcoming this difficulty was a big problem for most of the providers. According to Dr Jahan:

> The most important thing to consider in palliative care practice is developing communication with the patients and their family members. However, during the pandemic, talking with the patients while wearing a mask makes it hard to develop that communication. Somehow, I feel that the little mask over my mouth is creating a wall between me and the patient.

Moushumi, another nurse, talked further about the problems of wearing masks and avoiding touching patients, who were on their deathbed. She said:

> I think we have lost our basic speciality since the pandemic. I learnt in my palliative care training that we provide a peaceful and painless death. How do we that? We do that by talking compassionately with our patients. We do that by touching their hands or foreheads. We do that by being closer to them. These are our [palliative care providers] metaphorical medicines for the patients. Now I feel like I have lost those medicines.

This quote suggests the need for reflecting upon whether palliative care providers have been able to provide a good death since the onset of the pandemic. The families, patients and providers have all gone through difficult situations during the pandemic.

In relation to the impact of the pandemic, this chapter has reflected on my time during my fieldwork in Bangladesh. The chapter showed what I learnt from different families and providers while I was doing my fieldwork and is an addition to understanding how death was affected during the pandemic.

Chapter Nine- Concluding Thoughts

I began my study with the objective of understanding notions of what constitutes a good death among healthcare providers, dying patients and their family caregivers, to explore how all concerned negotiate the idea of a good death, and to reveal the current palliative care practices aimed at ensuring a good death in Bangladesh. Underlying all this, my core objective was to understand how a good death is provided and understood in Bangladesh in comparison with the prevalent notions of a good death in the existing literature, which is mostly based on findings from western palliative care settings.

In relation to the objectives, my study shows how a good death is delivered and understood in the research settings, presented and discussed in Chapters five to seven. Chapter five shows how ‘total care’, an important component of palliative care, is delivered in the palliative care settings by the providers to ensure a good death. Despite structural limitations, and lacking in formal palliative care provisions, care is provided through informal arrangements with the involvement of community through a unique family-like relationship between PCAs and patients. Chapter six shows how, in terms of awareness of dying, patients and families respond to the providers’ anticipation of ‘open awareness’ among patients and families, regarded as an important attribute of a good death in most literature, again, mostly derived from a western context. Rather than notions of autonomy and choice on the part of the patients, the chapter shows how awareness of dying among patients is dependent on the decisions of family caregivers. Chapter seven shows how family members and their dying relatives shape their own notions of a good death, and how the notion of mutual obligation shapes caregiving activities in the final days of dying relatives. Through the three chapters, the study revealed three significant features of good death in Bangladesh that are different from the practices followed in the west. First, how both formal and informal management takes place in tandem; second, hows the importance of family in making decisions, and third, how family or home remains the most desired context where patients and family members can realize their end-of-life activities. Finally, the study reveals that palliative care and notions of what constitutes a good death have a local character in the setting of Bangladesh, in terms of the providers’ communication, the family caregivers’ mediation of the patient’s awareness of dying and the cultural obligations of caregiving. The local character can be explained in contrast to the notions of a good death that predominate in current academic literature and professional practices, which are mostly derived from a western context. These three key features, the key contributions of the study, are explained further below.

Original contribution of the thesis

The original contribution of the thesis is threefold. In the chapter five, I argued that, despite institutional care arrangement is highly prioritized in The Economist's death index, the reality of institutional care delivery is compromised due to structural limitations in Bangladesh. Despite the limitations, non-physical care can still be delivered with the community approach that utilizes natural neighborhood network in Bangladesh, I highlighted upon the complications of opioid availability in the country. Opioid unavailability is a tip of the iceberg of the structural limitations exists in relation to the overall health services in the country. Such structural limitations in the country are truly reflected in the inequities between the higher-income countries and the lower and lower-middle income countries. In reference to the inequity in vaccine allocation between the higher-income and lower and lower-middle income countries during Covid-19 pandemic, I argued that, international responsibilities for palliative care can be approached from care ethics perspective. However, the chapter finally showed that, despite the limitations in opioid availability that obstructs physical care for the dying patients, non-physical care (mental, psychological, and spiritual care) can still be delivered through the application of compassionate community model (also called as Kerala model) in Bangladesh. Instead of multiple professionals, informal caregivers recruited from the community can deliver non-physical care to the dying patients in the neighborhood through a family-like relationship. As the country is not yet prepared with institutional arrangements suggested by the index, in which most high-income countries are equipped with, a Bangladeshi version of compassionate community can show guidelines for non-physical palliative care in the country due to the supportive community neighborhood network exist in the country. Despite community is weighed lower in the index, community model can play an influential role for the arrangement of palliative care in lower-middle income country context. Acknowledgement of compassionate community model shall help the policymakers to reconceptualize the palliative care service delivery model. The arrangement provisions are not straight forward like the components suggested in the index. The result of the chapter has relevance to other countries of global south where opioid availability is still a major obstacle and structural limitations still severely exist.

In the Chapter Six, the main contribution is that, the end-of-life care decision-making process is significantly relied upon the family members of their dying relatives. Patients' choice and their ability to take decisions at the end of life are regarded as a key notion of good death, mostly in the western settings. The notions are resonated in most palliative care institutions such as hospices, hospitals, care home and others. Such institutional care arrangement is prioritized in the death index published by the Economist Intelligence Unit, which are mostly followed in the west. Individual autonomy is at core of these notions and it is expected that the patient will decide themselves about what they want in their final days. However, in the present study, it is found that, the involvement of family members is more significant. Despite patients' awareness of their terminal illness is an important step for deciding plan for final days, the study found that, it is highly replied upon the family members' decision and wishes whether their dying relatives will be informed or not of their condition. The chapter found four awareness context which are highly reliant on the family involvement. The awareness contexts found in the study are different from the explanations of Timmermans, which was patient-centred. Through this, the study argued that the essentiality of patients' involvement is not always followed in Bangladesh. Family-centric awareness and family involvement in end of life care is prevalent also in many western settings. Despite that, a patient-centric awareness and decision-making is implicit and prioritized in end-of-life care policies. Relational autonomy is not prioritized or considered like the individual autonomy is highlighted in the policies or most of the institutional care arrangements. The chapter concludes that, there is not only a singular narrative of good death that is based only upon the individual decisions and wishes in the final days. The findings of this chapter challenge this singular interpretation of good death by acknowledging that family members are strongly involved in the decisions about their relatives' final days. The result significantly matters because it reveals limitations of core notions of institutional palliative care in which patients' autonomous decision are considered only. It also indicates that, family-oriented values are more prominent in Bangladesh, than the values of individual autonomy that is mostly practiced in the western countries. Besides individual autonomy in decision making, the notions of good death will be broadened with the importance of relational autonomy in decision making and preferences in the final days of the patients. As values guides the logistics to attain a good death (Zaman et al., 2016), family-oriented palliative care arrangement should be prioritized, not just the institutional care arrangements that inspire the individualistic values of the west.

In Chapter Seven, it is found that the notions of good death between the family members and their dying relatives is centred around the notions of the mutual obligations of caregiving and care receiving. Family caregivers deliver care to their dying relatives motivated by the religious, cultural and social values of responsibility they feel towards them. On the other hand, dying relatives expect care from their family members based on the notions that motivates the family members themselves, determined by cultural, social and religious values of responsibility. They reflect upon their life based on the roles and responsibilities set according to family expectations. Both family caregivers and dying relatives remain engaged in thoughts about their counterparts. This does not mean that individual autonomy is absent among them. Rather it reveals that the value of individual autonomy is not a priority in the final moments of a patient’s life or the final days of a family’s relative. In this regard, I compare this reality with the idea of a good death found in most literature that is derived from a western context. In the west it is understood within end-of-life care policies that a good death evolves around the notions of control and choice Having control and exercising choice in the final days suggest the accomplishment of dignity and quality of life. Rather than prioritizing palliative care at the end of life, family members engage themselves in the arrangements involved in caring for their dying relatives. Rather than the notion of choice and control over their own lives in their final days, patients find comfort and dignity by submitting themselves to their family members to receive care from them. Both construct the meaning of a good death according to the cultural values of how a dying relative can be best taken care of in the final days in the family. End of life care is about upholding dignity of patients. Providers deliver palliative care and ensure that the patients’ dignity and independence in unharmed, in terms of their choices and preferences. Good death is shaped around the notions of such choices and preferences. But in Bangladeshi settings, good death is shaped around the notions of interdependence and mutual responsibilities. In contrast to the notions practiced in a palliative care institution, end of life days is still shaped by the family-centric values of responsibilities, obligations, and duties. Rather than independence, an interdependent dynamic is prominent. The findings are significant because, although family-centric values are significantly embedded at the end of life, dynamics of family relationship has got very little attention. Medical and institutional aspects are prioritized, not the social elements that can still play a key role in delivering end-of-life care in a setting like Bangladesh.

Besides, in Chapter eight, I have demonstrated how death and dying was looking like in Bangladesh. The pandemic showed that our existence was full of vulnerabilities. However, that also gave room for thinking about how different arrangements can be built, which give consideration for the vulnerable nature of humankind and the planet.

Why the contribution matters?

The present study shows that values of a good death in Bangladesh are to be understood not only through the values that exist in the understandings found in palliative care contexts, but also within a cultural reference of the caring relationships that exist in people’s lives in Bangladesh. The meanings of palliative care can be broadened not only within the settings of palliative care but also beyond these settings. In other words, by looking at how a good death is understood among families, dying relatives and providers, the study reveals that a good death can be understood beyond the notions of palliative care. For example, a good death is revealed between families’ and dying relatives’ understanding of their mutual obligation towards each other. A good death is also found between the dying patients and their Palliative Care Assistants (PCAs), based on the notion of interdependence that is shaped according to the meaning of the patient’s needs and the identity of the providers in the final days of care. Rather than the notions of choice, control and the meaning of dignity in one’s own choice, a good death is revealed differently between patients and providers, in the awareness of dying and in the mutual obligations between the patients and their families. Rather than being about the patient’s agency and choice, their care in the final days is shaped by the values practiced in the family. The way the patient is dependent upon their family members is reflected in the way they become dependent upon PCAs. Both types of dependency can be seen as an essential aspect of caregiving and care receiving in the present context. Based on the notions of choice and agency in the context of a good death, such dependency may suggest that the patient has lost their agency and control of their life in their final days. The notions of a good death that are found in most of the western literature mostly highlight the fact that the patient retains control and exercises choice in the final moments of their life. That way, autonomy is accomplished. It seems that, in this context, retaining autonomy is more significant than death itself. In contrast to that, my study suggests that relationships and dependency are formed around the reality of death. Death is being defined in terms of interdependency and the vulnerabilities of patients, rather than in terms of autonomy, choice, agency or control. A good death, in the present study, is defined by relationality and mutuality.

Although the notions of choice, agency and autonomy are prioritized in the western literature, there are a small number of works from the west which question the notions of choice, agency and autonomy at the end of life. Such a work is Erica Borgstrom's PhD thesis – titled *Planning for death?: An ethnographic study of choice and English end-of-life care* (2014) – in which wider aspects of personhood beyond individual patienthood during the end of life are explored. Borgstrom's exploration of English end-of-life care took a relational approach to the study of end-of-life care and challenged the emphasis on the dying individual (Borgstrom, 2014; Borgstrom & Walter, 2015). The degree of importance given to choice in end-of-life care policies is not always found in people's final moments of life, Borgstrom argued. Another notable work is Julia Lawton's *The Dying Process: Patient's Experiences of Palliative Care* (2000). By exploring a hospice in the UK Lawton showed in the study how a dying body is sequestrated from wider society. She described the hospice as a 'no-place', as it enables a different identity for disabled and decaying bodies who cannot perform as productive individuals in daily lives. She criticized the western notion of choice and autonomy in her study, along with other authors from the west who are critiquing the notions of autonomy or choice in palliative care provided in hospices and other healthcare settings. However, *The Economist* still assesses the quality of death from the perspective of palliative care notions, while in the non-west there is already a differential practice which does not give a high priority to autonomy and choice.

It showed how the palliative care notions of choice, autonomy and agency do not synchronize with the notions found in the settings of the present study. In this regard, I argue in line with the components proposed by Zaman at al. (2017), who suggested that there are two components of a good death: value and logistics. Value means the judgement in a society about what constitutes a good death, and logistics refers to the arrangements needed to achieve the values. The values prioritized by palliative care provision in the west are around patient choice, control and agency. The logistics required to achieve these values involve a well-equipped hospice and palliative care facilities, trained professionals and opioid availability, by which to enable dying in a pain-free and controlled process. Zaman et al. concluded by proposing that, based on the values in different contexts, there are possibilities for plural or different arrangements for a good death (Zaman et al., 2017). For example, Lawrence Cohen's *No Aging in India* (1998) showed how Alzheimer's and ageing are perceived differently in India in contrast to the United States. The way Alzheimer is given importance in the United States, is not handled in the same way in India. In India, family values prioritise care for the elderly which is different than the institutional arrangements (logistics) available to treat Alzheimer in the United States. Family takes care of the elderly which can be regarded as values in that context.

The thesis finally argues that, how 'follow west' mindset does not fully work to deliver end-of-life care to the increasing numbers of death and dying in the country. Rather than the common path, there are possibilities for alternative pathways. The study extends to post-colonial understanding of death and dying. The study reiterates the position Zaman et al. (2016) took utilizing Dipesh Chakrabarty's (Post-colonial thinker) concept of 'waiting room of history (Chakrabarty, 2007). According to historian Dipesh Chakraborty, underdeveloped countries or low-middle income countries are staying in the waiting room to catch the train of modernity. Modernity is an inevitable destination. Regardless of the differences of all races or regions, every country or ethnicities or nationalities should reach a common goal in terms of the uses of technology, lifestyle, and culture (Chakrabarty, 2007). Based on this theory, Zaman and others are claiming that a common destination is being prioritized in the field of palliative care. The ranking of The Economist is the best example of the complications (Zaman et al., 2016).

Through the original contributions in the study, the thesis reinforces the idea that the notions are different in the palliative care settings of Bangladesh. This directs us towards the understanding that there are possibilities for different kinds of arrangements for providing a good death in terms of the notions found in the study. Rather than following the same prescriptions as are followed in high-income settings or west, arrangements can be made differently. In this regard, the arrangements are to be focused on the notions of interdependent relationships between providers and patients, and the relational and mutual obligations between the family caregivers and their dying relatives which is revealed in this study. This study suggests that the logistics required can be different and can go beyond the understanding of death rooted in hospice or palliative care found in most western literature on the subject.

What is good death and Implications of the study

Based on the present study, the concept of ‘good death’ should encompass following features. Good death should encompass interdependence as an essential feature. Not only formal institutions are important here; the community can play an important role. At the time of death, the focus remains on dignity ignoring the realities of human vulnerabilities. For example, in the West, dignity means that a person can continue to express their own decisions, own choices, own preferences, own dignity. In Bangladesh, the meaning of dignity becomes different. Instead of one's individual thoughts, family thoughts become important. For example, the first thought of a dying father or mother is that their children can serve them by their side at the time of death, otherwise his life will be considered a failure. It is like giving their children the burden of all final decisions.

Based on these findings of the study, I conclude with several recommendations which can be addressed in future end-of-life care policy making in Bangladesh. Although there are as yet no national palliative care or end-of-life care policies in Bangladesh, the following recommendations can help to navigate the designing of future policy. First, there should be more focus on opioid availability regarding the revising of the legislation around its usage, so that both providers and family caregivers can access opioids without interruption. Second, there should be training on communication for the providers. The academic curriculum should prioritize training on how providers can communicate with dying patients and their family caregivers. Third, as the family plays a central role in their relative’s end-of-life care, there should be a focus upon the wishes and expectations of family caregivers in the policy. Fourth, more targeted policies should focus on marginalized and poverty-stricken families. For example, support should be given to address the financial difficulties of families living in slums, and of people living below the poverty line. This should include support such that the families are not burdened by caregiving activities.

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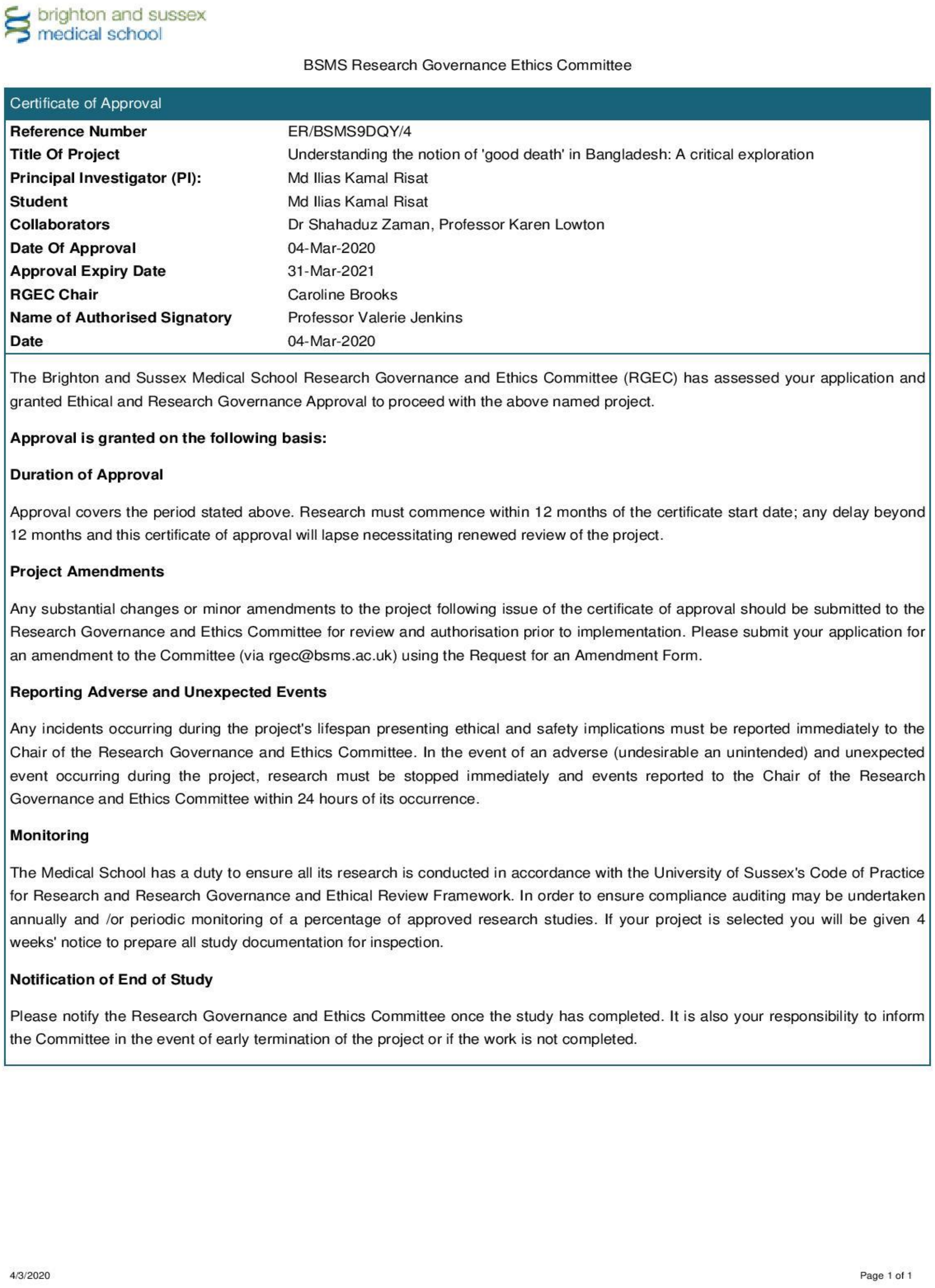
Appendix One- BSMS Ethics committee approval 1



brighton and sussex medical school

BSMS Research Governance Ethics Committee

Certificate of Approval	
Reference Number	ER/BSMS9DQY/4
Title Of Project	Understanding the notion of 'good death' in Bangladesh: A critical exploration
Principal Investigator (PI):	Md Ilias Kamal Risat
Student	Md Ilias Kamal Risat
Collaborators	Dr Shahaduz Zaman, Professor Karen Lowton
Date Of Approval	04-Mar-2020
Approval Expiry Date	31-Mar-2021
RGEC Chair	Caroline Brooks
Name of Authorised Signatory	Professor Valerie Jenkins
Date	04-Mar-2020

The Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) has assessed your application and granted Ethical and Research Governance Approval to proceed with the above named project.

Approval is granted on the following basis:

Duration of Approval

Approval covers the period stated above. Research must commence within 12 months of the certificate start date; any delay beyond 12 months and this certificate of approval will lapse necessitating renewed review of the project.

Project Amendments

Any substantial changes or minor amendments to the project following issue of the certificate of approval should be submitted to the Research Governance and Ethics Committee for review and authorisation prior to implementation. Please submit your application for an amendment to the Committee (via rgec@bsms.ac.uk) using the Request for an Amendment Form.

Reporting Adverse and Unexpected Events

Any incidents occurring during the project's lifespan presenting ethical and safety implications must be reported immediately to the Chair of the Research Governance and Ethics Committee. In the event of an adverse (undesirable an unintended) and unexpected event occurring during the project, research must be stopped immediately and events reported to the Chair of the Research Governance and Ethics Committee within 24 hours of its occurrence.

Monitoring

The Medical School has a duty to ensure all its research is conducted in accordance with the University of Sussex's Code of Practice for Research and Research Governance and Ethical Review Framework. In order to ensure compliance auditing may be undertaken annually and /or periodic monitoring of a percentage of approved research studies. If your project is selected you will be given 4 weeks' notice to prepare all study documentation for inspection.

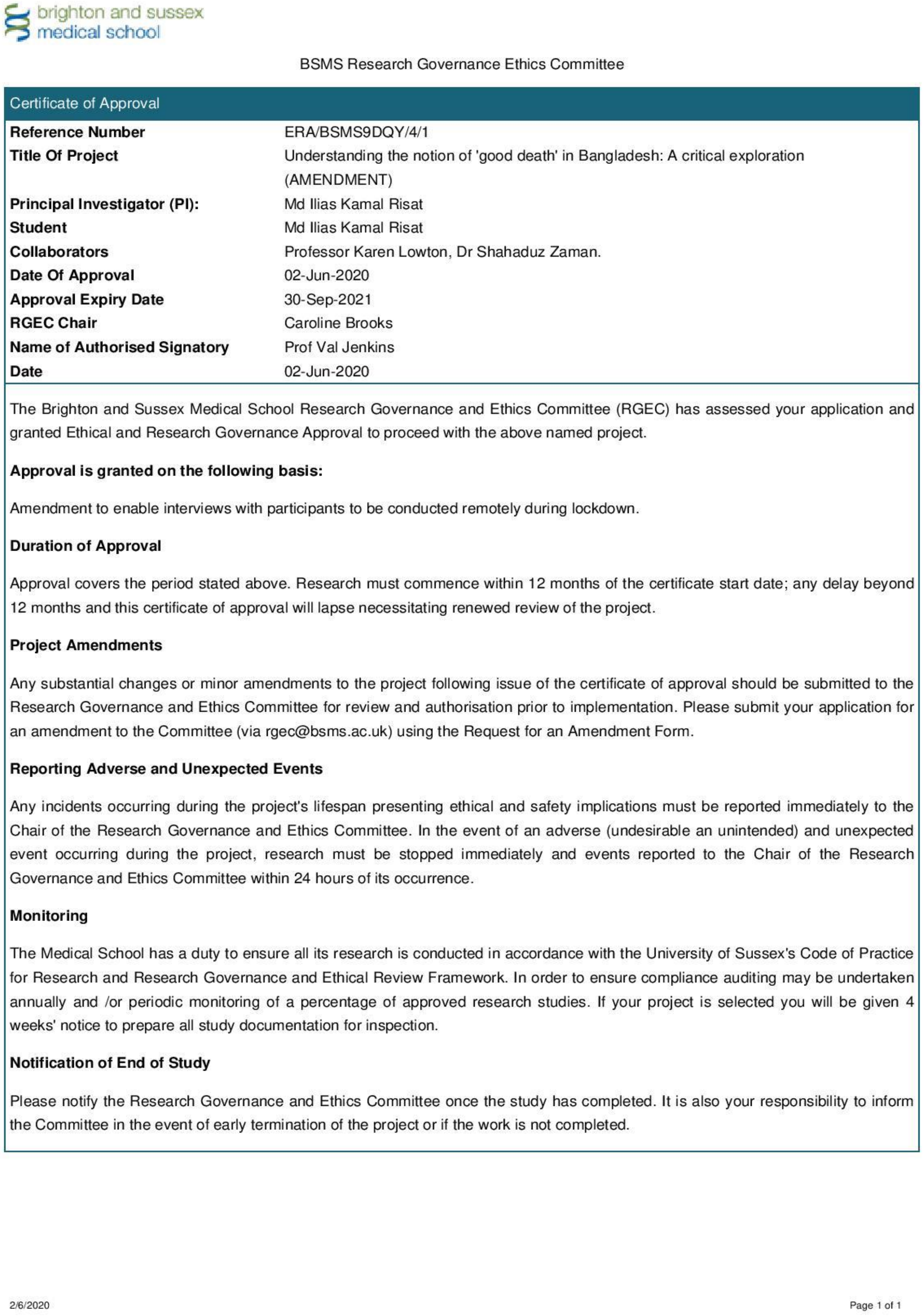
Notification of End of Study

Please notify the Research Governance and Ethics Committee once the study has completed. It is also your responsibility to inform the Committee in the event of early termination of the project or if the work is not completed.

4/3/2020

Page 1 of 1

Appendix Two- BSMS Ethics committee approval 2



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BSMS Research Governance Ethics Committee

Certificate of Approval

Reference Number	ERA/BSMS9DQY/4/1
Title Of Project	Understanding the notion of 'good death' in Bangladesh: A critical exploration (AMENDMENT)
Principal Investigator (PI):	Md Ilias Kamal Risat
Student	Md Ilias Kamal Risat
Collaborators	Professor Karen Lowton, Dr Shahaduz Zaman.
Date Of Approval	02-Jun-2020
Approval Expiry Date	30-Sep-2021
RGEC Chair	Caroline Brooks
Name of Authorised Signatory	Prof Val Jenkins
Date	02-Jun-2020

The Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) has assessed your application and granted Ethical and Research Governance Approval to proceed with the above named project.

Approval is granted on the following basis:

Amendment to enable interviews with participants to be conducted remotely during lockdown.

Duration of Approval

Approval covers the period stated above. Research must commence within 12 months of the certificate start date; any delay beyond 12 months and this certificate of approval will lapse necessitating renewed review of the project.

Project Amendments

Any substantial changes or minor amendments to the project following issue of the certificate of approval should be submitted to the Research Governance and Ethics Committee for review and authorisation prior to implementation. Please submit your application for an amendment to the Committee (via rgec@bsms.ac.uk) using the Request for an Amendment Form.

Reporting Adverse and Unexpected Events

Any incidents occurring during the project's lifespan presenting ethical and safety implications must be reported immediately to the Chair of the Research Governance and Ethics Committee. In the event of an adverse (undesirable an unintended) and unexpected event occurring during the project, research must be stopped immediately and events reported to the Chair of the Research Governance and Ethics Committee within 24 hours of its occurrence.

Monitoring

The Medical School has a duty to ensure all its research is conducted in accordance with the University of Sussex's Code of Practice for Research and Research Governance and Ethical Review Framework. In order to ensure compliance auditing may be undertaken annually and /or periodic monitoring of a percentage of approved research studies. If your project is selected you will be given 4 weeks' notice to prepare all study documentation for inspection.

Notification of End of Study

Please notify the Research Governance and Ethics Committee once the study has completed. It is also your responsibility to inform the Committee in the event of early termination of the project or if the work is not completed.

2/6/2020 Page 1 of 1

Appendix Three- BSMS ethics committee approval 3

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BSMS Research Governance Ethics Committee

Certificate of Approval	
Reference Number	ERA/BSMS9DQY/4/2
Title Of Project	Understanding the notion of 'good death' in Bangladesh: A critical exploration (AMENDMENT)
Principal Investigator (PI):	Md Ilias Kamal Risat
Student	Md Ilias Kamal Risat
Collaborators	Prof Karen Lowton (Supervisor); Dr Shahaduz Zaman (Supervisor).
Date Of Approval	30-Nov-2020
Approval Expiry Date	30-Sep-2021
RGEC Chair	Prof Valerie Jenkins
Name of Authorised Signatory	Caroline Brooks
Date	30-Nov-2020

The Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC) has assessed your application and granted Ethical and Research Governance Approval to proceed with the above named project.

Approval is granted on the following basis:

Amendment to commence fieldwork comprising interviews and observation safely.

Duration of Approval

Approval covers the period stated above. Research must commence within 12 months of the certificate start date; any delay beyond 12 months and this certificate of approval will lapse necessitating renewed review of the project.

Project Amendments

Any substantial changes or minor amendments to the project following issue of the certificate of approval should be submitted to the Research Governance and Ethics Committee for review and authorisation prior to implementation. Please submit your application for an amendment to the Committee (via rgec@bsms.ac.uk) using the Request for an Amendment Form.

Reporting Adverse and Unexpected Events

Any incidents occurring during the project's lifespan presenting ethical and safety implications must be reported immediately to the Chair of the Research Governance and Ethics Committee. In the event of an adverse (undesirable an unintended) and unexpected event occurring during the project, research must be stopped immediately and events reported to the Chair of the Research Governance and Ethics Committee within 24 hours of its occurrence.

Monitoring

The Medical School has a duty to ensure all its research is conducted in accordance with the University of Sussex's Code of Practice for Research and Research Governance and Ethical Review Framework. In order to ensure compliance auditing may be undertaken annually and /or periodic monitoring of a percentage of approved research studies. If your project is selected you will be given 4 weeks' notice to prepare all study documentation for inspection.

Notification of End of Study

Please notify the Research Governance and Ethics Committee once the study has completed. It is also your responsibility to inform the Committee in the event of early termination of the project or if the work is not completed.

30/11/2020

Page 1 of 1

Appendix Four- Centre for Palliative Care approval for fieldwork 1

Centre for Palliative Care
Department of Palliative Medicine
Bangabandhu Sheikh Mujib Medical University
Shahbag, Dhaka

Date: 08.01.2020

To
Md Ilias Kamal Risat

Reference: Project titled "Understanding the Notion of 'Good Death': A Critical Exploration".

Thank you for your application which was considered by the Department of Palliative Medicine, Bangabandhu Sheikh Mujib Medical University (BSMMU). Your submitted research proposal, consent forms and data collection methodology were reviewed.

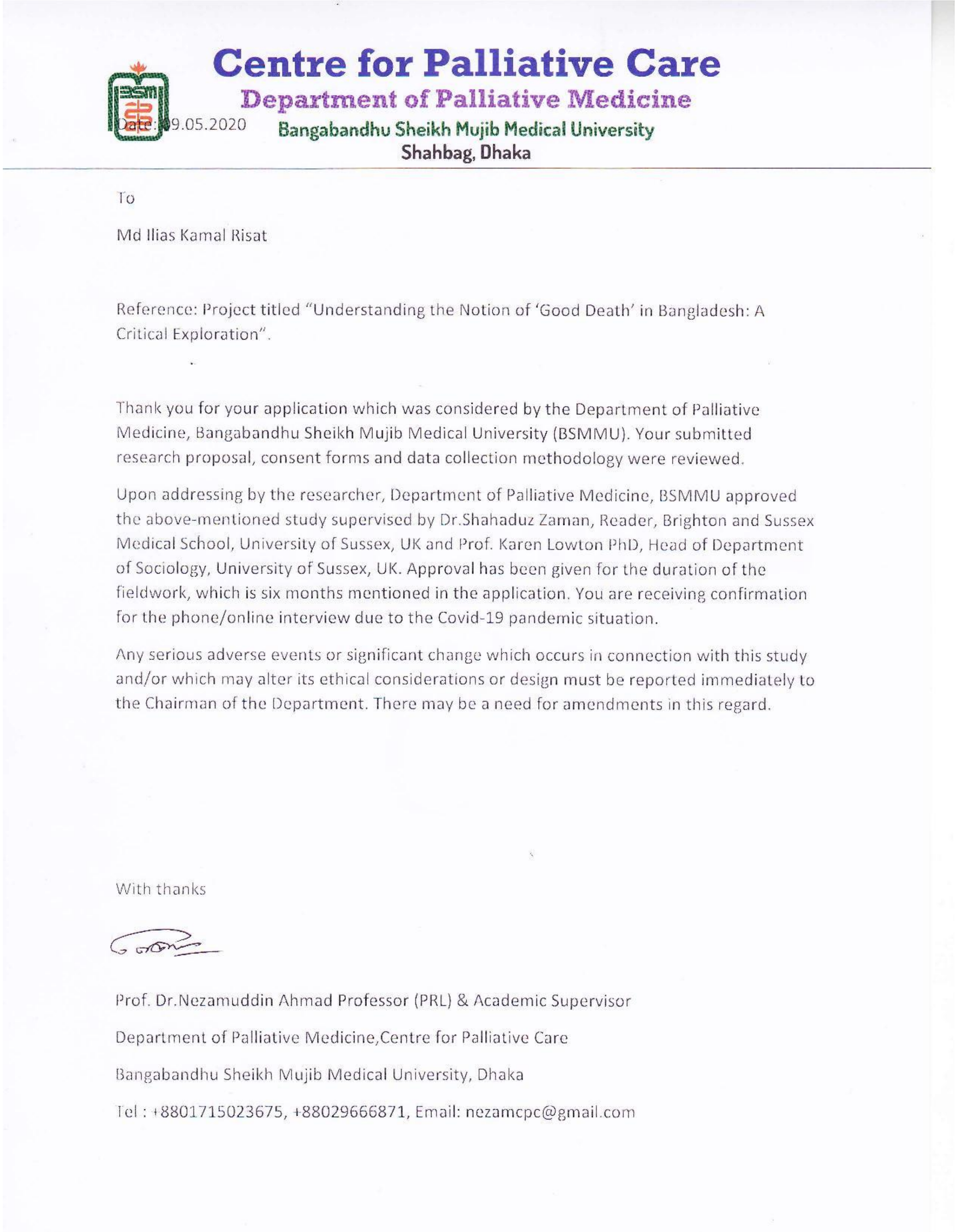
Upon addressing by the researcher, Department of Palliative Medicine, BSMMU approved the above mentioned study supervised by Dr. Shahaduz Zaman, Reader, Brighton and Sussex Medical School, University of Sussex, UK and Prof. Karen Lowton PhD, Head of Department of Sociology, University of Sussex, UK. Approval has been given for the duration of the fieldwork, which is six months mentioned in the application.

Any serious adverse events or significant change which occurs in connection with this study and/or which may alter its ethical considerations or design must be reported immediately to the Chairman of the Department. There may be a need for amendments in this regard.

With thanks

Prof. Dr. Nezamuddin Ahmad
Professor (PRL) & Academic Supervisor
Department of Palliative Medicine
Centre for Palliative Care
Bangabandhu Sheikh Mujib Medical University, Dhaka
Tel : +8801715023675, +88029666871, Email: nezamcpc@gmail.com

Appendix Five- Centre for Palliative Care approval 2



Centre for Palliative Care
Department of Palliative Medicine
Bangabandhu Sheikh Mujib Medical University
Shahbag, Dhaka

Date: 09.05.2020

To

Md Ilias Kamal Risat

Reference: Project titled "Understanding the Notion of 'Good Death' in Bangladesh: A Critical Exploration".

Thank you for your application which was considered by the Department of Palliative Medicine, Bangabandhu Sheikh Mujib Medical University (BSMMU). Your submitted research proposal, consent forms and data collection methodology were reviewed.

Upon addressing by the researcher, Department of Palliative Medicine, BSMMU approved the above-mentioned study supervised by Dr.Shahaduz Zaman, Reader, Brighton and Sussex Medical School, University of Sussex, UK and Prof. Karen Lowton PhD, Head of Department of Sociology, University of Sussex, UK. Approval has been given for the duration of the fieldwork, which is six months mentioned in the application. You are receiving confirmation for the phone/online interview due to the Covid-19 pandemic situation.

Any serious adverse events or significant change which occurs in connection with this study and/or which may alter its ethical considerations or design must be reported immediately to the Chairman of the Department. There may be a need for amendments in this regard.

With thanks

Prof. Dr.Nezamuddin Ahmad Professor (PRL) & Academic Supervisor

Department of Palliative Medicine,Centre for Palliative Care

Bangabandhu Sheikh Mujib Medical University, Dhaka

Tel : +8801715023675, +88029666871, Email: nezamcpc@gmail.com

Appendix Six- Participant Information Sheet (PIS)

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(Previous version)

PARTICIPANT INFORMATION SHEET

STUDY TITLE

Understanding the notion of 'Good Death' in Bangladesh: A critical exploration

INVITATION PARAGRAPH

You are being invited to take part in a research study. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will try to explore. Please take time to read the following information carefully.

WHAT IS THE PURPOSE OF THE STUDY?

The aim of this study is to understand the current perception and practice of end of life care treatments within the palliative care centres in Bangladesh. By that, the research will explore how the terminally ill patients are being taken care of by their caregivers and the health professionals in the palliative care centres. In this way, the research will try to engage in a discussion on recent trends of palliative care practices in Bangladesh.

WHY HAVE YOU BEEN INVITED TO PARTICIPATE?

You have been chosen because we think you have experience in relation to palliative care programmes in Bangladesh.

DO YOU HAVE TO TAKE PART?

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

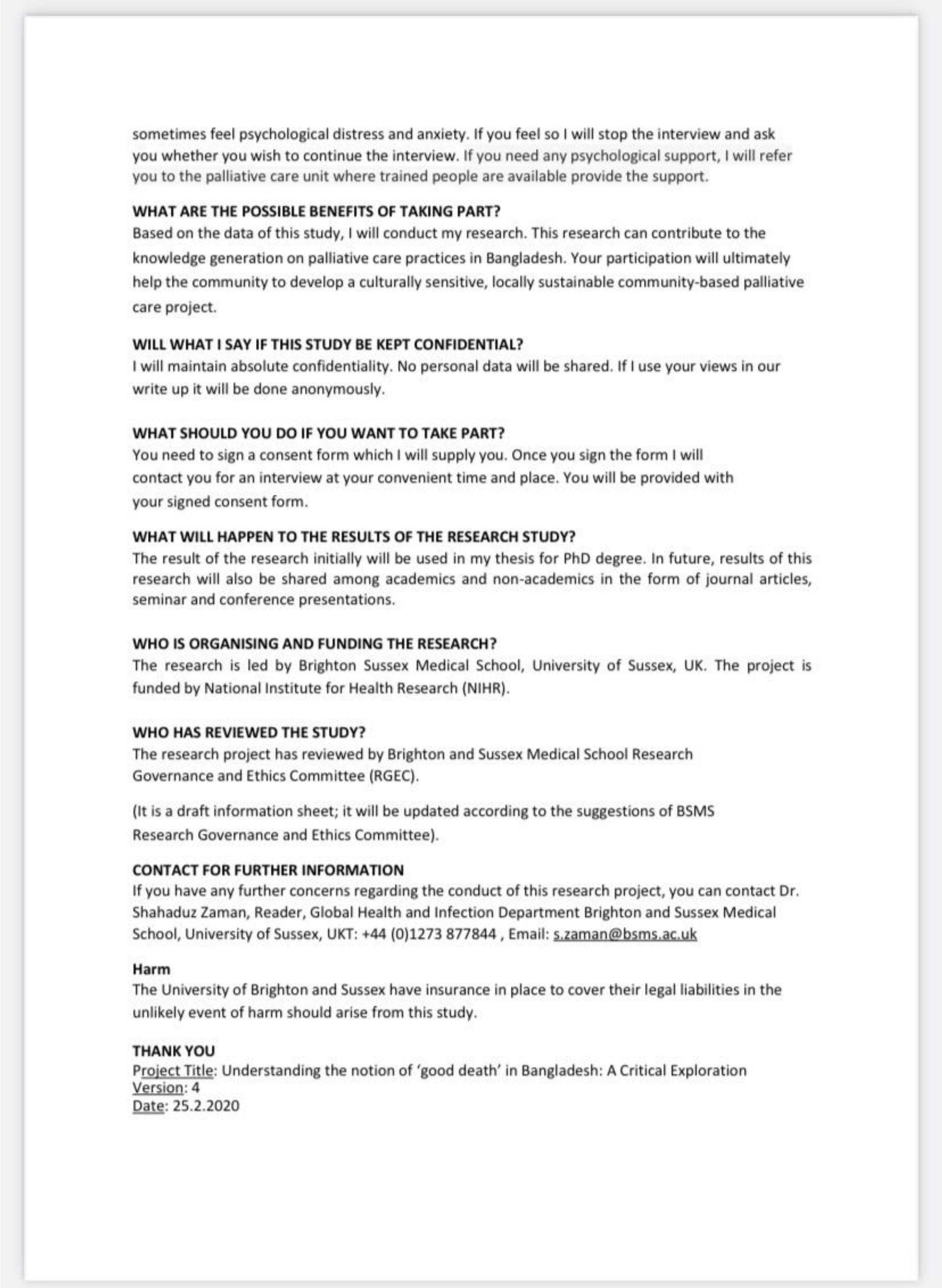
WHAT WILL HAPPEN TO YOU IF YOU TAKE PART?

If you participate in the study, I will request you to take part in an interview and observation related to your experience of palliative care programmes. Both will be conducted by me. The interview will be conducted in a place convenient to you. If any question is unclear to you or if you want to know why I am asking you these questions, you can ask me. If you are not willing to answer any question, you can skip it. You have the full right to refrain from participation at any point. If you feel uncomfortable or distressed during interview, I will stop it. Besides, I will take all the care to make you comfortable contacting healthcare professionals in the centre. If you do not want to continue to talk or want to arrange another time, I will do that accordingly. The interview will take about one hour or more of your valuable time. A follow up interview can be taken if needed.

If you decide to take part in the in-depth interview, in that case you also have the right to withdraw your data from the research after taking part in the in-depth interview. In that case, you can inform me to withdraw/remove your data within two (2) weeks of your in-depth interview. In some cases, provided you permit I may want to observe the care practice at your cabin or ward. My observation period will last for the period of the care giving and the consultation. During observation, you don't have to participate with me. I will observe the care services you are getting.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

I don't anticipate any possible disadvantage and risks of taking part in this study. However, because discussion about end of life care and palliative care is a sensitive situation you may



sometimes feel psychological distress and anxiety. If you feel so I will stop the interview and ask you whether you wish to continue the interview. If you need any psychological support, I will refer you to the palliative care unit where trained people are available provide the support.

WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

Based on the data of this study, I will conduct my research. This research can contribute to the knowledge generation on palliative care practices in Bangladesh. Your participation will ultimately help the community to develop a culturally sensitive, locally sustainable community-based palliative care project.

WILL WHAT I SAY IF THIS STUDY BE KEPT CONFIDENTIAL?

I will maintain absolute confidentiality. No personal data will be shared. If I use your views in our write up it will be done anonymously.

WHAT SHOULD YOU DO IF YOU WANT TO TAKE PART?

You need to sign a consent form which I will supply you. Once you sign the form I will contact you for an interview at your convenient time and place. You will be provided with your signed consent form.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

The result of the research initially will be used in my thesis for PhD degree. In future, results of this research will also be shared among academics and non-academics in the form of journal articles, seminar and conference presentations.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

The research is led by Brighton Sussex Medical School, University of Sussex, UK. The project is funded by National Institute for Health Research (NIHR).

WHO HAS REVIEWED THE STUDY?

The research project has reviewed by Brighton and Sussex Medical School Research Governance and Ethics Committee (RGEC).

(It is a draft information sheet; it will be updated according to the suggestions of BSMS Research Governance and Ethics Committee).

CONTACT FOR FURTHER INFORMATION

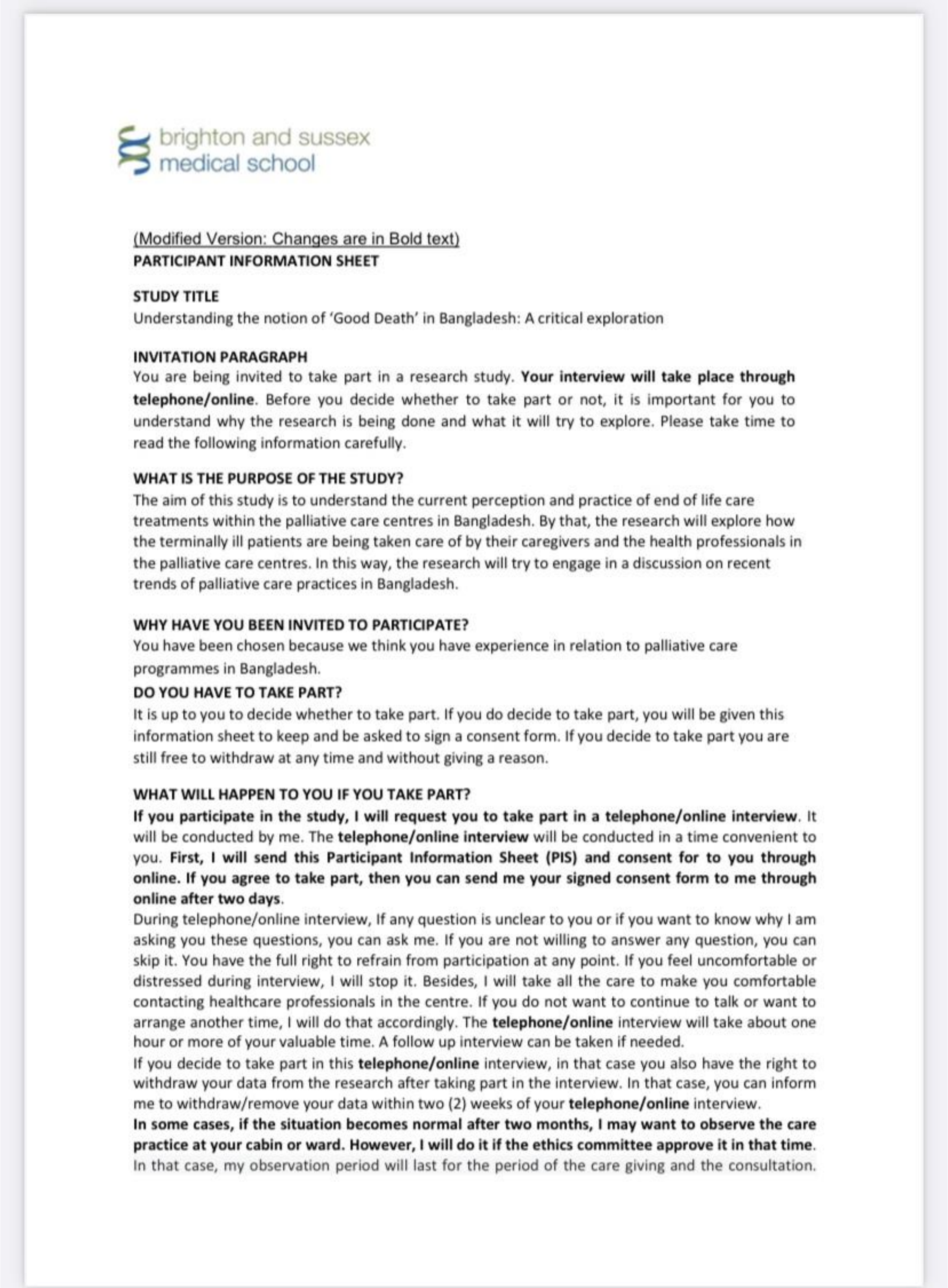
If you have any further concerns regarding the conduct of this research project, you can contact Dr. Shahaduz Zaman, Reader, Global Health and Infection Department Brighton and Sussex Medical School, University of Sussex, UKT: +44 (0)1273 877844 , Email: s.zaman@bsms.ac.uk

Harm

The University of Brighton and Sussex have insurance in place to cover their legal liabilities in the unlikely event of harm should arise from this study.

THANK YOU

Project Title: Understanding the notion of 'good death' in Bangladesh: A Critical Exploration
Version: 4
Date: 25.2.2020



brighton and sussex
medical school

(Modified Version: Changes are in Bold text)

PARTICIPANT INFORMATION SHEET

STUDY TITLE

Understanding the notion of 'Good Death' in Bangladesh: A critical exploration

INVITATION PARAGRAPH

You are being invited to take part in a research study. **Your interview will take place through telephone/online**. Before you decide whether to take part or not, it is important for you to understand why the research is being done and what it will try to explore. Please take time to read the following information carefully.

WHAT IS THE PURPOSE OF THE STUDY?

The aim of this study is to understand the current perception and practice of end of life care treatments within the palliative care centres in Bangladesh. By that, the research will explore how the terminally ill patients are being taken care of by their caregivers and the health professionals in the palliative care centres. In this way, the research will try to engage in a discussion on recent trends of palliative care practices in Bangladesh.

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You have been chosen because we think you have experience in relation to palliative care programmes in Bangladesh.

DO YOU HAVE TO TAKE PART?

It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

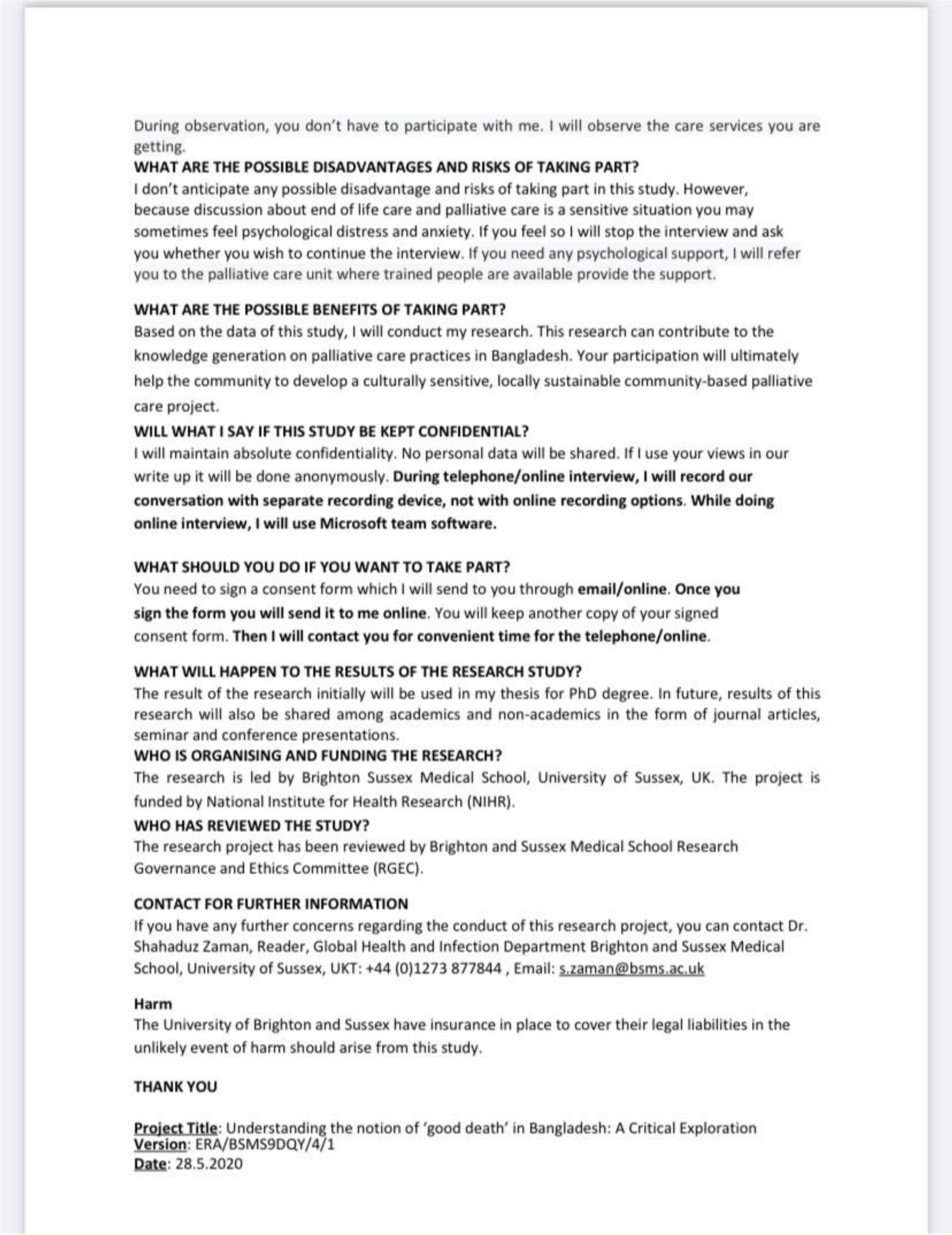
WHAT WILL HAPPEN TO YOU IF YOU TAKE PART?

If you participate in the study, I will request you to take part in a telephone/online interview. It will be conducted by me. The **telephone/online interview** will be conducted in a time convenient to you. **First, I will send this Participant Information Sheet (PIS) and consent for to you through online. If you agree to take part, then you can send me your signed consent form to me through online after two days**.

During telephone/online interview, If any question is unclear to you or if you want to know why I am asking you these questions, you can ask me. If you are not willing to answer any question, you can skip it. You have the full right to refrain from participation at any point. If you feel uncomfortable or distressed during interview, I will stop it. Besides, I will take all the care to make you comfortable contacting healthcare professionals in the centre. If you do not want to continue to talk or want to arrange another time, I will do that accordingly. The **telephone/online** interview will take about one hour or more of your valuable time. A follow up interview can be taken if needed.

If you decide to take part in this **telephone/online** interview, in that case you also have the right to withdraw your data from the research after taking part in the interview. In that case, you can inform me to withdraw/remove your data within two (2) weeks of your **telephone/online** interview.

In some cases, if the situation becomes normal after two months, I may want to observe the care practice at your cabin or ward. However, I will do it if the ethics committee approve it in that time. In that case, my observation period will last for the period of the care giving and the consultation.



During observation, you don't have to participate with me. I will observe the care services you are getting.

WHAT ARE THE POSSIBLE DISADVANTAGES AND RISKS OF TAKING PART?

I don't anticipate any possible disadvantage and risks of taking part in this study. However, because discussion about end of life care and palliative care is a sensitive situation you may sometimes feel psychological distress and anxiety. If you feel so I will stop the interview and ask you whether you wish to continue the interview. If you need any psychological support, I will refer you to the palliative care unit where trained people are available provide the support.

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Based on the data of this study, I will conduct my research. This research can contribute to the knowledge generation on palliative care practices in Bangladesh. Your participation will ultimately help the community to develop a culturally sensitive, locally sustainable community-based palliative care project.

WILL WHAT I SAY IF THIS STUDY BE KEPT CONFIDENTIAL?

I will maintain absolute confidentiality. No personal data will be shared. If I use your views in our write up it will be done anonymously. **During telephone/online interview, I will record our conversation with separate recording device, not with online recording options**. **While doing online interview, I will use Microsoft team software.**

WHAT SHOULD YOU DO IF YOU WANT TO TAKE PART?

You need to sign a consent form which I will send to you through **email/online**. **Once you sign the form you will send it to me online**. You will keep another copy of your signed consent form. **Then I will contact you for convenient time for the telephone/online**.

WHAT WILL HAPPEN TO THE RESULTS OF THE RESEARCH STUDY?

The result of the research initially will be used in my thesis for PhD degree. In future, results of this research will also be shared among academics and non-academics in the form of journal articles, seminar and conference presentations.

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If you have any further concerns regarding the conduct of this research project, you can contact Dr. Shahaduz Zaman, Reader, Global Health and Infection Department Brighton and Sussex Medical School, University of Sussex, UKT: +44 (0)1273 877844 , Email: s.zaman@bsms.ac.uk

Harm

The University of Brighton and Sussex have insurance in place to cover their legal liabilities in the unlikely event of harm should arise from this study.

THANK YOU

Project Title: Understanding the notion of 'good death' in Bangladesh: A Critical Exploration
Version: ERA/BSMS9DQY/4/1
Date: 28.5.2020

Appendix Seven- Consent form for participants in Bangla language

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গবেষণায় অংশগ্রহণকারীদের সম্মতিপত্র

প্রজেক্টের নামঃ বাংলাদেশের প্রেক্ষিতে 'ভাল মৃত্যু' ধারণা অনুধাবনঃ একটি সমাজবৈজ্ঞানিক অনুসন্ধান

গবেষক ও প্রতিষ্ঠানের নামঃ মোঃ ইলিয়াছ কামাল রিসাত, ব্রাইটন এন্ড সাসেক্স মেডিক্যাল স্কুল, যুক্তরাজ্য

টিক চিহ্ন

১।আমি গবেষকের নিকট টেলিফোন/অনলাইন সাক্ষাৎকার দেবার জন্য সম্মতি প্রদান করছি।

২। আমি আমার সাক্ষাৎকারের অডিও রেকর্ড করার সম্মতি প্রদান করছি।

৩। আমি পরবর্তী প্রয়োজনে আরেকটা সাক্ষাৎকারেরও সম্মতি প্রদান করছি।

৪। আমি অবগত আছি যে, আমার সাক্ষাৎকারের অংশ গবেষক তার গবেষণায় ব্যবহার করার পূর্বে আমার সম্মতি নিয়ে তা করবেন।

৫। আমি বুঝেছি যে আমার প্রদত্ত তথ্য গোপনীয় থাকবে এবং গবেষক ও অন্য কোন তৃতীয় পক্ষ দ্বারা এই গোপনীয়তার লংঘন হবেনা।

৬। আমি অংশগ্রহণকারীর তথ্য সংবলিত ফরমটি পড়েছি এবং গবেষককে এ ব্যাপারে প্রশ্ন করার সুযোগ পেয়েছি। এছাড়া এ সাক্ষাৎকারের সমূহ

ঝুঁকি সম্পর্কেও অবগত হয়েছি।

৭। আমি এই গবেষণা অধ্যয়নের উদ্দেশ্যে আমার ব্যক্তিগত তথ্য এবং তথ্য প্রক্রিয়াকরণে সম্মতি জানাচ্ছি। আমি বুঝতে পারি যে এই জাতীয় তথ্য কঠোরভাবে গোপনীয় হিসাবে গণ্য হবে এবং সাধারণ তথ্য সুরক্ষা নিয়ন্ত্রণ (জিডিপিআর) ২০১৮ অনুসারে পরিচালিত হবে।

৮। আমি বুঝতে পেরেছি যে এই সাক্ষাতকারে আমি স্বেচ্ছায় অংশগ্রহণ করছি। পরবর্তীতে আমার ইচ্ছায় আমি এই প্রকল্পের অংশ নেয়া বা নেওয়া বেছে নিতে পারি এবং যে কোনও উপায়ে দণ্ডিত বা সুবিধাবঞ্চিত না হয়ে প্রকল্পের যে কোনও পর্যায়ে নিজেকে প্রত্যাহার করতে পারি

৯। আমি এই টেলিফোন/অনলাইন সাক্ষাৎকারে অংশ নেয়ার জন্য সম্মতি জ্ঞাপন করছি।

নামঃ

সাক্ষরঃ

তারিখঃ

Appendix Eight- Field notes

*লায়লা আপাকে যখন করোনার নেগেটিভ নিউজগুলো নিয়ে মন্তব্য করতে বলছিলাম তখন তিনি অন্য বিষয়ের দিকে আলোকপাত করতে বলেছেন। তিনি বললেন এটা অস্বীকার করার উপায় নেই যে করোনাতে আত্মীয়-স্বজন ফেলে যাবার ঘটনা ঘটে থাকলেও উল্টো ঘটনাও ঘটেছে। বিএসেমেমিউ তেই অনেক আত্মীয়-স্বজন রোগীর সাথে দিনের পর দিন অবস্থান করেছেন নিজের জীবনের করোনা আশংকা ধুলিস্যাত করে করে দিয়ে টানা যত্ন নিয়ে গেছেন রোগীর। এই ঘটনাগুলো উপেক্ষা করলে চলবেনা।

*সিপিসিতে প্রোভাইডার যাদের সাথেই কথা হয়েছে তারা কমিউনিকেশন এর ভূমিকার কথা বললেন। প্যালিয়েটিভ কেয়ারের স্পিরিচুয়াল দিকটার কথা বলতে গেলে তিনি এক ৩৭ বছর বয়স্ক মহিলা রোগীর কথা উল্লেখ করলেন। সেই রোগী লায়লা আপাকে প্রায়ই বলতেন যে তিনি হয়তো এই জীবনে অনেক পাপ করেছেন যার ফলস্বরূপ এমন শাস্তি কিংবা এত অল্প বয়সে ক্যান্সার ভোগ করছেন।

*আমার মায়ের কাছে এক রোহিংগা বয়স্ক মহিলা আসত। আম্মুর সাথে তার খুব ভাল যোগাযোগ ছিল আমাদের বাসার কাজ করে দিত প্রায়শই। আজকে শুনলাম তিনি মারা গেছেন বছর কয়েক আগে। আমি মাকে বললাম তোমাকে কে এই খবরটা দিয়েছে? বললেন উনার মৃত্যুর ৮ দিন পর উনার মেয়ে এসেছিল আমার মায়ের কাছে ফাতেয়ার জন্য টাকা যোগাড় করতে। আমার মা অভিমান করে ঐ মেয়ের সাথে কথাই বলেননি এই কারণে যে কেন তাকে এতদিন পর জানানো হল।

মৃত্যুর বছরখানেক আগে আমার মাকে ঐ বৃদ্ধা একটা আবদার করেছিলেন আংটির জন্য। আম্মু জানতে চাইল আংটি দিয়ে কি করবা? তখন তিনি বলেছিলেন, আমার তো কিছু নেই তাই আমার মৃত্যুর পরে কেউ হয়তো গোসল করাবেনা কিছু সহায় সম্পত্তি নেই দেখে। একটা আংটি যদি হাতে থাকে সেটা পাবার আশায় আমার কাছের মানুষেরা আমাকে মৃত্যুর পরে গোসল করিয়ে পরপারে সুন্দরভাবে যাবার ব্যবস্থা করতে পারে।

-আজকে সকালবেলা ফয়েজ আলমের বক্তব্য শুনছিলাম ওরিয়েন্টালিজম এর উপর। উনি বাংলা ভাষায় ওরিয়েন্টালিজমের অনুবাদক।তিনি বলছেন যে সাঈদের প্রাসংগিকতা আজ আমরা চাইলেই আমাদের যে কোন সমস্যার মধ্যে খুঁজে পেতে পারি। আমাদের মধ্যে যে হীনমন্যতা আমাদের আজকের রাষ্ট্রীয় ব্যবস্থায় নানা গলদের মাঝেই খুঁজে পেতে পারি পশ্চিমের দিকে ভক্তির চোখে তাকানোর উৎসটি আসলে কোথায়। প্যালিয়েটিভ কেয়ারের যে ডিসকোর্স তার দিকে তাকালে গুড ডেথের যে একটা ইউনিভার্সেল সংজ্ঞা দেয়ার চেষ্টা সে অনুযায়ী কি আমাদের প্যালিয়েটিভ কেয়ার এগুচ্ছে? এই চিন্তা ধরে এগুলেই আমার ডাটার মধ্যে এর সূত্র খুঁজে নিতে পারি। উদাহরণস্বরূপ নওরিন আপুর কথাই বলা যাক। উনাকে যখন জিজ্ঞেস করলাম প্যালিয়েটিভ কেয়ারের এসব কারিকুলাম আসলে কারা করেছেন। উত্তরটা তিনি খুব রাগের ভংগিতে দিলেন।বললেনঃ এসব নিয়ে তো আসলে প্রশ্ন করার কিছু নাই। সকল উন্নত দেশ থেকে এসব নিয়ম এসব নীতি করা হয়েছে। এগুলা অনেক চিন্তা ভাবনা করে করা। এই যে পশ্চিমের জ্ঞানকান্ডকে বিনা প্রশ্নে মেনে নেয়া এতে সামাদের সাংস্কৃতিক মনোজগতের দাসত্বটা পরিষ্কার ফুটে উঠে।

-দীপেশ এর লেকচার দেখছিলাম গতকাল। রবীন্দ্রনাথ, মহাত্মা গান্ধী, স্বামী বিবেকানন্দ, জওহরলাল নেহেরু তখনকার সময়ের প্রেক্ষিতে সিভিলাইজেশন আর আধুনিকতাকে ডিল করেছেন। একটা বাতচিতের মধ্য দিয়ে গেছেন। এই প্রবণতা এখন আছে কি নেই তার উদাহরণ দিতে গিয়ে বর্ণনা করেছেন ভ্যালেন্টাইন্স ডেতে একজন হিন্দু কট্টরবাদী নেতার কাজকর্ম ও তার বিপক্ষে নারীবাদীদের পিংক চাড্ডি আন্দোলন। রবীন্দ্রনাথ যেভাবে সিভিলাইজেশনের সংগা দিয়েছেন তার মধ্যে যে সেলফ রিফ্লেক্সিভিটি আছে তার বয়ান দিচ্ছিলেন। সহজ ভাষায় সিভিলাইজেশন আমাকে নিজের এমন সমালোচনা করার ক্ষমতা দিবে তা যেন আমরা আমাদের মার্জিনালকেও তা রপ্ত করতে দিতে পারি তাতে করে সেও আমাকে সমালোচনার সুযোগ পাবে। পশ্চিমের দেশগুলোর সেই বৈশিষ্ট্য আছে।

-ফ্রানজ ফানন কলোনিয়াল সাবজেক্ট এর সাইকো এনালিসিস করেছিলেন। তিন ধরণের সাংস্কৃতিক জাতীয়তাব্দের ইংগিত তিনি দিয়েছেন। প্রথমে যে জাতীয়তাবাদ তাতে কালরা সাদার মতই হতে চায়, অনুকরণ করে। দ্বিতীয়ত, যখন টের পায় তার পক্ষে সাদা হওয়া সম্ভব না তখন সরে আসে।তৃতীয়ত, নিজের সমালোচনা ও সেই সাথে বাস্তবতা মেনে নিয়ে আন্দোলন।

হোমি কে ভাবা বলছেন সাঈদের সাথে ফাননর মৌলিক পার্থক্য আছে। সাঈদ পলিটিকস অব রিপ্রেসেন্টেশনে গিয়ে যখন বলেন যে আমাদেরকে রিপ্রেজেন্ট করতে গিয়ে আমাদেরকে জানতে গিয়ে পশ্চিম যে জ্ঞান লাভ করেছে তা দিয়েই আমাদেরকে দখল করে এবং পরে সেই জ্ঞানএর ভিত্তিতেই আমরা নিজেদের পরিচয় নির্মাণ করি। এতে করে পশ্চিমা এনলাইটেনমেন্টের যে বাইনারী ডিকটমি তার খপ্পরে আমরা পড়ে যাই। আমাদের জ্ঞান আছে/নাই; আমরা অজ্ঞ/অজ্ঞ না ইত্যদি।

-Yasmin Gunaratnam

One of the consequences of the pandemic is that it is slowly surfacing what has been decades of underfunding of health and social care services and the lack of care provided to our care professionals. In the UK there has been a year-on-year decline in the increase of government funding to the Department of Health and Social Care since 2008. The research institute The King’s Fund has **found** that “Budgets rose by 1.4 per cent each year on average (adjusting for inflation) in the 10 years between 2009/10 to 2018/19, compared to the **3.7 per cent average rises** since the NHS was established”.

- I din’t include anything about Ars Moriendi yet in my writing. I must include it as it’s the pioneering descriptions of good death in the west

-হসপিস বাংলাদেশ এর একটা লাইবে প্যাডিয়াট্রিক প্যালিয়েটিভ কেয়ার নিয়ে বলতে গিয়ে ডঃ জোহরা জমিলা খান বলেছেন শিশুদের স্পিরিচুয়াল কেয়ার নিশ্চিত করতে গিয়ে তাদের লেভেলে পৌঁছুতে হবে বলে উল্লেখ করেন। সে কক্সবাজার যেতে চেয়েছিল, বিদেশী চকলেট খেতে চেয়েছিল। উনারা তা প্রোভাইড করেছিলেন। ইচ্ছে পূরণ করেছিলেন। বড়দের সিপিরিচুয়াল কেয়ার আলাদা। তারা প্রিয় ধর্মীয় গুরুর দোয়া চান, গান শুনতে চান।

-আজকে জন ভাইয়ের ইন্টারভিউ নিলাম। সেখানে যেটা মনে হল যে ডাক্তারদের বক্তব্যতে সবসময় মেডিক্যাল আস্পেক্ট এর উপর বেশি গুরুত্ব থাকে। তারা মনে করেন রোগীরা হাসপাতালের প্রতি নির্ভরশীলতা অনুভব করেন। কারণ, ব্যথা অনেক ভোগায় এবং ব্যাথা থেকে নিষ্কৃতির উপায়গুলো হাসপাতালে আছে। আলাপের এক পর্যায়ে একটা আগ্রহোদ্দীপক কথা বললেন জন ভাই। মারমা ধর্মে বুদ্ধের যে প্রভাব সে অনুযায়ী হচ্ছে ব্যাথা নিয়ে মৃত্যু হলে পরজন্মে ভাল অবস্থা হবেনা এরকম একটা বিশ্বাস কাজ করে।

আমার কাছে এই ব্যাপারটা খুব ইন্টারেস্টিং লেগেছে। কারণ, এই বিশ্বাসে বিশ্বাসী যারা তাদেরকে প্যালিয়েটিভ কেয়ারে অনেক তাড়াতাড়ি ইন্সপায়ার্ড করা যাবে। আরেকটা হচ্ছে, তথাকথিত

পুরো স্বাস্থ্য ব্যবস্থায় বায়োমেডিক্যাল চিন্তাভাবনা যে জেঁকে বসেছে তার নিরিখে ভিন্ন একটা বইয়ান দাঁড় করানো যাবে যেখানে ভাল মৃত্যুর কথা ধর্মীয় ভাবেই বলা আছে।

এ থেকে আমার মাথায় যে প্রশ্নটা ঘুরে ফিরে আসছে তা হল। এই যে আমরা মৃত্যুর আগে আমাদের কাছের মানুষদের ব্যথা কমাতে চাই এর ধর্মীয় অনুপ্রেরণা কি? শুধুই কি ধর্মীয় অনুপ্রেরণা নাকি এতে হিউম্যানিজমও ঢুকে পড়েছে? তা হলে তা কিভাবে? এ নিয়ে ধর্মীয় শাস্ত্রগুলোতে এসব খুঁজে দেখার বিষয় আছে। (৯.১০.২০২০)

-আজ বিশ্ব হসপিস ও প্যালিয়েটিভ কেয়ার দিবস। এবারের প্রতিপাদ্য বিষয়ঃ আমার স্বস্তি, আমার আরাম। সিপিসি থেকে কয়েকটা ওয়েবিনার ও অনুষ্ঠানের আয়োজন করা হয়েছিল। এটেন্ড করেছি। আজকে পরিষ্কার হলঃ বাংলাদেশে মূলত হাসপাতাল ভিত্তিক প্যালিয়েটিভ কেয়ার পরিচালিত হয় সিপিসিতে। এবং এই সিসিপির উদ্যোগেই কমিউনিটি এপ্রোচ পরিচালিত হয় মমতাময়ী করাইলে ও মমতাময়ী নারায়ণগঞ্জে। জুলহাস ভাইয়ের বক্তব্যে করোনার সময়ে কিভাবে নারায়ণগঞ্জ কমিউনিটিতে প্যালিয়েটিভ কেয়ার প্রদান রেখেছেন। এই প্রজেক্টে নিম্ন আয়ের মানুষ বেশি থাকাতে উনারা দেখতে পেয়েছেন অনেক পরিবারের আয় বন্ধ হয়ে গেছে।এমন সময়ে উনারা স্পেশাল ফুড প্যাকের ব্যবস্থা করেছেন, টেলিফোন কেয়ার অব্যহত রেখেছেন, লকডাউনের কারণে ফিজিওথেরাপির অভাব হয়েছিল ধীরে ধীরে ফিজিওথেরাপিস্ট ঘরে যাবার ব্যবস্থা করেছেন, এভাবে এখন ধীরে ধীরে হোম কেয়ার থেকে শুরু করে সব সেবা চালু করেছেন।

ঢাকায় মিক্সড আপ্রোচে প্যালিয়েটিভ কেয়ার চলছে। করোনা চ্যাপটারে বৈশ্বিক গবেষণাগুলোর পাশাপাশি জামান ভাইয়ের ব্র্যাকের গবেষণাগুলো আমি কাজে লাগাতে পারি। এছাড়া করাইলকে নিয়ে যে কাজ উনি করছেন তাও কাজে লাগাব। (১০.১০.২০২০)

-শেন্ডেল বাংলাদেশ নিয়ে একটা প্রবন্ধে লিখেছেন যে এথনোগ্রাফিক গবেষণায় অনেক লোকাল এক্সপ্রেশন চলে আসে যা অনেক শক্তিশালী বিশ্লেষণে ভূমিকা রাখে। আমার গবেষণায় এমন অনেক লোকাল এক্সপ্রেশন খুঁজে বের করতে হবে যেন তা কনসেপ্ট হিসেবে কাজ করতে পারে।

-গতকাল সিপিসিতে গিয়েছিলাম। অনেকক্ষণ বসে থাকতে হয়েছিল অপেক্ষাগারে। সেখানে গল্প করলাম তিন ভাইয়ের সাথে। সেই তিন ভাই এর মা ক্যান্সারে ভর্তি হয়েছে দুই দিন হল। কথা বলতে গিয়ে জানা গেল। করোনার আগে থেকেই মায়ের ব্যথাজনিত সমস্যা হচ্ছিল। এরপরে শুরু হল লকডাউন। যেখানেই যায় করোনাজনিত বাধার সম্মুখীন হয়েছে। অনেক দেরিতে পরীক্ষা হয়েছে মায়ের কি হয়েছে। পরে জানতে পারল ক্যান্সার। এরপর ঢাকা বিএসএমএমই তে এসে জানতে পারল যে দুই জায়গায় ক্যান্সার হয়েছে। এখন শেষ ভরসা হিসেবে সিপিসিতে

এসেছে। করোনার নিয়ম কানুন অনুযায়ী তার কেউ মায়ের পাশে অবস্থান করতে পারেনা। অপেক্ষাগারে বসে থাকতে হয়। এই নিয়ম কানুনের জন্য অন্য কোন আত্মীয় স্বজন আসতে পারছেন না। তারা জানেন এবং বুঝতে পারছেন যে মা কিছুদিনের মধ্যেই মারা যাবেন। কিন্তু মাকে এখনো বলেন নি সবকিছু। বললে মায়ের মানসিক অবস্থা ভেঙে পড়বে। তারা ভাবছেন খুব শীঘ্রই দেশের বাড়ি নিয়ে যাবেন যেন মায়ের শেষ সময়টা প্রিয়জনদের পাশেই কাটে।

গতকাল রাতে ৩টার দিকে এক ভদ্রলোকের স্ত্রী মারা গেছেন। তখন ওয়েটিং রুমে আত্মীয়রা ঘুমাচ্ছিলেন। একজন নার্স এসে চিৎকার দিয়ে ঘোষণা দিলেন যে ৩ নম্বর বেডের রোগী মারা গেছেন। ছোট ছেলে আমাকে বলছিলেন যে এভাবে বলা ঠিক না ঘুমের মাঝে। যেকেউ ভয়ে অর্ধেক অসুস্থ হয়ে যাবে। এটা ঠিক করা উচিৎ। তিন ভাই খুব গিলটি ফিল করছে যে অন্য আত্মীয়-স্বজন আসতে পারেন নি।

লায়লা আপার সাথে কথা হল। লায়লা আপা এসে বলছেন গতকাল এক রোগীর শরীর থেকে পানি বের করা হয়েছে। এরপর উনার খুব ভাল লাগছিল। তিনি স্বস্তিতে লায়লা আপাকে জড়িয়ে ধরে ছিলেন। উনার ভাল লাগছিল জড়িয়ে ধরতে। এদিকে লায়লা আপার করোন নিয়ে ভয় লাগছিল। উনি ভেবেছিলেন যে প্রথমে বৃদ্ধাকে সরে যেতে বলবেন। কিন্তু তিনি বৃদ্ধার স্বস্তি টের পেয়ে আর কিছু বলার উৎসাহ বোধ করেননি।

আরেক বৃদ্ধ নাকি সিগারেট খাচ্ছিল ওয়ার্ডে বসেই। লায়লা আপা তাকে মানা করার পর তিনি বলছিলেন- 'কি হবে কয়িদিন পরে তো মারা যাবই। সিগারেটটাও যদি না খেতে দেন তাইলে কি করব?'

এরপর তিনি বাথরুমে গিয়েই খেলেন। তাও সিগারেট খাওয়া বন্ধ করলেন না। (২১/১০/২০২০)

-আজকে সকালে প্রথম কোন কেয়ারগিভারের ইন্টারভিউ নিলাম। রোগীর নাম সায়েরা খাতুন। কেয়ারগিভারের নাম লিপি। সম্পর্কে ছোট মেয়ে হন। করাইলের বস্তিতে দুই রুমে তারা ছয়জন থাকেন। একরুমে তার অসুস্থ মা ও ছোট ভাই। আরেক রুমে তার স্বামী ও দুই সন্তান। তার ছোট সন্তান প্রতিবন্ধী। লিপি আক্তারকে মোট দুই জনের সেবা করতে হয়।

তার সাথে কথা বলে মনে হল তারা প্যালিয়েটিভ কেয়ার কিংবা এন্ড অব লাইফ কেয়ারের প্রাতিষ্ঠানিক অর্থ সম্পর্কে অবগত নন। গরিবরা সেবা পাচ্ছেন, তাদের অনেকের উপকার হচ্ছে এমন একটা মোদ্দা ধারণা তার মধ্যে আঁচ করতে পারলাম। মৃত্যুর কথাটা বলতে চ্যালেঞ্জ অনুভব করেছি কারণ মমতাময়ী করাইল সম্পর্কে তাদের ধারণা একটা স্বাস্থ্যসেবার মতই মনে হল। ঘুরিয়ে ফিরিয়ে জিজ্ঞেস করতে হয়েছে এ সম্পর্কে। আধ্যাত্মিকতার কথা বলতে গিয়ে কেঁদে দিয়েছেন। দুইজন অসুস্থ মানুষের সেবা করতে গিয়ে হিমশিম খেয়ে যান মাঝে মধ্যে।নিজের ইবাদত বন্দেগী নামাজ কালাম নয়, বরং এই সেবা শুস্রুষা। ঘুরে ফিরে চলে আসে ফ্যামিলির প্রসংস। রোগীর স্বামী অনেক আগে দ্বিতীয় বিয়ে করে আলাদা থাকে। (২৯/১০/২০২০ সকাল ৯ টা)

- এরপরে গেলাম সিপিসি। আজকে একটা রোগীকে নিয়ে আসল তার স্ত্রী আর ছোট ছেলে। তাদের এক আত্মীয় পিজির বড় ডাক্তার। রোগীর অবস্থা দেখে আত্মীয়দের বললেন সিসিপিতে ভর্তি করতে। ঐ ডাক্তার তাদেরকে এটা বলেননি যে রোগীকে বাঁচানোর জন্য এখন আর কিছুই করার নেই, শুধু ব্যথা কমানো ছাড়া। তারা এসে ডাকারদের সরাসরি বললেন ভর্তি করাতে। ডাক্তার নার্স বললেন, আগে করোনা টেস্ট করে আসতে। তারপর নিয়ম অনুযায়ী ভর্তি করবেন জানিয়েছেন। আমি রোগীর স্ত্রীর সাথে গল্প করছিলাম। তাদের বাড়ি বরিশাল। চার ছেলে। বড় দুই ছেলে ইতালি ও ব্রিটেনে থাকে। গত ছয় বছর আগে রোগীর ক্যান্সার ধরা পড়েছে। বিআরবি হাসপাতালে কেমো দেয়া হয়েছে। এখন গত কিছুদিন ধরে খাওয়া দাওয়া করতেই পারছেন না। খুব ক্লান্ত হয়ে আছেন। এই সমস্যা নিয়ে তারা এসেছেন। ছোট ছেলে আউটডোরে গেছিলেন ভর্তির আনুষ্ঠানিকতা সারতে। তখন জানতে পারলেন যে এখানে রোগী বাঁচানোর জন্য কোন চিকিৎসা দেয়া হয়না। এই বিষয়টা মাকে এসে জানালেন। তখন মা বললেন তাহলে এখানে আসার কোন দরকার নেই, বিআরবিতেই দেখাবেন। আউটডোর থেকে ঘুরে আসার পর মা-ছেলের মধ্যে অনেক টেনশন এর একটা ভাব দেখা গেল। তারা দুজন তখন চিন্তায় পড়ে গেলেন সিপিসিতে ভর্তির চেষ্টা করবেন নাকি চলে যাবেন? ছেলে এক পর্যায়ে বললেনঃ এখানে ঘটনা অন্য। এখানে শুধু ব্যাথা কমাইব। কিছু করাইতে পারবনা।

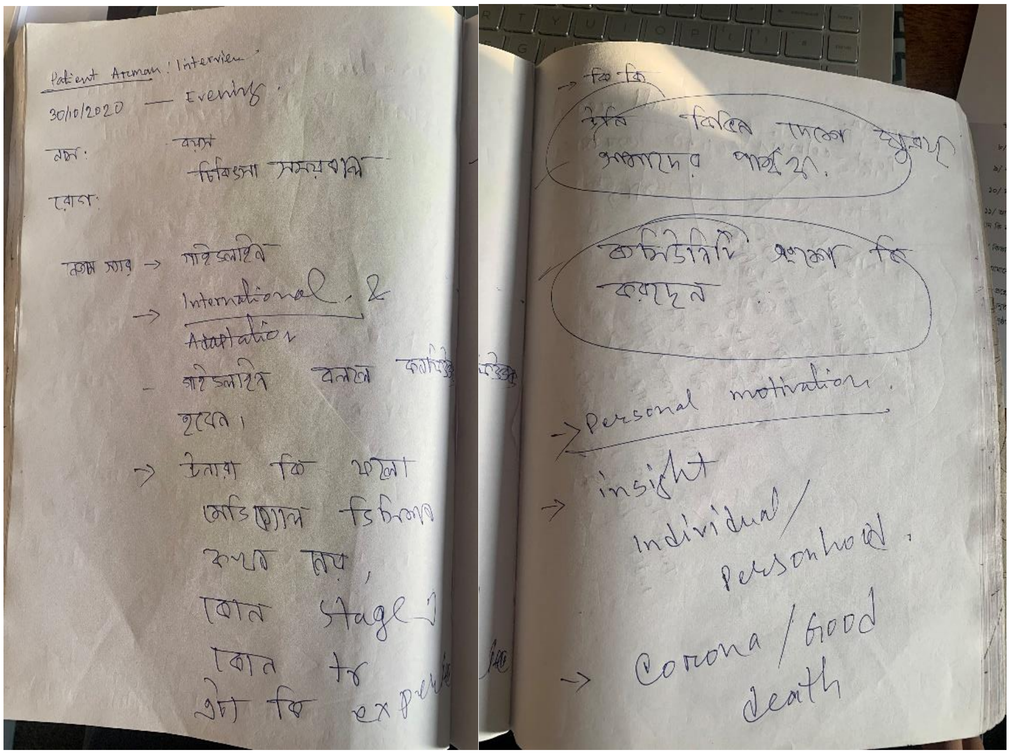
(২৯/১০/২০২০ দুপুর)

-এরপরে একজন ৭০ ঊর্ধ্ব মা ভর্তি আছেন। তার চার মেয়ের সবাই হাসপাতালে দেখাশোনা করেন মায়ের। উনারও ক্যান্সার। বেশ কিছুদিন আগে তাদের ডাক্তার তাদের জানিয়েছেন কি হয়েছে। এরপর মৃত্যু আসন্ন জেনে মা তাদের মেয়েদের ডেকে সম্পত্তি ভাগ করে দিয়েছিলেন। এরপর থেকে তার মায়ের মৃত্যু সম্পর্কে ধারণা হলঃ তোদেরকে নিয়ে আমার আর টেনশন নাই। তোদেরকে দেখে দেখে মরে যেতে পারলেই বাঁচি। এজন্য কি তারা সবাই নিষেধ সত্ত্বেও হাসপাতালে থাকছে গত ২১ তারিখ থেকে? এদিকে মায়ের অবস্থা খারাপের দিকে। গত তিন চারদিন ধরে কথা বলতে পারছেন না। চোখে দেখতে পারছেন না। টর্চ দিলে দেখতে পারেন। তাদের গ্রামের বাড়ি বরগুনা হলেও তারা সবাই মূলত বিক্রমপুরে জন্ম। এই সূত্রে ঢাকাতে থাকেন সবাই। তাদের মা তাদের বলে দিয়েছেন গ্রামের বাড়ি কবর না দিতে। তার সন্তানরা যেখানে আছে সেখানেই তিনি শায়িত হতে চান। এই ধারণা অন্যরকম একেবারেই।বড় মেয়ে আমার সাথে কথা বলতে বলতে এক পর্যায়ে নিজের ছেলের অকাল মৃত্যুর কথা স্মরণ করলেন। ১২ বছর বয়সে নাকি তার মৃত্যু হয়েছিল টিউমারে। কান্নায় ভেঙে পড়লেন বলতে বলতে। খুব মেধাবী ছিল। তার বন্ধুরা এখন একেকজন ইঞ্জিনিয়ার ডাক্তার।

খুব গুরুত্বপূর্ণ একটা কথা বললেন তিনিঃ আমরা জানি আমাদের মা বেশিদিন বাঁচবেনা। তাও আমরা তাকে বুঝতে দিতে চাইনা যে আমরা তাকে অবহেলা করছি। এইযে এখানে ভর্তি করাইসি ডাক্তার আসছে, দেখছে, ঔষধ দিচ্ছে এতে করে তিনি এতটুক আশ্বস্ত হচ্ছেন যে তাকে কেয়ার

করা হচ্ছে। এই কেয়ারের ফিলসফির মধ্যে ব্যক্তির ডিগনিটিকে হাইলাইট করে। তার পরিবারের কাছ থেকে আচার ব্যবহারের মাধ্যমে সে এই ডিগনিটিটা পাচ্ছে। পরিবারের মধ্যে মর্যাদাবোধের আকাঙ্খা প্রবল আমাদের এখানকার মানুষজনের। তিনি এই বললেন যে, এই সেন্টারের চিকিৎসা অর্থহীন। তার মানে যে চিকিৎসা বাঁচাতে পারেনা তা অর্থহীন। তাহলে কি এই যে সেন্টারে এনে এত আয়োজন তা পরিবারের মমত্ববোধ প্রদর্শন? ভালবাসার বহিঃপ্রকাশ? সেন্টারের চিকিৎসা শুধুই পোশাকি? সিম্পটম্যাটিক চিকিৎসা তো দিনশেষে পোশাকি চিকিৎসা...(২৯/১০/২০২০ বিকাল)

Appendix Nine-Memo



Patient Arman: Interview
30/10/2020 — Evening.
নাম:
বয়স
চিকিৎসা সময়কাল
রোগ:
কেমন আছ → গাইডলাইন
→ International &
Adaptation
- গাইডলাইন বদলে কাস্টমাইজড
হবে।
→ উনারা কি অন্য
মেডিক্যাল ট্রিটমেন্ট
করছে নয়,
কোন Stage?
কোন tr
এটা কি experie

→ ~~কি কি~~
ইনি কিভাবে দেখেন মৃত্যুকে
আমাদের পার্থক্য।
কমিউনিটি প্রসঙ্গে কি
করছেন।
→ Personal motivation.
→ insight
Individual/
personhood.
→ Corona / Good
death

Appendix Ten- Interview Guideline and Initial code list

Interview guideline for Palliative care health professionals:

Here’s the interview guideline I have used so far during the four (4) interviews I have conducted so far.

a) Personal life history of a palliative care provider e.g. which aspects motivated oneself to become a palliative care provider?
b) While you (palliative care provider) serve a dying patient, do you use the word ‘death’ or you avoid using it? How do you convey death news to the carer (relatives) of the dying patient?
c) What expectations a dying patient have in your palliative care centre? Do they visit the centre to ensure a ‘good death’ or something else?
d) How do you compromise between ‘good death’ perception of healthcare professionals and the ‘good death’ notions of the dying patients and their carers? If the later is starkly different than yours how do the patients and carers adapt with it?
e) Do you share all sensitive information with the dying patients and their carers? If not, how do you negotiate with the information you didn’t share with them?
f) While providing palliative care, do you follow any international or national guideline? Please describe in detail.
   If yes, can you follow it fully or you need to change it?
g) Overall assessment on palliative care in Bangladesh
h) What changes you observed regarding Covid-19 and Palliative care for the last Six (6) months?

Code list:

Here's the code list from the interview guideline:

a) Inspiration of a provider
b) Mode of talking with patients and carers
   Creative communication regarding death

c) Patient expectation
   Palliative care for which reason?- Good death/Other?

d) Negotiation of good death
   Adaptation of good death

e) Sharing information with patients
   Sharing information with the carers

f) Standard Protocol for care
   Adaptation of protocol

   Reasons behind adaptation

g) Palliative care in Bangladesh
h) Covid-19 impact:
   -Change in cultural practice

   -Transition in institutional practice

Overview on Coding:

Till now, I conducted four (4) interviews of healthcare professionals. Based on the interview guideline, I designed the above code list which are 'apriori code'. Right now after completing the transcription of the 4 interviews, I am doing coding of those.

First, I am marking information in the transcription according to the apriori code. Then I am marking information which are repetitive in all transcription but not reflected in the apriori code. Based on that new information I am rearranging a new code list to code the other transcriptions. This new information was grounded in the interview transcriptions. This is how I am continuing my coding.

Further Interviews:

Furthermore, I am planning to conduct other interviews with remaining healthcare professionals and then the carers and the patient very soon.

Field Plan-Interview guide

Healthcare professionals

1.Awareness of death

a) How do you say to your patients about their imminent death? Do you directly mention it to your patients or not?

c) What do you say to their carers/family members when you tell them about the services they will get in the palliative care centre?

d) Interaction with the patients and carers: in detail.

2. Good death

a) Differences between patients ‘good death’ and the centre’s ‘good death’

b) Understanding of good death

c) Good death is regarded as painless death: understanding of this in the context of Bangladesh.

3. Challenges to execute global notion of ‘good death’

a) What are the challenges they face while executing global framework of good death?

b) How do they compromise with this?

c) Potential of home as a place of service to provide non-institutional components of palliative care.

d) Do health care professionals face any dilemma while complying to the international protocols of palliative care? if yes, what are these dilemmas? How do they tackle these dilemmas?

f) Do patients mention about euthanasia at all? If yes, what did they tell about it?

4. Agency of patients

a) Do you think a terminally ill patient can decide about their treatment or not? Who takes the decision for overall treatment?

b) If you ask anything to patient, do they suggest you ask their carers about it or they themselves answer to them?

c) How patients perceive their agency? Questions related with personal autonomy and dependency

5. Overall comment of palliative care in Bangladesh

a) What are the strengths and weakness of existing palliative care model in Bangladesh?

b) Can you please mention some limitation which doesn't motivate healthcare professionals to pursue palliative care as a career?

c) Is the training enough for the professionals in Bangladesh?

6. Confusion about palliative care

a) Why there is confusion about palliative care in Bangladesh? Some tells it a place for dying, some tells it a care home, some tells it a geriatrics unit.

b) What needs to be done to settle this confusion?

7. Things to do to provide good palliative care

a) What do you think about culturally appropriate end of life care practices?

b) What are the limitations of existing model to provide culturally sensitive palliative care?

c) What do you think about the role of palliative care education to the masses?

d) What can be done to provide palliative care services to great number of dying population in near future?

7. Covid-19 and Palliative care

a) What's changed in the care mechanism of patients due to covid-19?

b) Is the idea of 'total care' is threatened due to covid-19 in Bangladesh?

c) What are the tensions you observed amongst the dying patients in relation with covid-19? How are you managing those?

Patients

1. Awareness of death

a) Are they aware why they are admitted in palliative care centre?

b) If yes, what are they told about palliative care centre? Who told them?

c) If no, ask about why they are in palliative care centre?

2. Place of care:

a) Do you prefer this centre as a place of proper care?

b) Why? Or why not?

c) Do you like to stay here till the end? Why or why not?

d) What's the difference between hospital and palliative care centre?

e) What's the difference between a mainstream healthcare professionals and a palliative centre's professionals?

f) What's your opinion regarding the service of palliative care centre?

3. 'Good death'

a) What do you think about an idea of good death?

b) Do you think you can accomplish a good death staying in this palliative care centre?

c) If yes how? If no, what steps you will take to ensure good death?

d) Intergenerational experiences of 'good death' in family/relatives/lineage/ancestry.

e) Intergenerational differences.

f) Do you have any unfinished job regarding your personal wishes or family responsibility?

4. Personhood/agency of a terminally ill patient

a) Who decided your admission into palliative care centre?

b) Did they force you or otherwise?

c) Do you think you can decide about your treatment/body at a terminal situation like this?

d) Is there any issue with family (being burden and others) that you moved to this centre?

e) Do you notice any changes amongst family members regarding taking care of the elderly or terminally ill patient of the family?

5. Dignity

a) What do you understand by dignity in death?

b) Can this centre hold your dignity the way you understand it?

c) Dignity has a social dimension in Bangladesh. can you please explain more on this? (career fulfilment of children, arrange marriage ceremony for every child, perform haj, more people during janaja etc)

d) dignity is west is – painless death. What's the impression in Bangladesh? what do you think about pain?

e) Pain is the basics of western palliative care. what's the scenario in Bangladesh? what if people of Bangladesh focus more on social attributes?

Caregivers

1.Awareness of death

a) What was your reaction after hearing about imminent death of the patient?

b) Have you told your patient about the death?

c) If yes, what exactly did you tell your patient?

d) If no, what have you told your patient?

e) what do you think about being aware of one's death?

2. Place of care

a) Why have you come to palliative care centre?

b) Are you getting expected care from it?

c) Rather than relieving pain, what other reasons motivated you to come here?

d) Evaluation of the care model of the centre

e) Difference between a mainstream hospital and this centre.

3. Good death

a) What do you think a good death is?

b) Have you come to the centre to have a good death or any other reasons?

c) Is there any changes you noticed in your patient after coming to the centre?

d) Good death: is it patient's understanding or the family? Or society?

4. Decision maker

a) Why you are taking care instead of others in the family?

b) Is there any relation to the patient's idea of 'good death' and you taking care of him/her?

c) Do your patient rely on your every decision you take regarding care and treatment?

5. Evaluation of existing palliative care model

a) Reality and expectation

b) Strength and limitations.

Appendix Eleven- Themes

Emerging themes:

I did the initial coding of three interviews of three healthcare providers. They are a doctor, a Palliative care coordinator, and a Palliative care assistant (PCA). After the initial coding, I found these themes emerging in the data:

1)Communicating death:

There are several ways providers communicate about the imminent death news with the patients and the family caregivers:

a) As a team: depends on the severity of the disease. Whenever the situation worsens, palliative care assistant, doctor, nurse convey the news together. Providers do it for several reasons:

1. Compassionate towards the patients.
2. Compassionate towards the caregivers.
2. Providers think that it helps to share the burden with other team members while delivering bad news. Providers think it's a difficult situation so they work as a team then.

b) Mutual acknowledgment: whenever the patient's condition deteriorates, providers share the condition with the family caregivers cautiously. Rather than using the word 'death' they share and talk about the symptoms (which caregivers and providers both see and understand together). They communicate through laymen's language, not through any medical scientific language. Medical symptoms are understood by all. Providers and caregivers both discuss the visible medical symptoms (objective). These are breathlessness and severe pain in most cases.

Besides, both the party observe some subjective conditions of the patient. These are: patients talk about death, sometimes they remain silent, sometimes they cry etc. Providers then indicate to the caregivers regarding these objective and subjective symptoms. It's like providers are sharing the information with the caregivers to reach an acknowledgment about the patient's imminent death. The relationship between the patient/ caregivers and providers is not like patron-client here. Rather, it’s more empowering for caregivers and patients.

<u>c) Absence of death vocabulary:</u> One respondent said that they don’t use the word ‘death’. Rather they tell to the caregivers like this: ‘Anything can happen anytime to the patient’.

However, there are differences of understanding between doctors and Palliative Care Assistant (PCA). Doctors said that it's futile to talk to patients regarding the news of imminent death as they will not understand this. They prefer to talk to the family caregivers instead of the patients about it. On the other hand, PCA mentioned that the patients understand better than the providers about their imminent worsening situation.

2) Good death (Patients’ notions according to the providers):

There are many similarities between the three providers. These are general perceptions they developed working with dying patients over the years.

a)See grandson/ granddaughter who lives far from them

b)Fulfilling age (closer to average life expectancy)

c)Wants to die in a hygienic atmosphere

d)not to die in a disabled condition

e)Painless death

f)Remain without medical instruments (Catheter, nebulization) before dying

g) Visit ancestral home before dying

h)Homely environment with all family members.

i)do not want to be a burden in the family

Regarding the good death notions, PCA knows more than doctors what the patients and caregivers prefer to have a good death.

3)Patient's expectation: What do they want from the providers?

a)Frequent visit at the ward/home

b)Relieve from pain

c)medicine for free of cost: there are differences between low-income patients and moderate-income patients. The patients at the slum want medicine free of cost.

d)Medical appliances for free of cost: this is seen in the case of slum patients.

d) Demands daily essentials

There is a tendency of visiting acute care hospitals amongst the solvent patients.

4) Fictive relation: With Palliative Care Assistant (PCA)

a)Accompany: one patient told to PCA 'my pain and sufferings go away when you are beside me'

b)Sharing: They gossip about their private life e.g. conjugal life, family secrets, childhood life, personal life histories, relation with in-laws (specially female patients) etc

c)Caring: breaks standard protocol visiting frequently in addition to routine visits.

d)Relative titles: PCA calls the patient's Grandfather/grandmother/mother. On the other hand, patients call them son/daughter/grandson/granddaughter etc.

Emerging themes (Caregivers)

1)Extended self

a)childlike attachment

b)Patient body is my body

c)New perception of life: in terms of daily routine, life goals, career, spirituality, etc.

Several caregivers mentioned the patient becomes an extended self of their existence. One caregiver, who is a daughter of 70-year-old dying patients told that 'There's no difference taking care of my mother and my new-born 8 months baby girl. The way I take care of my baby, I treat my mother the same way every day. I bathe them, I dress them, I prepare soft food for them, etc.

Another carer, an 18-year-old college-goer son, takes care of his 55 years old mother, who is a patient with breast cancer. Son takes care of everything including cleaning of sores, defecation, giving medicines, visiting the hospital, and others. While asking about it, replied 'it's like I am taking care of my body. That's why I don't forget about those things. I feel guilty when I forget taking care of her'.

2) Good death: 'No man's land'/ A grey zone

a) Accepting death:

There are several stages after which a family or the carer accepts death. Frequent changes of specialists to confirm the patient has no other treatments possible to recover, financial difficulties, and spiritual acceptance of the unavoidable imminent death.

b) Communication on good death: Provider vs Carer

According to the provider, the first step of ensuring a good death is to have open communication with the family. So that providers can design end-of-life-care planning for the patients. On the other hand, some carers and families try their best to keep the death news a secret from the patient. The secret, according to the carers, can make sure a stress-free 'good death' of the patient. It's kind of a 'good death' based on a lie from the carers' perspective. However, when the carers and the family are advised by the providers regarding the material complications (unfinished financial arrangements, planning for the future of the family) of the secret, the family encounters a dilemma. There are distinguished differences between the carers and the providers what a good death means.

3) Role of demographic features: in terms of final days planning

a) Carer's perspective: the context becomes different whether the carer is the son or daughter or someone else.

b) Patients sex: difference of plans varies with sex

There are several cases of the father being the dying patient. In that case, children talk about property issues, financial issues e.g. banking, insurance, unfinished property arrangements. On the other hand, if the patient is a mother, children prioritize more of the emotional want of her. There is a case where all the daughters remain well dressed and well make-up in the palliative care centre in front of their dying mother. Mother's last wish was to see her daughter look like fairy angels before her death.

c) Patient's age:

Carer prefers, in most cases, palliative care when the patient is almost at the age of 60-70. However, the scenario changes if the patient is financially solvent. Carers, in that case, look for opportunities in foreign countries hoping that their parents can recover.

Carer's remain incapacitated when the patient is comparatively young. In those cases, parents become the carer despite several limitations. Sometimes, the patient himself/herself is the sole earner. In that case, parents become perplexed while planning end-of-life care. On the other hand, if the daughter is the patient and if she is married, then a negotiation takes place between the girl's parents and the in-laws' house. When I asked about what they are planning about the child of the daughter, the mother replied to me 'We don't have much to say over the future of the child. Her in-laws will take care of this.

4) Family dynamics:

a) conflict around responsibility

b) Conflict around treatment: Palliative care vs curative care

c) Financial hardship

d) Burnout: psychological

spiritual

is palliative care a blessing or negligence?

Appendix Twelve- Participants interview transcript in Bangla

হাসিনা একেবারে জীবনের শেষ পর্যায়ে। সিপিসিতে সেবা নিচ্ছেন। মা সেবা করছেন সিপিসিতে।

ডাক্তার মাকসুদা আপা আমার সাথে উনাকে আর উনার মাকে পরিচয় করিয়ে দেন। মায়ের সাথে হাসিনা আপার খালাও ছিলেন সেখানে।

মাকসুদাঃ আপনি আমার সাথে যে কথা বলতেসিলেন, ছেলে মেয়েদের নিয়ে কিসব করতে চান এসব নিয়ে যে বলতেসিলেন এসব নিয়ে রিসাত কথা বলবেন আপনার সাথে।

রঃ ঘুম কেমন হইসে?

হঃ মোটামুটি। (খুব অসুস্থ স্বরে কথা বলছেন। কথা বলার শক্তি বলতে গেলে একেবারেই নেই উনার)। ব্যথার অশুধ খাইলে ঘুম ভাল হয় আর ব্যথার যন্ত্রণায় ...

রঃ ব্যথা অনেক বেশি তাই না? অপোরেশনের কথা বলতেসিলেন না ডাক্তার আপাকে?

হঃ বলসিলাম। জীবনে বাঁচা মরার রিস্ক একবার নিয়ে দেখব। হয়ত বাঁচমু নয়তো মরমু। এরকম ধুঁকে ধুঁকে মরার থেকে একেবারে মরে যাওয়া ভালা।

রঃ আপনার মেয়ে কই এখন? শ্বশুর বাড়ি?

হঃ মেয়ের ১১ বছর বয়স। এখন বাসায় আছে। (আমার প্রশ্নটা একটু ভুল বুঝেছেন। আমি বুঝিয়েছিলাম উনার শ্বশুর বাড়িতে নাকি)

রঃ মেয়ের জন্য খারাপ লাগে?

এর মধ্যে হাসিনা আপার মা আসে। আমি উনাকে বসতে বলি।

রঃ আপনার মেয়ে না?

মাঃ একটাই মেয়ে বাবা।

রঃ কবে থেকে হইসে এটা?

হঃ ধরা পড়ছে মার্চে।

রঃ এ বছর?

মাঃ আরো আগে হইসে বাজান। এ ডাক্তারের কাছে ঐ ডাক্তারের কাছে এমনে এক বছর ঘুরসি। ধরবারই পারিনা রোগ। শেষে ল্যাবএইডের একজনে ঠিকানা দিসে। ল্যাবএইডে যাইয়া ধরা পড়সে। ৩ পয়েন্ট উইঠা গেসে।

রঃ কি পরীক্ষা করসিলেন?

হঃ এন্ডোস্কপি।সিটিস্ক্যান।

মাঃ কোনটা বাদ দেয়নাই। গলায় ঢুকত না। খালি ইবনে সিনায় গেসে, পিজিতে গেসে, তারপরে বাসার সামনের ডাক্তারের কাছে গেসে হে কইসে যে একটা এন্টিবায়োটিক দিলাম। খাইয়া দেখেন কি হয়। ঠিকানা দিচ্ছি এই জায়গায় যান। ল্যাব এইডের ঠিকানা দিচ্ছি এখানে যান। ঐ জায়গায় গিয়া ধরা পড়সে। কান্না করতে করতে বললেনঃ এর বাপ নাই। আমার আরেকটা পোলা আছে। পোলাটার হাতভাঙ্গা রতভাঙ্গা। মাইয়াটারে ছয়টা থেরাপি দিসি। ঢাকা মেডিকেলের থেকে ছয়টা থেরাপি দিছি। এর পর থেইকা পেট ফুইলা যায়। চারবার পানি আইসে।

রঃ এইযে পেট ফুইলা গেসিল এটা কোন মাসে।

মাঃ এইযে কয়দিন আগে। পানি ফালায় আবার ভইরা যায় পানি ফালায় আবার ভইরা যায়।

রঃ তখন কেমন লাগে যখন এরকম পেট ফুইলা যায়?

হঃ টান দেয় পেটের থেকে, ব্যথা। পানি আইসে ফালাই আইসে ফালাই।

রঃ আল্লাহরে ডাকেন না যখন খুব খারাপ লাগে?

মাঃ এর বাইচ্চা আছে, মাইয়া আছে পুলা আছে।

রঃ ওরা কই এখন?

মাঃ বাসায় থুইয়া আইসি দাদীর কাছে।

রঃ দাদী আসছিল এর মধ্যে?

মাঃ আইসিল আগে। মাইয়াটার কদিন ধইরা জ্বর। খালি বমি করে খালি বমি (হাসিনা আপাকে ইংগিত করে বললেন)কিচ্ছুই খায়না। পানিও খায়না। শরীরে প্রেশার থাকবে কেমনে। পানি খাইলেও বমি কইরা দেয়। একটু যদি ভাইতের পানি দেই একটুউউউ কইরা তাও বমি কইরা দেয়। কিচ্ছু দাড়ায়না।

হঃ কিচ্ছু খাইতে পারিনা।

রঃ কিছু খাইতে মন চায় উনার?

মাঃ খাওয়াইতে তো পারিনা।

রঃ প্রিয় কোন খাবার আছে?

মাঃ আগে খালি খাইসে ডাবের পানি। দুই বছর ধইরা এই অবস্থা হইসে বুঝছেন? আঙ্গুর ফল, মাল্টা চিইপ্পা দিসে এগুলি খাইয়া বাঁচ্ছে এইযে ভাত খায়না দুই বছর।

হঃ এইযে এখন বইতে পারিনা (উনাকে ওপাশ ফিরানোর চেষ্টা করছিলেন মা)। পিঠের ভিত্রে জ্বালা যন্ত্রণা, পেটের ভিতর জ্বালা যন্ত্রণা

মাঃ মাইয়াটার স্কুলের থেকে ৫০০০০/- দিসে। মাইয়াটারে যে স্কুলে ভর্তি করসে ডেমরায় ওইখান থেইকা।

হঃ গার্জিয়ানরা টাকা তুইলা তারপরে দিসে।

মাঃ ঐ টাকা দিয়া থেরাপি দিসিলাম।

রঃ ছেলে ক্লাস সেভেনে পড়ে না?

মাঃ এইবার টেন উঠবে।

রঃ আপনার বিয়ে কত সালে হইসিল?

মাঃ (মায়ের উত্তর মা দিচ্ছিল) বিয়ে হইসে ১৬/১৭ বছর হইসে।

রঃ আপনাদের গ্রামের বাড়ি কই?

মাঃ গোপাল্লঞ্জ।

রঃ ঢাকায় কেউ আছে আত্মীয়-স্বজন?
হঃ ঢাকায় আমরাই থাকতাম ঘর ভাড়া কইরা।

রঃ আপনার স্বামী কখন আসে (হাসপাতালে)?

মাঃ আসে। গাজীপুরে ফার্নিচারের কাজ করে। খাট টাত।

রঃ এখন আপনার কি ইচ্ছা করতেসে? আপনার মনের কথাটা কনতো আমারে। সবকিছু মিলাই দুনিয়াদারি চিন্তা ভাবনা।

হঃ দুনিয়াদারি বলতে আমারে যদি আল্লাহ অপোরেশন কইরা সুস্থ করাইয়া দিত। টাকা যদি কিছু যায়ও অপোরেশনটা কইরা ফেল্লতে পারতাম। ভাল হইয়া যাইতে পারতাম। এই একটাই ইচ্ছা। দ্বিতীয় ইচ্ছা, যদি না বাঁচি আমার ছেলেমেয়ের দেখাশোনা

মাঃ ছেলেমেয়েরে বাইচা থাকলে ইচ্ছা আছে জায়গাবাড়ি বানাই দেওয়ার। ছেলেমেয়েরে মানুষ করার ইচ্ছা। পড়ার খরচ চেয়ার খুব ইচ্ছা।

হাসিনা আপার মা উনার বোনের সাথে পরিচয় করিয়ে দেন আমার সাথে। তিনি হাসিনা আপার খালা হন।

মাঃ আমরা এতিম। আমারো বাপ মা নাই এরও নাই।

রঃ উনি কি আপনার ছোট মেয়ে?

মাঃ মেয়েটা ছোট পোলাটা বড়। পোলাটার ঐ সামর্থ্য নাই যে টাকা পয়সা দিয়া সাহায্য করব।

হঃ আমার চিকিতসার দরকার। যে চিকিতসায় আমি তাড়াতাড়ি শরীরে শান্তি পাব (সাফারিংস এর যে হিউম্যানিটারিয়ান কনসেপ্ট হারারি দেন তা এর সাথে লিঙ্ক করা যায়, সাফারিংস এর মধ্যে সমস্ত সৃষ্টিজগতকে এক করার একটা দর্শন আছে, প্যালিয়েটিভ কেয়ারের এই অন্যের সাফারিংস এ নিজেকে একাত্ম করার দর্শনের মধ্যে ভবিষ্যতের প্রাগ্রসর চিন্তার একটা হদিস থাকতে পারে। এই সাফারিংস এর দর্শনে সক্ষম শরীর, অক্ষম শরীর, সক্ষম এজেন্সি, অক্ষম এজেন্সি, প্রাণীকূল, প্রকৃতি সকলের স্বার্থ একীভূত করা যায়) মইরা গেলে গেলাম। বাইচা গেলে গেলাম। চিকিতসার দরকার। আমারে চিকিতসার ব্যবস্থা কইরা দেন।

রঃ কোন খোঁজ টোজ নিসেন এরকম অপোরেশন করা যাবে নাকি?

হঃ শরীর অনেক দুর্বল।

মাঃ এ খালি অপোরেশনের কথা বলে। যাতে শরীর ভাল হইয়া যাইত। থেরাপি ছয়টা দিয়া আর দেয়া হইলনা। মহাখালি থাইকা আইসি দশদিন। মহাখালির থেইকা পাঠাই দিসে এই জায়গায়। ঢাকা মেডিক্যালে যাইয়া সার্জারির ডাক্তারের সাথে যোগাযোগের কথা কইসে। এতো কি যোগাযোগ করমু, মইরাই যায়। পরে তাড়াতাড়ি এই জায়গায় নিয়া আইসি। এখানে ভাল আছে। একবার থাইকা গেসি ১৮ দিন, আরেকবার ১০ দিন। এখানে অনেক ভাল দেখে।

রঃ এখানে কোন জিনিসটা ভাল লাগে বেশি?

হঃ এই টাইম টাইম দেখে যায় এইটা বেশি ভাল। আচার ব্যবহার সবই ভাল

মাঃ সব ভাল।

হঃ কিন্তু স্থায়ী একটা সমাধান তো দিব (প্রত্যাশা)। যেন এই ব্যথা আর করবনা।

রঃ স্থায়ী সমাধানটা কি আসলে? স্থায়ী সমাধান

মা/খালাঃ ব্যথাটা যেন না করে।

রঃ যদি ধরেন অপোরেশন করল আপনার। ৫০/৫০ চান্স আপনার। তখন আপনি কি চিন্তা করসেন? ভাবছেন কিছু?কি চিন্তা কইরা অপোরেশন করতে চাইতেসেন?

হঃ একেবারে হয় ভাল হমু নাইলে খারাপ।

রঃ ব্যথাটা এত বেশি, না?

মাঃ এই ব্যথা এই একটু ভাল, আবার উঠে, এই ভাল আবার উঠে।

হঃ বারবার মরার থেকে একবার মরা ভাল না?

মাঃ বাজানরে আমার মেয়ে এরকম ছিলনা। কি যে সুন্দর স্বাস্থ্য টাস্থ্য ছিল বাজান। এই কয়দিনে কি হইয়া গেছে দেখেন। (মেয়ের আগের ছবি দেখাতে দেখাতে বলতেসে) ওর কিছু হইলে আমি মইরা যাবরে বাজান।

খালাঃ এই ছবিটা এক বছর আগে আমার বোনঝির বাসায় তুলসিল। দেখেন কি সুন্দর স্বাস্থ্য।

রঃ এক বছর আগের ছবি এটা? আপনি আপনার চেহারা দেখসেন এখন?

খালাঃ নিজে নিজে আয়না দেখতে চায়। এক স্যার আছে

রঃ আল্লাহর কাছে ইবাদত তো করতে পারতেসেন। মনে মনে জিকির করেন?

মাঃ সব ভুইলা গেসে তাও কোরান শরিফ পড়ছে।

হঃ আল্লাহরে আমারে একবারে নিয়া যাও নয় একবারে ভাল কইরা দাও। আর কিছু চাইনা আমি আর। ছেলেমেয়ের ভাগ্য আল্লাহ যা রাখসে তাই হইব।

রঃ আপনার ছোটবেলার কোন ইচ্ছা আছিল যেটা পূরণ হয়নাই?

হঃ ইচ্ছা ছিল নিজের একটা ঘরবাড়ি থাকব। নিজের একটা বাড়ি, ছোট একটা ঘর, ছোট একটা রুম, বেশি বড়লোক না।

রঃ আর ছেলেমেয়েরে নিয়ে কোন ইচ্ছা আছে?

হঃ এরকম তো সব মা বাপের থাকে।

মা খালাঃ ছেলেমেয়ে সুন্দর হইসে রঙ।

রঃ এখানে কেমনে আইসেন এই সেন্টারে? এখানে কে আসতে বলসে?

মাঃ এখানে নিজেরাই আইসি। আসছি, গেসি।

হঃ পেটের পানি ফালাইতে আইসিলাম।

মাঃ পেটে পানি আইসিল। পরে ডাক্তার কইসে এখানে আইতে।

রঃ এখানের ডাক্তারদের সাথে আলাপ হইসে?উনার অবস্থা নিয়ে? কি বলসে?

হঃ খালি ঘুরাই। পানিটা ফালাইব। চাইরদিন ধইরা ঘুরাইতেসে।

রঃ পানি ফালানোর মত অবস্থায় আছিলনা মনে হয়।তখন কি আপনার রাগ উঠছিল?

মাঃ বাজান যেমন রাইতে চিল্লাইসে সকালে চিল্লাইসে চির চির কইরা ব্যথা উঠে। আমরা হুশ জ্ঞান হারাইয়া ফেলসিলাম। পরে চিল্লানোর পরে আইয়া পানি ফালাইসে। ১০০০ ফালাইসে। ৫ লিটারের বোতলে ভইরা ফালাইসে।

রঃ ব্যথা উঠার সময় কিছু কয়?

মাঃ কান্দে, চিল্লায়।

রঃ মুখে কিছু বলেনা?

মাঃ আল্লাহরে ডাকে। আল্লাহরে তো ডাকে।

রঃ কি বলে?

মাঃ ও আল্লাহ আমারে মাফ কর। ও আল্লাহ আমারে নিয়া যাও। ও আল্লাহ আর কত কষ্ট দিবা? আল্লাহ তোমার পায়ে পড়ি আমারে রহমত কর।

হঃ আস্তে আস্তে ব্যথা বাড়তেসে।

রঃ এখন ব্যথা করতেসে?

পানি খেতে চাইলেন হাসিনা আপা। মা বলছেন ‘এইটুক পানি খায় খালি’

মাঃ ঠোঁট শুকাইয়া আসে।

রঃ আপনার স্বামী কবে আসছিল?

মাঃ আগে আইসে। এর মধ্যে আসেনাই। ৪ দিন আগে আইসিল।

রঃ এর মধ্যে কথা হইসে?

মাঃ হ, দুইদিন কথা হইসে। কথা কওয়ার পারেনাতো। একদিন কথা হইসে।

রঃ আপনারে কি কইসে?

মাঃ জিগায় খাইসেনি।

হাসিনা আপা চুপ হয়ে যান। বেশ খারাপ লাগছিল উনার। আমিও চুপ।

রঃ কোন কষ্ট আছে?

মাঃ ব্যথা উঠবার লাগসে।

হাসিনা আপাকে পানি খাওয়াই দিচ্ছিলেন মা। এরপর ব্যথা বাড়াতে এমন একটা পজিশনে হাসিনা আপাকে শোয়ালেন যেন ব্যথা একটু কম হয়।

মাঃ আল্লাহ্‌র কি বিচার বাজান! করোনা হইসে রোগও ধরা পড়সে। যখন ধরা পড়ল মহাখালীতে নিয়ে গেসিলাম করোনার সময়। বলে একমাস পরে আসেন একমাস পরে আসেন এর মধ্যে পেটে পানি আইসা গেসে। খাওয়া দাওয়া কিছু করাবার পারিনাই মাইয়া তখন মইরা যায়।

তখন আর কি করমু? ঢাকা মেডিকেলে আইসা থেরাপি দিসি। কোন কাজ হয়নাই থেরাপিতে। কয়বার যে নিয়া গেসি মহাখালীতে। পরে আর কি করা। থেরাপিতে বলে কাজ হয়নাই। পরে আবার নিয়া গেসি মহাখালী। ১০ দিন আছিল খাওয়া দেয়নাই। ডাক্তাররা ভাল বুঝে এইটা। সার্জারির ডাক্তার দেখাইতে কয়।দেখাইতে পারিনাই। আইসা পেট ফুইলা গেসে। আবার অসুস্থ।

রঃ এখন এমনি কি চেষ্টা করতসেন? কোন চিন্তা ভাবনা করসেন?

শোয়া থেকে একেবারে পাশ ফিরে আমার দিকে তাকালেন হাসিনা আপা।

হঃ অপোরেশন। অপোরেশন কইরা একবারে ফালাইয়া দিমু। এত বড় বড় অপোরেশন হয়না? আমার থেকেওতো বড় বড় অপোরেশন হয়। তাগোরটা হইলে আমারটা হইবনা কেন? কেন হবেনা আমারটা? আমি আল্লাহর কাছে কি অপরাধ করসি? আল্লাহ্‌র কাছে কি অপরাধ করলাম আমি?

রঃ যদি অপোরেশন করতে পারেন কোন মানত করসেন আল্লাহর কাছে?

হঃ হ্যাঁ। অনেক কিছু মানত করসি। আমি এক মাস রোজা রাখব যেন অপারেশন হয়া যায়, আমি ভাল হইয়া যাই। জান দিয়া দিব। অনেক কিছু করব।

মাঃ অনেকবার কোরান শরীফ পড়াইসি। তিন চারবার মিলাদ পড়াইসি। এতিমখানায় দিসি। আল্লাহ আমার হাসিনা যেন ভাল হয়। এই ক্যান্সার, টিউমার সব এক্কেবারে চইলা যাক আমি এক মাস রোজা রাখমু। তাহাজ্জ্যতের নামাজে কত কইরা কই দুই বছর ধইরা। আল্লাহ এমন জ্বার হইসে আমার কথা শোনেইনা। একটু যদি সুস্থ করত আমার মারে। একটু পানি খাইলে অসুস্থ হইয়া যায়। একটু কিছু গালে দিলেই খাপা লাগে। দুইটা বছর ধইরা ভাত খাইতে পারতেসেনা।

মা/খালাঃ পাকস্থইলিতেও এখন ঘা হইয়া গেসে। আগে খালি পেট ফুলত। এখন এইটা হয়।

হঃ ধইরা বসাইলে সমস্যা আছে?

উনি বসতে চাচ্ছিল শোয়া থেকে।

অনেক কষ্টে তাকে বসাচ্ছিল। খুব কষ্ট হচ্ছিল হাসিনা আপার।

মাঃ সারারাত এমনে বইসাই থাকে। চাচারা একটু খোঁজ নিতেও আসেনা। আমি যে কত কষ্টে বাপের বাড়ি থাইকা মানুষ করসি।

খালাঃ প্রথম যখন ইবনে সিনায় ধরা পড়ল তখন ডাক্তার জিজ্ঞেস করসে স্বামী কি করে। আমি কইলাম ফার্নিচারের কাজ করে। ডাক্তার কইল ‘ডরাবেন না’। আমি তারে জিগেস করলাম ‘কেন, বড় ধরণের কোন রোগ ধরা পড়ছে?’ তখন ডাক্তার কিছু অষুধ দিয়া কইল এগুলা খাইয়েন। তখন বাসায় নিয়া আইসা দেখি কিছু ঘুমের ওষুধ আর গ্যাস্ট্রিকের ওষুধ ছোট ছোট মাছের মত দিসে। একটা ডাক্তার কইসিল মাথা নষ্ট হইয়া গেসে আমার মেয়ের।

মাঃ এই ডাক্তাররাই এত্তবড় রোগ বানাইসে। এই রোগ যদি একবছর আগে ধরা পড়ত আমার হাসিনা ভাল হইয়া যাইত।

খালাঃ পিজিতে আইসা জানতে পারসি।

মাঃ দুই বছর হইয়া গেসে ৩ পয়েন্ট উইঠা গেসে। লাস্টে যাইয়া ধরা পড়সে। এর পরে মহাখালি লইয়া গেসি। করোনার ভিতরে। ডাক্তার ও ওইখানে দূরে বইয়া থাকে। আমরা এইখান থেকে কথা কই (দূরত্ব বুঝাচ্ছিলেন)। এক মাস পরে আনসে। আমার পোলা কানসে। ডাক্তারগোরে কইসে। আরো এক মাস। আর আপনেরা কন কিচ্ছু হবেনা এক মাস থাকসে থি পয়েন্ট উইঠা গেসে। বাসায় আসতে আসতে পেট ফুইলা গেসে। মহাখালি বাস স্ট্যান্ড থেইকা বাসায় আসতে আসতে পেট ফুইলা গেসে। এরপরে কোথায় কোথায় যাব। পরে কেমনে কেমনে ঢাকা মেডিক্যাল আইসা ৬টা থেরাপি দিলাম।

কান্না করতে করতে বললেন- রাইতে দিনে এমনেই বইসা থাকি। এইরকম কিছুক্ষণ বইসা থাকে আবার কিছুক্ষণ শোয়া লাগে। আবার কয় এই কাইত কর। আবার কয় ঐ কাইত কর। ঘুম নাই বাজান চোখে।

রঃ আপনিই কি থাকেন সবসময়?

মাঃ হ

রঃ স্বামী আসেনা?

মাঃ আ আ সে (একটু কেমন করে জানি বলছিলেন)। হে বাচ্চা কাচ্চা কাম সামলাইব নাকি এখানে আইব? কাম কইরা খায়তো।

রঃ উনি খরচ দিতাসে না?

মা; হ। মাইনসে বেশি দিসে। সব মাইনসে বেশি দিসে। বাসায় আইসা আইসা জিগাইসে ভাল আছে? মহিলারা বাসায় আইসা আইসা ২০০০, ৩০০০, ৫০০০, ৭০০০ কইরা দিসে।

রঃ কারা উনারা?

খালাঃ যে স্কুলে বাচ্চারা পড়ে বুঝছেন?

মাঃ ৫০০০/৬০০০/৮০০০ ও দিসে। খুব ভাল তারা। বাসায় আইসা মাঝেমধ্যে বাজারও কইরা দিয়া গেসে। তারাও কিন্তু ভাড়া থাকে। বাজার কইরা দিয়া গেসে। তারা মুখা কালা করেনাই। হাসিনার ব্যবহারে তারা তারে এত আদর করসে। কেমনে এরকম অসুখে এরকম হইয়া গেসে দেখলেনতো। দেখলে টেইলারির কাম কাজ কইরা মাইয়া পোলার পড়ালেখা জুগাইসে। টেইলারির মেশিন চালাইসে ঘরে বইসা বইসা। আমার হেই মাইয়া কি হইয়া গেসে। এখন আর কি করমু? বাজান! টাকাও শেষ। শুধু শুধু এ জায়গায় আইসা বইসা আসি। এখানে তো ক্যান্সারের চিকিতসা হয়না, সুস্থ হয়না। কি করমু চিন্তা কইরাও কুল পাইনা।

রঃ উনার বাবা কখন মারা গেসে?

খালাঃ মাইয়ার তিন মাসের সময় মারা গেসে।

মাঃ চিন্তা করেন আমি কত কষ্ট করসি এই দুইটা চাওয়াল নিয়া। লেখাপড়া করাইসি, মানুষ করসি। এমনে আল্লাহ আমারে কি করতাসে কি জানে। আমারে নিয়াই যাক আল্লাহ কি জানে। মাইনসের কাম করসি আমি। রাইতে ৪ টা সাড়ে ৪ টা বাজে উইঠা আমি মাইনসের কামে গেসি । আমার চাওয়াল দুইটা নিয়া আমি কাম করসি স্বামী নাই এমন অবস্থায় আমি মাইনসের কাম করসি বুঝছেন? এই দুইজনি মানুষ

করসি এই চাল মাইয়া। দুইটা চাল মাইয়া নিয়া এই মহাখালি ঢাকা কতখানে দৌড়াইসি ও আল্লাহ। একলাই দৌড়াইসি।

খালাঃ মহাখালি ভর্তি হইসে একলা।

মা/খালা দুজনে একসাথে খুব কান্না করছিল।

মাঃ ও আমার আপন বোন।

রঃ উনার পরিবার কই?

মাঃ ওর কিচ্ছু নাই বাজান। ওর ছাল মাইয়া স্বামী অর্থ সম্পত্তি ভিটা কিচ্ছু নাই। এই দুইটা ছাল মাইয়া আমাদের দুই বোনের, এই দুইটাই আমাদের অর্থ সম্পত্তি। পোলাটার করোনা হইসিল।বাজানরে মাথাটা ঠিক নাই। করোনা হইসিল আবার গলায় আলসার হইসিল।

রঃ এখন ভাল হইসে?

মাঃ এখন শ্বশুরে চেষ্টা করতেসে। ভাল হইতেসে। করোনা ভাল হইসে।

কপালের ভাগ্য।

হাসিনা আপা শুইতে চাইতেসিল তখন।

মাঃ আগেতো ডাকডুক দিসে। এখন ডাকও দেয়না।

মা/খালাঃ যখন ব্যথা পায় খুব ভয় পায়।

টাইট করে লাগাই দিতে বলে কোলেস্টেরল ব্যাগ।

খালাঃ আহারে সব জায়গায় খালি হাড্ডি গুড্ডি।

মা ডাকছে হাসিনাকে। কোন সাড়া শব্দ করছিলনা।

মাঃ এর গা প্রত্যেক দিন স্যাভলন দিয়া তিনবেলা করে মুছাইসি।

হাসিনা আপার শরীর খুব খারাপ লাগতেসিল। আমি জিজ্ঞেস করলাম ডাক্তারকে ডাকব নাকি।

মাঃ কত শখ করে মেয়ের নাম দিসিলাম হাসিনা। মজিবরের মেয়ের হাসিনা (আমাদের প্রধানমন্ত্রী)। ছেলের নাম রবিউল।

রঃ করোনার সময় খুব সমস্যা হইসিল না?

হাঃ হু।

মাঃ করোনার জ্বালায়ই তো ডাক্তাররা ভর্তি রাখলনা। ডাক্তাররা চেইত্তা যায়। মহাখালির ডাক্তাররা চেইত্তা যায়। আমরা এইযে নিচ্ছিনা। হেরা কইসে নল দিয়া খাদ্য খাইতে। পরীক্ষা নিরীক্ষা দিসে। ও এর ভিতরে যেদিন পরীক্ষা করামু ঐদিন কয় ডাক্তার আসবনা। আইসে আইসা দেখে কি নল কাইট্টা গেসে। ডাক্তাররা আমাগোর সাথে অবহেলা করল। বুজছেন? এতকিছু করব কইয়া হঠাত কইরা নল কাইট্টা দিল। দুই গালে তাদের দুয়া পরুক। মহাখালির ডাক্তাররাই আমগো সাথে ইয়ে করল। হঠাত নল কাইটা দিল ক্যান। এইটা চিন্তা ভাবনা করনের আছে। তারা কত পরীক্ষা দিল, রক্ত পরিক্ষা দিল এক্সরে দিল কিন্তু কিছু করলনা, আসলনা। কি করল কিছু বুঝবার পারলাম না। ডাকতারগো হে জাগাত কত কত রোগী কত হাজার হাজার রোগী। কত ভাল ভাল রোগী। এইসব রোগী রাইখা এই জটিল রোগী ফেরত দিল ক্যান? হে কয়কি ঢাকা মেডিকেলে নিয়া যাও সার্জারির ডাক্তার দেখাও।

রঃ কোন মাসে হইসে এই ঘটনা।

মাঃ এইতো গেসে মাসে। একমাসও হয়নাই। হে সময় ও (হাসিনা) তক্কও করসে ডাকতারের লগে। হে সময় ও কথা কইতে পারে। হে কইসে এত জটিল জটিল রোগীর অপোরেশন হয় আমার হইবনা কিল্লাইগা। ডাক্তারের সাথে তক্ক করসে শুইয়া শুইয়া।

রঃ ডাক্তার তখন কি কইসে।

হঃ কিকইব? পরীক্ষা নিরীক্ষা দিসে। এ সময় ১৪/১৫ জন ডাক্তার আইসে। কিচ্ছুতো করাইলনা। শেষমেশ এ বিদায় দিয়া দিল। ডাক্তাররাই আমার মাইয়াটারে অবহেলা কইরা এরকম করসে। করোনার ভিতরে। কইল যে একমাস পরে আইসেন। পরে যখন একমাস পরে গেসি ১৪/১৫ জন ডাক্তার আইসে। তখন ডাক্তারে কয় আপনারা এতদিনে কি করসিলেন? তখন একটা বেটি ওই ডাক্তাররে কয় ‘আনসিল, আমরা রাখিনাই। পাঠাইয়া দিসি। ’ বুজছেন? তাগো ভিতর তারা ঠেলাঠেলি লাইজ্ঞা গেসে। এই ডাক্তাররা আমার রোগী মাইরা ফেলসে। ম্যাডামরা স্বীকার গেসে। কয় যে আনসিল আমরা রাখিনাই। মহাখালির ডাক্তার আর ইবনে সিনার ডাক্তার আমার মাইয়ারে মারার পথ নিসে। ইবনে সিনায় নিয়া কিচ্ছু হয়নাই। খালি ঘুমের ওষুধ দিয়া থুইসে। এরা কয়নাই যে অমুক একটা প্রাইভেটে নিয়া যাও হেন কর তেন কর। কিচ্ছু কয়নাই। তখন করোনাও আসিলনা।

রঃ খরচ যোগাড় করতে সমস্যা হইসিল?প্রাইভেটে যখন গেসিলেন?

খালাঃ তারা ৫০০০০ চাইসিল। ৮ টা কেমোতে দুই লাখ।

রঃ পারসিলেন?

মা/খালাঃ পারলাম না দেইখাই তো এখানে আইলাম।

উনারা এখানে ৭ দিন ধরে আছে।

মাঃ ডাক্তাররা রাখতে চেষ্টা করতেসে। বাসায় সবসময় মুইছা ধুইয়া স্যাভলন দিয়া রাখতাম। কলসি ভইরা পানি গরম কইরা গামছা দিয়া ছ্যাক দিয়া দিতাম। পেটে ছ্যাক দিতাম

হাসিনা আপা ব্যথায় গোঙাচ্ছিল তখন।

মাঃ পেট ব্যথার জন্য কথা কইতে পারেনা

হাসিনা আপা কাত করে রাখতে বলে মাকে।

রঃ খালা , আমি তাইলে উঠি আজকের মত। উনার মনে হয় খারাপ লাগতাসে।