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Case study describing access to palliative care in Pakistan

by

Salma Amin Rattani

A thesis submitted in partial fulfillment of the requirements for the degree of

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Faculty of Nursing
University of Alberta

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Abstract

Around the world, cancer is a leading cause of death and the burden of cancer is expected to increase in low-and middle-income countries (LMICs), where 82% of the world's population resides. In these countries, which include Pakistan, aspects of the culture and traditions, inaccessibility to diagnostic and treatment facilities impede access to palliative care. In many cases people do not reach treatment facilities until they are at the stage when the person is at the end-of-life and is dying. This paints the picture of cancer as a deadly disease and as soon as it is diagnosed nothing can be done but to mourn. Little is understood about people's experiences accessing palliative care in Pakistan.

This study followed Yin's methodology of case study research to describe how people accessed palliative care through Bait-ul-Sukoon Cancer Hospital and Hospice, the research setting (and bounded case) selected for this study. Theoretical propositions that guided the research were derived from the literature and from my professional experience. Data collection occurred through unstructured observations, interviews of patients, family members and the health care provider, physical artifacts, and through my reflections. Four patients, three family members and five healthcare providers were interviewed. Data analysis occurred simultaneously with data gathering and involved a reflexive analysis of the data. This study was guided by the theoretical propositions, the study objectives, and research questions which were derived from these propositions. Through this analysis process, two main themes were developed with subthemes to describe the case. I was also attentive to identify the rival cases, data that is contrary to the propositions. As the analysis progressed, linkages between the data were noted to see where the data were converging and diverging.

The findings have described the suffering of people due in a large part to the late diagnosis of cancer. However, late diagnosis is also related to cultural beliefs, the social stigma of having cancer, the financial (and social) burden of seeking treatment, lack of education about cancer prevention and detection, healthcare system inadequacies and corruption, and healthcare providers' knowledge deficits. Poverty underlies most of the suffering and is largely the reason for late diagnosis. Participants suggested that policy-level change was needed to meet palliative care needs, and enhance early diagnosis. Policy level change for poverty alleviation would improve the determinants causing obstructions in accessing palliative care and improve access to pain and symptom management.

This research underscores that at present, military and defense funds are the focus in the budget priorities in Pakistan. This deprives the population of fulfilling the need for social development and the health of the people in the country, which ultimately ruins the health and quality of life of the individuals. As a result, individuals feel emotionally distressed at the prospects of little or no betterment of their lives, their children's lives, and the generations that follow. These findings highlight the need for policy change by involving the stakeholders from social sectors, health, and education at the country level and through collaboration with the World Health Organization. Dissemination of these research findings, focusing on a public health approach and providing universal health coverage to all, is critically important for improving access to palliative care in Pakistan.

This study identifies a clear need to educate the healthcare providers about palliative care. Therefore, it is recommended that in LMICs palliative care should be included in medical and nursing curricula. The findings of this study suggest that nurses should work within the scope of their practice. This is also needed for their own safety and for the safety of their patients. This

requires close monitoring and supervision by the statutory bodies like Pakistan Nursing Council. There are implications for policy change to provide universal access to health and to achieve the sustainable development goals. Corruption is identified as one of the major hurdles in accessing health must be controlled to start with and then be eradicated.

Key words: Palliative care, LMICs, Cancer, Pakistan, Nursing

Preface

This thesis is an original work by Salma Amin Rattani. The research project, of which this thesis is a part, received ethics approval from the University of Albera Research Ethics Board, Project Name “Case study describing access to palliative care in Pakistan” No. Pro00079346

Dedication

I dedicate this work to my mother, Zarina Amir Ali Jiva, who inspired for me to attain the education which paved the way for me to reach my current level of education. I also honor Dr. Grace P. Miller, a Director Nursing Services, Aga Khan Univeristy Hospital, who retained me when, due to extreme morning sickness, I handed her my resignation. Neither of them are with us today and I pray their souls may rest in eternal peace.

I am grateful for Amin Akbar Ali, my husband, who backed me so I could continue my profession and education. The support he provides I cannot define in a few words. My love and dedication also goes to my son, Sani, and daughter, Sarwat. We three continued our studies together while I was in my Masters program and they were in school. Now we three are all university students. Shukkur Allah.

Acknowledgements

To reach this stage of writing this dissertation is not solely an individual or independent process. It is possible only through the support of so many individuals and divine support. I consciously mention that all my support starts with the presence of God, 'Allah', the most merciful, the most beneficent. I believe nothing can be achieved without His support not only for a human being but for the entire Universe. So I say 'Thank you God' 'Shukkur Allah'.

I live in a country where getting an education is difficult and continuing until the doctorate level is a miracle especially in the era when I entered nursing. There are a number of contributors that made this happen for me. In my country, Pakistan, the Aga Khan University enrolled its first nursing students in 1980 and in less than four decades the University has made major contributions to change the face of nursing in the country. The University has invested in my development. I received scholarships for my RN, RM Diploma; BScN; MScN degree; and my PhD program. Insha Allah. Some scholarships for my education in the PhD program also came from the University of Alberta and I feel delighted to mention them here. I was the recipient of: the Doctoral Recruitment Scholarship (2012- 2015); the Dr. Christine Newburn Cook International Graduate Award in Nursing (2015); the Alice R. Thomas & Bryan Campbell-Hope International Graduate Scholarship in Nursing Award (2017); and the Dr. Herman and Elly de Jongh Graduate Scholarship Award (2018).

To be enrolled in a PhD program required that the applicant identify a supervisor who was ready to invest his/her intellect in the student. It was Dr. Zeenat Khanukanji, an alumna the University of Alberta and a dear colleague who connected me with Dr. Brenda Cameron and I feel blessed for her accepting my request and staying with me to this date. Thank you Dr. Brenda. Thank you Zeenat.

As this acknowledgement is mainly for my dissertation I start with my research participants who shared their real life stories as they were living them. Hearing these stories, witnessing and reflecting on these gave me goosebumps. Also, to listen was to travel into an emotional turmoil with their stories. But the strength of these stories gives me hope as I now must translate this knowledge so that it benefits the society. I am hopeful that I will be able to do this well.

I share the joy of this research with my supervisors, Dr. Brenda Cameron and Dr. Sherry Dahlke. I thank them for investing themselves in me and holding me throughout the process of my research. I am also obliged to Dr. Susan Duncan, for providing her supervision and guidance along with Drs. Cameron and Dahlke.

The conceptualization of my research started with my independent inquiry course. This was a valuable component the University of Alberta curriculum. In this course my research topic/focus evolved with the facilitation from Dr. Brenda Cameron and Dr. Anna Santos Salas. The refinement of the proposal occurred with helpful feedback from my candidacy committee: Chair Dr. Solina Richter and the examiners Dr. Joanne Olson and Dr. Anna Satos Salas, along with my supervisors Drs. Cameron and Dahlke. It has been a privilege to work with all of you. Thank you all.

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Chapter One: An Overview

In the 1950s, cancer care focused mainly on the potential for curative treatment (Clark, 2007), and a person dying from cancer was abandoned by physicians who told them to go home as there was nothing more that could be done (Clark, 2007; Odagiri et al., 2018). Cicely Saunders, of Brazil, pioneered in drawing attention to the end-of-life care needs of patients with advanced malignant disease (Clark, 2007). Thus, the concern about the medical neglect of patients dying from cancer generated the beginning of palliative care (Corrêa, Mazuko, & Clark, 2019; Parkes, 2018). Since the late 1960s, palliative care and hospices have developed rapidly (Goh & Lee, 2018) and in the 1970s palliative care came to be synonymous with the physical, social, psychological, and spiritual support of patients with life-limiting illness (Clark, 2007; Parkes, 2018; World Health Organization, 2017a). The World Health Organization (WHO) identified that in most parts of the world, the majority of cancer patients present with advanced disease and for them, the only realistic treatment option is pain relief and palliative care. Thus, in 1986, the WHO, developed a three-step ladder for cancer pain relief in adults, as seen in Appendix A (WHO, 1996a; WHO, 2018a). This three-step approach of administering the right drug at the right dose at the right time is inexpensive and 80-90% effective (WHO, 2018a). In order to maintain freedom from pain, the drug should be given “by the clock”, that is every 3-6 hours, rather than “on-demand” (WHO, 2018a). In 2002, the WHO, in its book titled National Cancer Control Programmes Policies and Managerial Guidelines, presents the quality of life dimension of palliative care (please see Appendix B).

Siegel, Miller, and Jemal (2016) describe cancer as a major public health problem worldwide and in 2018 the cancer burden rose to 18.1 million new cases and 9.6 million cancer deaths (WHO. International Agency for Research on Cancer, 2018). Globally, about 1 in 6 deaths

is due to cancer (WHO, 2018b). However, in regions with more developing countries, the proportion of cancer deaths is higher than the incidence: in Asia, deaths are calculated at 57.3% whereas new cases are 48.4%. Africa's numbers are 7.3% for cancer deaths and 5.8% for new cases (Becze, 2018). In developing countries, also referred as low-and middle-income countries (Riley, 2015), an absence of screening and prevention programs, combined with poor access to specialist oncological training, radiotherapy and essential medicines, paints a challenging picture for the management of cancer (Weller, Mackenzie, & Knott, 2017). Hence, in these countries, a multifaceted approach and the establishment of targets set by the World Health Organization and the United Nations are the vital steps towards improving cancer control (Weller et al., 2017) and prevention.

The World Health Organization recognizes palliative care as a human right (Brennan, Lohman, & Gwyther, 2019; WHO, 2016a) and advocates palliative care to be initiated early in the course of an illness (WHO, 2017b). Although palliative care improves the quality of life for patients and their families (National Cancer Institute, 2010; WHO, 2017c), palliative care is not accessible to all who are in need (Hunt, Bristowe, Chidyamatara, & Harding, 2019; Wolf, White, Epstein, & Enfield, 2019). Only 1 in 10 people in need of palliative care is currently receiving it. Although most palliative care is provided in high-income countries, almost 80% of the global need is in low- and middle-income countries (De Lima, 2015).

The social determinants of health help to explain disparities in accessing healthcare. These disparities arise from a complex interplay of economic, social, and cultural factors, which include elements such as income, education, and health insurance coverage (Freeman & Rodriguez, 2011). Socioeconomic status (SES) influences the risk of disease and access to safe housing, secure neighborhoods, a healthy environment, social support, good nutrition, and

physical activity (Marmot, Friel, Bell, Houweling, Taylor, & Commission on Social Determinants of Health, 2008; Raphael, 2011; Wilkinson & Marmot, 2003). Additionally, SES affects an individual's access to appropriate preventive services, early detection and diagnosis, treatment, and palliative care (Marmot, Allen, Bell, Bloomer, & Goldblatt, 2012; Masood et al., 2018; Smedley, Stith, & Nelson, 2003). In general, the lower an individual's socioeconomic position, the greater his or her health challenges (Marmot et al., 2008; Ullah, Malik, & Hassan, 2019; WHO, 2016b), because people with low incomes generally are more likely to be exposed to avoidable risk factors, such as environmental carcinogens, tobacco use, alcohol abuse, and infectious agents. Also, these people have less access to health services and less education and less political influence that can empower them to make decisions to protect and improve their own health (Vaalavuo, 2016; WHO, 2007).

In low-and middle-income countries (LMICs) palliative care is not accessible to all who need it (Goh & Lee, 2018; Knaul et al., 2018; Pain & Policy Studies Group, 2013; WHO, 2017c). The options for the early detection of cancer and treatment are limited. This results in a late diagnosis of cancer (American Association for Cancer Research, 2015, Hannon et al., 2016; Pain & Policy Studies Group, 2013; Singh & Harding, 2015). Additionally, individuals' financial condition and their cultural and religious beliefs lead to late diagnosis of cancer (Azami-Aghdash, Ghojzadeh, Aghaei, Naghavi-Behzad, & Asgarlo, 2015). Other factors that obstruct access to palliative care include regulatory authorities' restrictions on opioids (Pain & Policy Studies Group, 2013; WHO, 2017c) and an inadequate system for law enforcement which leads to illicit production, consumption, and trafficking of opioids (Pettus, 2013). Access is also obstructed due to healthcare professionals' lack of awareness and training about palliative care (Goh & Lee, 2018) and also due to a dearth of research focusing on palliative care in LMICs

(Bridges et al., 2011; Hannon et al., 2016; McCarthy & Brajovic, 2009; Pastrana et al., 2010; Punjwani et al., 2015; Qidwai, 2012). Therefore, in order to understand and improve healthcare and social systems, research is needed and must be an integral component of healthcare (Hannon et al., 2016). In my research, I aimed to understand the experiences of access to palliative care in Pakistan. In the current World Bank economic classification, Pakistan is a lower-middle income country (The World Bank Group. (n.d.a).

Pakistan: An Overview

On August 25, 2017, Pakistan's sixth census findings were reported and the country was listed as the world's fifth-most-populous nation reaching 207.7 million, an increase from the fifth census, in 1998, of 130 million (Rana, 2017). The population is predicted to reach near 210 million by 2020 and get to 245 million by 2030 (World Population Review, 2019b). The existing environment does not have the capacity to sustain such a large population and also provide a good quality of life. The literacy rate remains low at 58% (Mustafa, Batool, & Raza, 2019). Ullah et al. (2019) describe that according to fundamental human capital theory, individuals' education and health are the basic components for increasing productivity and economic growth. However, in the Human Development Index, Pakistan is ranked 147th (Hussain, 2017) with close to 30% of the population living below the poverty line (Hussain, 2017; Ullah et al., 2019). In 1995 Pakistan spent 0.7% of gross domestic product (GDP)¹ on health and in 2014 that number increased to only 0.9% of GDP (The World Bank Group, 2017a), which is less than 1% whereas, the WHO suggests developing countries spend 5% of their GDP on health (Ullah et al., 2019).

¹ The GDP is used the total market value of all the goods, products and services that are produced within a country in a specific duration of time. GDP is used to measure the size of an economy and overall growth or decline in the economy of a nation.

As my study describes access to palliative care to patients with cancer, knowing the prevalence of cancer in Pakistan is important. However, in Pakistan, there is no national cancer-based population registry (Ashraf & Jamil, 2016; Khaliq, Mahmood, Sarfraz, Gondal, & Zaman, 2019; Qureshi et al., 2016). Therefore, the exact burden of cancer is not known; rather, it is estimated based on the data received from the International Agency for Research on Cancer Registry (IARC) (Ashraf & Jamil, 2016). The IARC has recognized the Karachi cancer registry and Punjab Cancer Registry (Badar, 2018). To understand these two registries, knowing the background about the administrative units of Pakistan is important. Administrative units of Pakistan consist of four provinces; Balochistan, Khyber Pakhtunkhwa, Punjab, and Sindh. Pakistan also has two autonomous territories; one is Azad Jammu and Kashmir, and the other is Gilgit-Baltistan. The country also has one federal territory; Islamabad, the capital territory of Pakistan. Each province and territory is subdivided into divisions, which are further subdivided into districts. These districts subdivide into tehsil or taluka which are further subdivided into union councils. In the province of Sindh is the Karachi Cancer Registry. Established in 1995 Karachi Cancer Registry was the first regional registry of the Karachi South district, which is one of the six districts in Karachi. However, after the demise of Dr. Yasmin Bhargri in 2012, the founder of the Karachi Cancer Registry, the registry stopped working (Badar, 2018; Qureshi et al., 2016). Badar (2018) states that the professionals in Karachi are attempting to set-up a cancer registry for the city of Karachi. Describing the Punjab Cancer Registry, Badar asserts that with the support of the Shaukat Khanum Memorial Trust and through a collaborative effort in Lahore, the capital of the Pakistani province Punjab, the Punjab Cancer Registry was established in 2005. In the Punjab Cancer Registry, in accordance with the minimum data items required for cancer registries, are captured on a prescribed data collection form and extensive reports on cancer

incidence in the district of Lahore have been published (Badar, 2018). Lahore is Pakistan's second-most populous city after Karachi. Masood et al., (2018) conducted research to generate trends and patterns of most common male and female cancers from 1984 to 2014 for the city of Lahore. Masood et al. (2018) report that the risk of cancer is continuously increasing among males and females. Overall, in Lahore, lymphomas are the most common type of cancer in males and breast cancer is the most common type in females and these cancers are almost the highest rates in the Asian Pacific region. Masood et al. (2018) add that the incidence of head and neck, brain, and lung cancers, as well as leukemia, have rapidly increased among males, whereas, ovarian, cervix, head and neck cancers and lymphomas have become more common among females.

Qureshi et al. (2016) describe cancer patterns in all districts in Karachi. Qureshi et al. (2016) add that these are the first results from 2010 - 2015 which they present from the data that they collect from the pathology based cancer registry of the largest government-run diagnostic and reference center of Karachi. A total of 13,508 cancers were diagnosed. Of these 5,665 were males and 7843 were females. Qureshi et al. (2016) report that Karachi has the highest incidence of cancers of breast, lip and oral cavity, esophagus and larynx in females and cancer of the lip and oral cavity and larynx in males compared to any of the Asian populations. Highlighting the importance of cancer patterns in Karachi, Qureshi et al. (2016) describe that Karachi is the largest city in Pakistan. In 2016, Karachi had an estimated population of more than 16 million people, which makes it the 7th largest urban populated city in the world (Rana, 2015; World Population Review, 2019a). Describing the population data of Karachi, Qureshi et al. (2016) states that the population in Karachi is diverse in terms of religious and ethnic background. Therefore, Karachi can be truly considered as a representative of the Pakistani population and

thus, cancer statistics from Karachi potentially reflect the national-level picture, becoming even more relevant in the absence of a national level cancer registration process (Qureshi et al., 2016).

Need of Palliative Care Research

In cancer care, palliative care is an integral component but in Pakistan, it competes with the military, health, and developmental issues. This makes palliative care a low priority issue (Salim, 2017). In 2002, the national cancer plan was initiated but its progress is very slow. In the country, the rates of cancer incidence are rising (Salim, 2017) and in Pakistan, like other LMICs, in most cases, cancer is diagnosed at a late stage (Hannon et al., 2016). Breaking the news of the incurability of cancer is catastrophic for patients and family members resulting in an appalling picture of terminally ill cancer patients (Salim, 2017). My research aimed to examine how the experiences of access to palliative care are described by patients, their family members and healthcare providers at Bait- ul-Sukoon Cancer Hospital which is located in Karachi, Pakistan. The research questions were: How do study participants describe their experience of barriers and facilitators to accessing palliative care?

- 1) How does the Bait- ul-Sukoon Cancer Hospital contribute to the facilitation of access to palliative care?
- 2) How do an individual's social determinants of health influence access to palliative care?

Methodology

I used a descriptive case study following Yin's (2014) methodology. Yin defines a case study as an empirical inquiry that investigates a "case" in depth and within its real-world context (2014, p. 16). In the case study, data is collected through multiple methods, and theoretical propositions are used to guide the data collection and analysis (Yin, 2014). Yin asserts that case

study strategies are appropriate to study complex multivariate conditions and not just isolated variables (Yin, 2014). Case studies are flexible and can be used for many purposes: exploring new areas, describing complex events of interventions and explaining complex phenomena (Yin, 2014).

In this study there are many complex issues related to palliative care, such as culture, late diagnosis, and limited access to pain control, to name a few. Case study research methodology helped to unveil the complexities of palliative care in Pakistan. This case study is guided by a number of propositions rooted in literature and some in personal experience (Baxter & Jack, 2008). These are (1) social determinants of health influencing access to palliative care (Jayasinghe, 2015). Individuals may be unwilling to get treatment because they do not want to use their family's resources (financial as well as time) for themselves if access to care depends on the ability to pay. Cultural challenges may exist in terms of a person's knowledge of his/her diagnosis. Individuals may first approach traditional healers and use alternative therapy and then these individuals come to hospitals for treatment (Campbell & Amin, 2014). This results in late diagnosis and treatment (Hannon et al., 2016). (2) Cancer pain management is not adequate as opioids are inaccessible in part because cancer pain is perceived as part of the disease and in part because access to opioids is obstructed by strict regulations and controls in Pakistan (Lebaron, Beck, Maurer, Black, & Palat, 2014). Access to opioids is also dependent on the income status; those with high income have access to opioids, while those with low income do not and thus they suffer (Krakauer et al., 2015); (3) Healthcare providers² lack palliative care education. This

² Healthcare providers referred by these authors are all those who have direct contact with patients. These healthcare providers are nurses, doctors and allied healthcare staff (Nevin, Hynes, & Smith, 2020).

influences cancer care and symptom management (Hannon et al., 2016; Khan, 2012; Lebaron et al., 2014; Pastrana et al., 2010; Punjwani et al., 2015; Stjernswärd, 2007; Yusuf, 2013); 4).

Policy level change is required for improving access to palliative care. The WHO and researchers recommend that a public health strategy to address the issue of palliative care (Callaway, Connor, & Foley, 2018; Dempers & Gott, 2017; Frieden, Myers, Krauskopf, & Farley, 2008; Hannon et al., 2016; Larjow, Papavasiliou, Payne, Scholten, & Radbruch, 2016; Lucas, 2002; Sepúlveda, Marlin, Yoshida, & Ullrich, 2002; Stjernswärd, 2007; Stjernswärd, Colleau, & Ventafridda, 1996; Stjernswärd, Foley, & Ferris, 2007; WHO, 1996b). These propositions are based on the literature review which is cited in Table 1, presented in Chapter Two.

Conclusion

Around the world, cancer is a leading cause of death and the burden of cancer is expected to increase in low-and middle-income countries (LMICs), where 82% of the world's population resides (Torre et al., 2015). These statistics indicate the high need for access to diagnostic cancer care and palliative care in these LMICs, one of which is Pakistan. In this study, I aimed to understand the experiences of access to palliative care in Pakistan. The study is described in greater detail in the literature and methodology chapters.

Chapter Two: Literature Review

An integrative literature review process outlined by Whittemore and Knafl (2005) was used to search literature as I was considering case study research as a methodology to investigate access to palliative care. This chapter is based on a review of the literature accessed through the University of Alberta Libraries. The databases selected for this review were the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Psychological Information Database (PsycINFO), PubMed, the Medical Literature Analysis and Retrieval System Online (MEDLINE), Web of Science, Scopus, and Journal Storage (JSTOR). The search was not limited to any particular years of publication but to the key terms: palliative care, palliative care providers, patients with cancer, low-and- middle-income countries (LMICs), and developing countries; and a phrase, palliative care in low-and middle-income countries. The search located 931 articles that were reviewed to get an idea of the general-purpose and content of the article (Mongan-Rallis, 2014). The process of data reduction included multiple phases. In the first phase articles which were related to the pediatric population; diseases other than cancer; countries other than the countries in LMICs group of countries, and articles which were not full-text articles were excluded. Thus, the number was then reduced to 248 articles. These articles were downloaded, and saved on a computer for thematic analysis and writing a review of the literature. Literature from the World Health Organization (WHO) was added to include a global policy context. However, as my doctoral study progressed, I refreshed and upgraded my literature and I cite it throughout this dissertation. In this chapter, I present the historical background for palliative care, a description of low-and middle-income countries, need for palliative care, public health approach to palliative care, barriers (culture and traditions) in

accessing palliative care, inaccessibility to diagnosis, treatment and pain control, and lack of palliative care research.

Historical Background of Palliative Care

Palliative care is situated in the concept of hospice (Sheehan, & Forman, 1996) which in ancient times was referred to as a place for shelter and rest for the weary and ill travelers on a long journey (Clark, 2007; Clark, 2017; National Hospice and Palliative Care Organization, 2016). In the 19th century, hospice was identified as a place for the dying (National Hospice and Palliative Care Organization, 2016), and the place was provided with dedicated nursing care (St Christopher's, 2017). In 1948 Cicely Saunders, a British nurse, began her work with the terminally ill (Saunders, 2001a; Saunders, 2001b) and eventually created the first modern hospice named St. Christopher's Hospice in a residential suburb of London in 1967. St. Christopher's was committed to education, research and excellence in clinical care (Clark, 2007; Meghani, 2004; St Christopher's, 2017). In the late 1990s, the British government built a cancer care facility called Cancer Star which extended palliative care as a national strategy for end-of-life care (Clark, 2007).

The Canadian surgeon Balfour Mount introduced the term "palliative care" in 1975 to replace "hospice" which he felt should be avoided because of the poor reputation associated with hospices as it was for people who were dying of cancer. These people could not be admitted to the hospitals as the hospitals were geared to aggressive therapy and prolongation of life, and they did not offer a good milieu for dying. Also, a person was not necessarily better off at home if he was alone or was to be surrounded by an anxious, grieving family ill-prepared to give him proper care (Holden, 1976). Clark (2007) asserts that in 1976 the First International Congress on the Care of the Terminally ill was held in Montreal, Quebec, Canada; thereafter Balfour Mount and

colleagues continued organizing it every 2 years. In 1980 the International Hospice Institute was formed, which, in 1999, became the International Association for Hospice and Palliative Care (Clark, 2007). In 2000 the Latin American Association of Palliative Care was created and in 2001 the Asia Pacific Hospice Palliative Care Network was founded, representing 14 countries. In 2002 the United Kingdom Forum for Hospice and Palliative Care become operational throughout the world (Clark, 2007). The forum aims to coordinate the work of relevant groups in the United Kingdom, to support education, to provide information, and to raise funds. Finally, in 2003, the African Association for Palliative Care was founded, seeking to represent all palliative care interests across the continent (Clark, 2007). Thus, Mount's vision of palliative care as a comprehensive hospital-based palliative care service which includes an in-patient ward, consultation service, home care program, and bereavement support service combined with research and teaching was considered as a way forward (Brooksbank, 2009; Lynch, Dahlin, Hultman, & Coakley, 2011).

Worldwide palliative care services have grown and they have their own cultural and health care frameworks. In some countries the term hospice and palliative care services are used interchangeably, others describe different types of services. For example, in the United Kingdom in the 1980s there was a rapid growth of in-patient hospices, home care services, and daycare units. In the hospital care setting, consultation services were provided by multidisciplinary teams and by 1987 palliative medicine was recognized as a specialty (Brooksbank, 2009; Higginson, 2005). In the United States of America, from 1989 onwards, nurses were offered palliative care specialization courses. Diplomas, undergraduate, and postgraduate degrees were awarded upon completion (Lugton & Mclytyre, 2005). In the 1990s the United States of America, the United Kingdom, Canada, Australia and New Zealand introduced cancer control plans and recognized

that palliative care principles are much more broadly applicable. Subsequently, in 2002, the WHO altered its definition of palliative care and emphasized the importance of early and active intervention in conjunction with ongoing anti-cancer treatment (Sepúlveda et al., 2002). The WHO described palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO, 2017a).

Moving from a place for weary and ill travelers in ancient times (Clark, 2007; National Hospice and Palliative Care Organization, 2016) to a place for the dying in the 19th century (National Hospice and Palliative Care Organization, 2016), palliative care in the present time has expanded beyond cancer to all chronic and life-threatening illnesses (Hannon et al., 2016; WHO, 2017a). The expansion of palliative care services also includes prevention, control, and early detection and treatment of diseases. All these components are enclosed in the public health model of palliative care (Bhurgri, 2004; Fitzmaurice, 2017; Hannon et al., 2016; Sallnow, Richardson, Murray & Kellehear, 2016; Sepúlveda et al., 2002; World Health Organization, 2017b).

Next, I move to a description of low-and middle-income countries. This description is needed because literature, population health, and practice indicate that LMICs have limited health funds required to improve the accessibility to health. Also, in LMICs traditional healers and cultural practice influencing access to palliative care. I elaborate on it and cite the literature as I move forward in this chapter.

Description of Low-and Middle-Income Countries

The World Bank Group (n.d.b) classifies countries by geographic region, by income group, and by the operational lending categories. Among these three, two; by income group, and by geographic region are defined here as they are related to the description of my research. By region countries are into seven regions. These are (1) East Asia and Pacific, (2) Europe and Central Asia, (3) Latin America and the Caribbean, (4) Middle East and North Africa, (5) North America, (6) South Asia, and (7) Sub-Saharan Africa. By income, the classifications are low-income economies, lower-middle-income economies, upper-middle-income economies, and high-income economies (World Bank Group, n.d.b) .

The income is measured using gross national income (GNI) per capita, in U.S. dollars, converted from local currency using the World Bank Atlas method (World Bank, 2017a). It is the method that smoothest exchange rate fluctuations by using a three-year moving average, the price-adjusted conversion factor (World Bank Group, 2014). Estimates of GNI are obtained from economists in World Bank country units; and the size of the population is estimated by World Bank demographers from a variety of sources, including the United Nations population biennial World Population Prospects (World Bank, 2017a). In 1978, the first World Development Report introduced groupings of "low income" and "middle income" countries using a threshold of \$250 per capita income as a threshold between the groups (World Bank, 1978). In the 1983 World Development Report, the "middle-income group" was split into "lower-middle" and "upper middle" groups, and in 1989 a "high income" country definition was introduced (The World Bank Data Team, 2019) . Since then, the thresholds to distinguish between the income groups have been adjusted for prices over time. As of 1 July 2019, low-income economies are defined as those with a GNI per capita, calculated using the World Bank Atlas method, of \$1,025

or less in 2018; lower-middle-income economies are those with a GNI per capita between \$1,026 and \$3,995; upper-middle-income economies are those between \$3,996 and \$12,375; high-income economies are those with a GNI per capita of \$12,376 or more (The World Bank Data Team, 2019). Countries are immediately reassigned on July 1 each year, based on the estimate of their GNI per capita for the previous calendar year. Income groupings remain fixed for the entire fiscal year (i.e., until July 1 of the following year), even if GNI per capita estimates are revised in the meantime (World Bank, 2017a; World Bank Data Team, 2019).

The WHO groups countries in LMICs into six regions: African Region, South-East Asia Region, Eastern Mediterranean Region, Region of American, European Region, and Western Pacific Region (WHO, 2016c).

The United Nations classifies countries as developing and developed countries. The United Nations used these categories to monitor the Millennium Development Goals (MDGs) established in 2000 and were targeted to be achieved by 2015. Several of the MDGs were not achieved by 2015. The United Nations then used the classification of developed and developing countries to monitor the Sustainable Development Goals (SDGs) started on September 25, 2015 (United Nations, 2017). These SDGs are also stated in the United Nations' World Economic Situation and Prospects 2019 (United Nations, 2019). In the developed economies, the United States, Canada, Japan, Australia, New Zealand, and Europe are listed. In developing economies, Africa, East Asia, South Asia, Western Asia, Latin America, and the Caribbean are listed (United Nations, 2019). The World Bank Country and Lending Groups list Pakistan in South Asia (World Bank, 2017b) and in the World Economic Situation and Prospects 2019 Pakistan is listed in the lower-middle-income group (United Nations, 2019). The World Health Organization member states are grouped into six regions: African Region, Region of the Americas, South-East Asia

Region, European Region, Eastern Mediterranean Region, and Western Pacific Region. These regions are organizational groupings and, while they are based on geographical terms, are not synonymous with geographical areas. Also, the WHO regions are not the same as those of the United Nations (WHO, 2020a). Pakistan is in the WHO Eastern Mediterranean Region (WHO, 2020b).

In the upcoming section, I describe the global need for palliative care and in low-and middle-income countries as my research focused on access to palliative care in Pakistan which as described above is a low-and middle-income country.

Need for Palliative Care

Kav, Brant, and Mushani (2018) describe that worldwide palliative care needs are growing. This is due to a growing aging population and an increasing prevalence of chronic illness. Describing the access to palliative care, Connor and Gwyther (2018) state that worldwide every year, 40 million people need palliative care, 20 million at the end-of-life, yet only about three million are able to access the care they need. Inaccessibility to all who are in need of palliative care results in 18 million people dying with avoidable pain and suffering. This is due to multiple reasons including a lack of access to pain medications and other essential medicines, lack of health professionals trained in palliative care, few national-level policies, weak government commitment, and a lack of funding for training and implementation (Connor & Gwyther, 2018). In the world, there are 195 countries. Of these, 54 countries are in Africa, 48 in Asia, 44 in Europe, 33 in Latin America and the Caribbean, 14 in Oceania, and 2 in Northern America (Worldometers, n.d.a). According to the United Nations, the two countries are the two countries in Northern America are the United States and Canada (Worldometers, n.d.b).

Over 95 countries have national hospice or palliative care provider associations and four regional associations represent and advocate for palliative care in their respective geographical areas. But at a time when global health policy is being set at the United Nations and its numerous bodies, there are very few voices that speak up for the inclusion of palliative care in the discussions required for policy change. This indicates that Palliative Care has been founded for 50 years; yet on the international stage, the advocacy for palliative care has been very limited (Connor & Gwyther, 2018). If improving the access to palliative care is to be achieved, advocacy is to be ascertained and sustained.

Public Health Approach to Palliative Care

Pfaff et al. (2019) suggest implementing a public health approach for improving palliative care. This approach provides the mechanism and structure for promoting a population health system of care across the trajectory of wellness, the onset of a life-threatening condition, and the end-of-life (Pfaff et al., 2019). A public health approach to palliative care has been advocated by the World Health Organization since the 1990s, with the aim of improving opiate availability, developing appropriate policies and integrating palliative care services into the mainstream (Sallnow et al., 2016). Kav et al. (2018) add that the World Health Organization's public health strategy is founded on four pillars, which include pertinent policies, drug availability, education, and service implementation. Kav et al. (2018) add that researchers have identified that in developing countries there is a paucity of research to inform palliative care practices. Thus, they advocate that research is necessary to inform evidence-based and contextually relevant clinical practice. Therefore, barriers to research practice, such as lack of infrastructure and mentorship, must be adequately addressed as they strongly influence clinical practice and inform policy decisions (Kav et al., 2018).

Describing the barrier to the World Health Organization's public health model, Connor and Gwyther (2018) state that lack of inclusion of palliative care in policies does not allow for palliative care to be included in national health planning, funding, or recognition of the specialty. Connor and Gwyther (2018) state that there is a global crisis related to the state of access to palliative medicines. The authors further add that the International Narcotics Control Board estimates that 75% of countries have no or very inadequate access to strong analgesics. Connor and Gwyther (2018) further add that without access to oral opioids, and the standard of care for moderate to severe pain in palliative care, cannot be effectively delivered. In regard to education, Connor and Gwyther (2018) suggest that every health professional who works with severely ill patients should have at least have a basic education in palliative care. Most patients needing palliative care should be receiving it as part of primary health care. Yet, palliative care curricula are still not taught in medical schools, nursing schools, social work and psychology graduate training, or in religious education (Connor & Gwyther, 2018). Describing the service implementation, Connor and Gwyther (2018) assert that the implementation of palliative care has been mainly driven by charities and private sector providers. To reach the enormous unmet need for palliative care, it is necessary or mandatory that governments realize that palliative care is not optional but an essential part of every health care system. Palliative care should be interwoven into primary health care, and countries should designate specific funding streams (Connor & Gwyther, 2018). Sallnow et al. (2016) add that public health encompasses a broad range of approaches from the traditional techniques of disease control and prevention, to the newer approaches of health promotion, focusing on education and empowerment. A health-promotion approach that emerged in the 1980s has paved the way for 'new public health' in which people are placed as active participants in their own health and the importance of the social determinants

of health must be recognized. Describing the success of using a public health approach, Sallnow et al. (2016) add that a health promotion approach has been used successfully in fields such as HIV/AIDS and cardiovascular disease for decades, with important improvements in health outcomes.

The WHO (2017a) estimates that 30-50% of cancer's morbidity and mortality rates can be controlled by the public health model: primary and secondary prevention and palliation (Frieden et al., 2008; Sepúlveda et al., 2002; Stjernswärd, 2007). Primary prevention focuses on reducing human exposure to cancer-producing risk factors (National Cancer Institute, 2015) by creating opportunities like engineering the environment to increase physical activity and by providing occupational safety in industries that use materials known to cause cancer (Frieden et al., 2008). Virus-associated cancers could be prevented by vaccinations. Cervical cancer could be controlled by human papillomavirus vaccine and hepatocellular cancer could be controlled by the hepatitis B vaccine (Frieden et al., 2008). Secondary prevention focuses on early diagnosis and treatment of cancer. For example, mammograms screen for breast cancer, and papanicolau smears and colposcopy can detect cervical cancer. Although, methods for early detection are identified as successful for breast and cervical cancers (Frieden et al., 2008), but for other types of cancers, methods of early detection and their efficacy are yet to be established. In the public health model, palliation focuses on patients with advanced cancers and improves their access to pain control and symptom management, therefore, improving their quality of life (Jamison et al., 2006; Potter, Perry, Stockert, & Hall 2011; Sepúlveda et al., 2002).

Primary prevention benefits the larger population and is financially feasible, but requires integration into the health care delivery system and national health policies. Therefore, countries

need to spend more in their budgets for primary prevention than the present allocation of budget for health (Frieden et al., 2008; Hannon et al., 2016; Sepúlveda et al., 2002; Stjernswärd, 2007).

In their editorial about cancer care in low- and middle-income countries Haier, Sleeman, and Schäfers (2019) state that universal health coverage is a central goal for healthcare systems worldwide and that health policy agendas have helped to improve the quality of care. However, in many low- and middle-income countries (LMICs), including the Eastern Mediterranean Region, sub-Saharan Africa, and East Asia, progress to date in achieving universal health coverage has not been optimal. Haier et al. (2019) add that adequate access to primary care as a key requirement of universal health coverage is not universally achieved in many countries, particularly for vulnerable populations.

Cultural and Traditional Barriers

Culture has been defined as a shared set of practices and behaviors determined by customs, habits, language, and geography; its neglect has been identified as the single biggest barrier to the advancement of global standards of health care (Napier et al., 2017). Hannon et al. (2016) speak of culture being so important that without close attention to the culture in an LMIC, it is not possible to accomplish much with palliative or end-of-life care. Hales, Zimmermann, and Rodin (2008) suggest that cultural norms regarding dying and death may be greatly affected by religious and existential beliefs, the degree of secularization, the understood relationship of the individual to the community, and resource availability. These are depicted by Ginsburg (2013) through a scenario quoted below:

“Imagine you are a 38-year-old woman in rural Bangladesh. You notice a large lump in your left breast, and it begins to grow. Three months later you also notice a lump under your left arm. You are married, have 4 children and live with your in-laws in their home.

Your priorities are clear: to feed and care for the family, tend the home, and ensure there is enough money for school uniforms, pencils, and books. Your husband tends the small family farm, and you all pray that the seasons will be favorable this year. As a dutiful mother, daughter-in-law, and wife, self-oriented considerations rarely, if ever, enter your mind. The health and well-being of everyone else should come first. Besides, you have never met, or even heard of anyone surviving a dreaded diagnosis of cancer. The very word instills fear, fear of bringing shame upon your family, fear of being cast-out from your community, and fear of an untimely death. What choice do you have but to carry on, and hope that (god willing) things will get better? (p. e36).

Lyons, Sankaranarayanan, Miller, and Slama (2018) describing cancer care in the WHO Eastern Mediterranean Region, where Pakistan is also situated, state that in the region there is substantial variation in terms of population health outcomes, health care infrastructure and quality and level of health expenditure. This variability is mainly because the region consists of low, middle and high-income countries. Besides, economic reasons political instability, conflict, and cultural practices present a number of development challenges in accessing palliative care in the region. In LMICs people strongly believe in the power of traditional healers to deal with palliative care patients (Campbell & Amin, 2014). In some cases, the reliance on these healers is associated with unrealistic hopes for a cure and a focus on the supernatural (Hannon et al., 2016). The potential for an alliance between traditional healers and palliative care providers is strong (Harding & Higginson, 2005). However, it requires opening a discourse between the traditional healer and health care providers. (Audet, Ngobeni, & Wagner, 2017; WHO, 2007).

Giving a specific example of culture, the Alliance Worldwide Palliative Care & World Health Organization. (2014) states that in many countries, in life-threatening illness, informing

patients of their diagnosis and prognosis is prohibited or strongly discouraged. Describing the culture in Pakistan, Moazam (2000), trained and practiced as a physician in the United States for many years, returned to Pakistan as she accepted an academic position. She writes that in Pakistan when a member of the family is ill, it is the family rather than the patient who takes center stage in the decision making the process. In the case of a conscious patient, the family and physician will generally protect the patient from the anxiety and distress associated with the knowledge of impending death. This is done by not disclosing the diagnosis or disclosing it in ambiguous terms. The doctor is often symbolically inducted into the family and is expected to direct rather than just facilitate medical management. “The "doctor sahib," [Sahib has an Arabic root meaning "lord"] remains the authority in matters relating to disease and medical interventions” (Moazam, 2000, p. 28). The family’s reluctance to reveal the diagnosis of terminal disease echoes a cultural reluctance to learn all the facts even when they suspected a grim prognosis. Moazam (2000) describes the cultural difference between Pakistan, an LMIC and the United States, a high-income country. While working in Pakistan she experienced that the role of the individual, the family, and the physician in life passages including birth, illness, and death are interlinked. Family members are responsible to care for the sick and it is the obligation of the physicians to be involved in the decision related to the end-of-life situation. Moazam finds this remains a seminal difference from many Western societies, in which moral direction for these events is usually sought through human reason, a concept rooted in the secular philosophy of different philosophers. The author adds that “while in secular society rationalism fuels the ethical and legal discourse of human relationships, in Pakistan religion and an interpretation of divine injunctions are the driving forces” (Moazam, 2000, p. 30). Pakistan in my experience remains very similar to Moazam’s description

By religions, Pakistan's population (2010 est) consists of 96.4% Muslims and 3.6% from other religions including Christians and Hindus. Muslims are from different ethnic groups; 44.68% Punjabi, 15.42% Pashtun (Pathan), 14.1% Sindhi, 8.38% Saraiki, 7.57% Muhajirs, 3.57% Balochi and 6.28% are described as others (Population of the world, 2019). Pertaining to culture, each religion and ethnic background has its own culture. Thus, the people living in Pakistan have a diverse culture and not all could be assessed through one yardstick. Affirming this notion describing the cultural life in Pakistan, Burki and Ziring (n.d.) state that the country shares influence that has shaped the cultures of South Asia. Adding further, Burki and Ziring (n.d.) state that cultural practices in Pakistan are broadly similar to those experienced in large parts of Afghanistan and northern India and the practices in this entire region are deeply influenced by the Arabic-Persians who arrived roughly around a millennium ago when Muslims conquered the region. Hence, Pakistan presents a picture of rich diversity and it is difficult to speak of a single Pakistani culture (Burki & Ziring, n.d.).

Describing beliefs and barriers in access of palliative/hospice care at the end-of-life among Muslims, Abbasi (n.d.) asserts that end-of-life care among Muslims is still a new subject and considering options like palliative care and hospice care are not yet widely agreed to or practiced. For many, dying is a family matter. Abbasi (n.d.) states that some people die in hospitals but the majority die at home with the support of their family and very little or no help from health care providers; therefore, many people with a malignant illness live with a great deal of pain until they die at home. Abbasi (n.d.) presents that for some, palliative care of a terminally ill person may be the moral and ethical alternative of euthanasia. Adding further, Abbasi (n.d.) states that among Muslims, another concern is about using morphine in palliative or hospice care as an accepted treatment options. Also in a hospital's protocol of "No Code" is accepted similar

to a “Do not resuscitate” order in the hospitals in the west (Abbasi, n.d.). Abbasi (n.d.) supports Moazam’s (2000) notion of culture hindering family to reveal the diagnosis of a terminal disease. Abbasi (n.d.) further adds that hospice care actually can help the family fulfill a cultural and religious obligation by focusing on comforting the patient. Abbasi (n.d.) asserts that Muslim patients do not give up hope because they believe life and death are in the authority of God and not in the power of medical science.

Focusing on cultural competence in the care of Muslim patients and their families, Attum, Waheed and Shamoon (2019) assert that to provide appropriate and culturally sensitive care to individuals with Muslim faith it is important to understand the difference in cultural and spiritual values of their faith. Among Muslims, there are Arabian decent (Abbasi, n.d.; Attum et al., 2019) and there are others who have converted to Islam (Attum et al., 2019). Describing the religion, Attum et al. (2019) elaborate that Islam is a monotheistic faith. However, Muslims are not a homogeneous group, and different groups may have varying cultures even though they share the same religious practices. Behaviors are often shaped by cultural practices that may not even be in agreement with the basic religious practices. There are Muslims who follow cultural practices from the pre-Islamic era. Though these practices are not typically part of Islamic practices they are given an Islamic dimension by the Muslims who follow these practices. Similarly, perspectives about Islam that the Muslim scholars from the Arab world hold are different than the Muslim scholars from India and Pakistan. Accordingly, they interpreted the religion and guide Muslims for their religious practices. Sharing his perspective, Abbasi (n.d.) asserts that although Islam is a flexible religion, individual Muslims may not be flexible. Thus, the rigidity may be presented and also viewed through the lens of religion but in reality, they are culturally driven.

Knowledge about culture could facilitate in providing palliative care. Emphasizing the importance of culture, Hannon et al. (2016) assert that models of palliative care and end-of-life care must be sensitive to societal and cultural norms. Speaking about death is a cultural taboo among patients, families, and healthcare providers in many LMICs (Hannon et al., 2016) as they view it might bring sadness or hasten the patient's death (Aehlert, 2011).

Inaccessibility for Diagnosis and Treatment

Ninety percent of high-income countries build resources in their public sectors to provide services for cancer diagnosis and treatment; however in LMICs only 35% have diagnostic facilities like pathology services and 30% have services for cancer treatment (WHO, 2017a). Facilities available in private sectors in LMICs are situated in major cities which are often inaccessible and unaffordable by most of the people in need (Anwar, Green, & Norris, 2012; Punjwani et al., 2015) therefore, they may not go for health checkups. This delays the diagnosis and treatment of diseases (Sloan & Gelband, 2007; Tfayli, Temraz, AbouMrad, & Shamseddine, 2010). Frequently an individual is seriously ill but cannot access or afford health care (Sloan & Gelband, 2007).

Talpur, Surahio, Ansari, and Ghumro (2011) researched two hospitals in Nawabshah, Pakistan, one private and the other public, and reported that breast cancer is associated with a lack of access to proper healthcare facilities, poor socioeconomic status, and low literacy rates. Similar findings were reported by Pace et al. (2015), who studied two rural cancer referral centers in Rwanda, situated in the African region of the WHO (WHO, 2015). These findings coincide with findings from Donkor et al.'s (2015) systematic review of the literature published between 1990 and 2014 for studies conducted in Egypt, Nigeria, Ghana, Kenya, and Libya, all of which are identified as LMICs. In Pakistan, the barriers are a high number of patients, poor

access to morphine (Majeed, Nadeem, Khokhar, & Qaisar, 2019), lack of training in medical (Patel, Deo, & Bhatnagar, 2019; Tariq, Hasan, & Haider, 2018) and nursing schools, no specialized palliative care team, no support from the government in terms of funding and infrastructure for palliative care services, few hospices, a limited numbers of trained nurses, and overburdened oncologists. These barriers are similar in other LIMCs (Shad, Ashraf, & Hafeez, 2011). In these countries a high proportion of patients are diagnosed at a late stage of the disease and their cancer is metastasized (Haier et al., 2019). The WHO (2018) states that between 30–50% of cancers can currently be prevented by avoiding risk factors and implementing existing evidence-based prevention strategies. The organization also adds that as many cancers have a high chance of cure if diagnosed early and treated adequately (WHO, 2018). Thus, through early detection of cancer and the management of patients who develop cancer the burden of cancer can be reduced (Haier et al., 2019; WHO, 2018). It is also important to recognize that illiteracy and social taboos add obstruction to early diagnosis and treatment. To overcome these barriers and to improve knowledge and practices there is an urgent need to of massive awareness campaign at the national level (Haier et al., 2019)

Inaccessibility to Pain Control

The WHO recognizes pain control as one of the main pillars of palliative care and recommends adequate drug availability. Appropriate policies; education of policymakers, health care workers, and the public; and implementation of palliative care services at all levels throughout the society are the remaining three of the four pillars that the WHO recommends for the public health approach for palliative care. This approach has demonstrated that it provides an effective strategy for integrating and establishing palliative care into a country (Stjernswärd et al., 2007). For pain control, the WHO in the early 1980s began to develop a global initiative to

advocate for pain relief with a major emphasis on cancer pain and worldwide availability of opioids (Sepúlveda et al., 2002; Stjernswärd, 2007; WHO, 2000). At current levels, world heroin consumption (340 tons) and illegal seizures represent an annual flow of 430-450 tons of heroin into the global heroin market. Of that total, opium from Myanmar and the Lao People's Democratic Republic yields some 50 tons, while the rest, some 380 tons of heroin and morphine, are produced exclusively from Afghan opium. While approximately 5 tons are consumed and seized in Afghanistan, the remaining bulk of 375 tons is trafficked worldwide via routes flowing into and through the countries neighboring Afghanistan (United Nations Office on Drug and Crime, 2017).

The Balkan and northern routes are the main heroin trafficking corridors linking Afghanistan to the huge markets of the Russian Federation and Western Europe. The Balkan route traverses the Islamic Republic of Iran (often via Pakistan), Turkey, Greece and Bulgaria across South-East Europe to the Western European market, with an annual market value of some \$20 billion. The northern route runs mainly through Tajikistan and Kyrgyzstan (or Uzbekistan or Turkmenistan) to Kazakhstan and the Russian Federation. The size of that market is estimated to total \$13 billion per year (United Nations Office on Drug and Crime, 2017). LMICs suffer greatly from the illegal trading in opioids and the corruption that comes with it, limiting access to opioids when needed and thus often intractable pain at end-of-life.

In LMICs, even if opioids are included in a hospital formulary they are often not available because supply and procurement must be approved by the narcotic control agencies, which is a long process (Abbas, Muhammad, Mubeen, & Abbas, 2004; Cleary et al., 2013; Reville & Foxwell, 2014; Lebaron et al., 2014). If opioids are available in the hospital, even then healthcare personnel are reluctant to administer opioids to their patients. This is because

healthcare providers fear patients' addiction to opioids (Aljawi & Harford, 2012; Cazap, Magrath, Kingham, & Elzawawy, 2015; Hannon et al., 2016; Kurji, Dias, Rattani, Khowaja, & AliSher, 2019; Rattani, 2015; Story et al., 2012). Abbas et al. (2004) conducted a survey to learn about palliative medicine among Pakistani doctors and reported that only 32 out of 70 mentioned pain control as the primary aim for palliative care management and 34 (48.8%) said they were never involved in palliative medicine. Presently, in Pakistan, pain management and palliative care are missing in medical (Khan, 2012; Stjernswärd, 2007; Yusuf, 2013) and the nursing curriculum (Punjwani et al., 2015; Stjernswärd, 2007). Therefore, it is important that both these curricula should be revised. Nurses are frequently in contact with people suffering from needs that require pain and other symptom control. More palliative care education for nurses, especially understanding the disease process and advanced assessment and management of symptoms, would lead to better care for and advocacy for palliative care needs of people. Mills (2019) states that limited training and awareness of palliative care among health professionals represents a major obstacle to improved access to palliative care. Mills (2019) also stresses that while palliative care is a human right, in LMICs, lack of access to opioid analgesia for pain control coupled by a variety of policy, education, social, cultural, financial and implementation barriers, access to palliative care is compromised. Adding to the description of inaccessibility to pain relief, Lyons et al. (2018) affirm it to be related to inadequate or overly strict legislation; unbalanced policies; limitations on available forms of medication especially oral opioids; lack of supply and distribution systems; limitations on who can prescribe; insufficient knowledge of the use of controlled medicines; and inappropriate attitudes towards controlled medicines. Attending to these restrictions and overcoming barriers are essential for improving the access to palliative care in LMICs.

Lack of Palliative Care Research

The dearth of palliative care research in LMICs (Cazap et al., 2015; Hannon et al., 2016; Punjwani et al., 2015; Qidwai, 2012) results in only one in five countries having data necessary to drive cancer policy (WHO, 2017a) and understand the etiology of the disease and its diagnostic journey and treatment modalities (McCarthy & Brajovic, 2009) and to identify populations at risk, develop referral mechanisms and guidelines for cancer control, and measure the social burden of cancer (Bridges et al., 2011). Contextual-based research is critical but LMICs lack funding, training, and interest in palliative care (Hannon et al., 2016). Evidence from high-income countries demonstrates the value and benefits of early palliative care but research findings related to specialist-based interventions in tertiary care centers in high-income countries cannot be readily extrapolated in LMICs (Hannon et al., 2016).

The lack of palliative care research in LMICs was reported by Singh and Harding (2015), who conducted a systematic review of various databases and found only 16 relevant articles published between 1980 and 2013. Of these 16, 14 were from India and were largely focused in the state of Kerala; one was from Pakistan and one from Nepal (Singh & Harding, 2015). Complementing findings from Singh and Harding (2015), Cheong, Mohan, Warren, and Reidpath (2019) affirm little published research outputs in LMICs. The authors suggest that in LMICs, much work is required to drive research and to generate the evidence required for the development of palliative care services (Cheong et al., 2019). Aggarwal et al. (2018) emphasize that international collaboration is also required for research in LMICs.

The Declaration of Venice, adopted in 2006 at the Fourth Research Forum of the European Association for Palliative Care (Hospice and Palliative Care, 2007), called for strategies to improve palliative care research in LMICs. These include identifying research

priorities in these countries based on their regional, cultural, and socioeconomic contexts and identifying funding resources to support palliative care research (Hannon et al., 2016). Research is being recognized as an important component of palliative care. Lyons et al. (2018) inform that a draft of the Framework for Cancer Control in the WHO Eastern Mediterranean Region will explain the scaling up cancer care in the WHO Eastern Mediterranean Region. Six core areas for cancer control are included in the document: governance; prevention; early detection; treatment; palliative care; and surveillance and research. Lyons et al. (2018) believe that the framework will support Eastern Mediterranean Region countries to develop a more systematic approach to cancer control.

Conclusion

Palliative care has emerged from the word hospice which in ancient times was defined as a shelter for weary and ill travelers on a long journey (Clark, 2007; National Hospice and Palliative Care Organization, 2016). In the 19th century, hospice was identified as a place for dying (National Hospice and Palliative Care Organization, 2016). In the present time, a goal of palliative care is to adopt a public health approach for the prevention, early detection, and treatment of cancer to improve the quality of life for patients and their family members (World Health Organization, 2017b). However, palliative care is not accessible to all who are in need, especially those living in LMICs which includes Pakistan. Culture and tradition, and inaccessibility to diagnostic and treatment facilities impedes access to palliative care. Understanding culture, traditions, and religion are important to improve access to palliative care. Improving access to the public health approach to cancer care requires policy change at various levels and that in turn requires changes to budgeting priorities within the country. Much research is needed in Pakistan and other LMICs to better understand the facilitators and barriers to

palliative care. This research aims to describe and understand experiences related to access to palliative care in Pakistan. Participants in this study were patients, their family members and the healthcare providers at Bait-ul- Sukoon Cancer Hospital. Upcoming chapters cover a detailed description of my research including the findings and discussion of the findings.

Chapter Three: Methodology

This chapter provides a general description of the descriptive case study research methodology by Yin (2014) that I followed for my research. The chapter also includes a few of the other publications about case study design and the research process that I followed to examine access to palliative care in Pakistan.

General Description of the Case Study

The case study research originated by Sister Mary Edward Healy (1947), a social anthropologist, began using it (Creswell, 2013; Denscombe, 2003; Lincoln & Guba 1986). It soon found use in the social sciences, education, business, law, and health as a way to address a wide range of research questions (Harrison, Birks, Franklin, & Mills, 2017; Rosenberg & Yates, 2007). The aforementioned disciplines also use case studies in teaching. In teaching, case study materials may be deliberately altered to demonstrate a particular point more effectively. In research, any such step would be strictly forbidden (Yin, 2018). Case study research is also different than the clinical case study, which focuses on an individual patient (Walshe, Caress, Chew-Graham, & Todd, 2004).

For many years the case study as research methodology was compared with quantitative research methods and therefore was not considered a valid research methodology. In the 1960s, as interest in qualitative research grew, case studies re-emerged as a practical approach to examine complex issues in context (Anthony & Jack, 2009). The re-emergence of case studies positioned them as a credible and valid research design (Creswell, 2013; Harrison et al., 2017; Yin, 2014). In case study research methodology data collection is considered with qualitative methods (Creswell, 2013). The data could also be collected through a mix of quantitative and qualitative methods (Yin, 2014). The “*case*” should be situated within a setting, with a physical,

social, historical, and/or economic context (Creswell & Poth, 2017). Researchers using the case study design need to identify the case that is significant for the research question, the required methodological approaches, the data collection process (Flick, 2014) and the type of case study (Creswell & Poth, 2017).

Published Case Study Research

The case study methodology is used in many disciplines, including nursing. In the process of identifying if case study research would be helpful in this study focusing on palliative care in Pakistan, I reviewed the research that used the case study as a research methodology. Six publications that have used case studies for nursing questions and/or researching palliative care are described in this section.

The first study is from nurse researchers Salami, Nelson, Hawthorne, Muntaner, and Hall, (2014). The authors used a single typical holistic case study research design to explore the motivations of Philippine educated nurses who from 2001 to 2011 migrated to Canada through the Live-in Caregiver Program which is a Canadian domestic worker program. Salami et al. (2014) describe that a typical case represents a predominant circumstance, situation, or condition. The authors rationalize that their case study had a typical case approach because more than 85 percent of live-in caregivers are from the Philippines and around half of the individuals who migrated to Canada through the Live-in Caregiver Program are settled in Ontario (Salami et al., 2014). Salami et al. (2014) state that their case study aimed to explore factors that motivated baccalaureate-qualified Filipino nurses to be domestic workers in Ontario, Canada. This research selected the Canadian Live-in Caregiver Program (CLCP) as its “*case*”. The ‘unit of analysis’ was Philippines-educated nurses who immigrated to Ontario through the CLCP. Data were collected through document reviews and interviews with participants. Fifteen CLCP immigrants

were interviewed by the primary investigator. The first author kept a reflexive journal throughout the research process, recording her awareness and positioning in the field. Data gathering and data analysis were simultaneous processes. Linkages built between the data and the reflexive journal enabled the researchers to look at the data critically and identify the rival explanations (Yin, 2014). For the theoretical propositions, the researchers used “global care chains” by Hochschild (2000) to describe the growing trend of women migrating to perform care and socially reproductive work. Researchers paid attention to the intersecting effect of gender, class, nationality, and race on the experience of migrant domestic workers in Canada (Salami et al., 2014).

The analysis indicates that parents in the Philippines encourage their children to enter the nursing field so they can find work abroad to earn higher salaries and support family members in the Philippines. The Filipino nurses’ motivation was to migrate to the Middle East mainly for financial reasons. This goal was achieved as participants found well-paying, tax-free jobs with good benefits including annual leave and free travel between the Middle East and the Philippines. The participants said their motivation to migrate to Canada was for Canadian citizenship for themselves, their children, and spouses, and to obtain a better social status and lifestyle. Although pay in Canada was low compared to that in the Middle East, the Middle East did not allow families to stay permanently. Thus, this case study research methodology enabled the researchers to understand the multi-step immigration process in which nurses’ migration from the Philippines to the Middle East is mainly economically driven and their migration from the Middle East to Canada is primarily motivated by their desire for Canadian citizenship for their family. Also, nurses’ perceptions of social status and lifestyle in Canada are better as compared to the Middle East.

The second study that I cite in this chapter is also by nurses. In this case study O'Rourke, Higuchi, and Hogg (2016) examined stakeholders' participation in the system change process that led to the introduction of the first Nurse Practitioner-Led Clinic (NPLC) in Ontario. O'Rourke et al. (2016) followed a qualitative case study research design guided by the principles of stakeholder and system change theory. The authors selected NPLC as their case and bounded it by place (Sudbury), time (January 2006–January 2008), activity (stakeholders participation), and process (introduction of an innovation, the first Nurse Practitioner-Led Clinic in Ontario, during a primary care system change). Potential participants, who were identified from publicly available documents, were invited through a letter and were selected purposefully. The primary investigator collected all of the data through a field visit, field notes, face-to-face and telephone interviews, and a review of the documents. These documents included media release, policy papers, and website information using the search term NPLC. In the interview data, as the maximum saturation was achieved after the 16th interview the data collection process was terminated. In data analysis, categories and themes were identified and a conceptual framework developed. Field notes provided the researchers with a basis to develop a chain of evidence. Case study methodology allowed the researchers to look for similarities and differences in the data in the system change process and to develop a model. The authors presented the model through a diagram with key themes supported by participants' narratives. To ensure rigor, the authors invited all of the participants to engage in a member-checking process. Participants responded that the summary of the findings reflected their perspectives (O'Rourke et al., 2016).

The third study is by the nurse researchers Boblin, Ireland, Kirkpatrick, and Robertson (2013). The authors state that Stake (1995), Merriam (1988), and Yin (2003, 2009) have contended that the case study allows for a holistic understanding of a phenomenon within a real-

life context from the perspective of those involved. Boblin et al. (2013) describe their use of a single instrumental case study design based on the methodology described by Stake. Their case study explored the implementation of a falls-prevention best-practice guideline (BPG). The researchers chose an issue, the implementation of the Falls BPG, as their case, and bounded it by time (three years) and location (three acute care hospitals). The researchers used the Promoting Action Research in Health Services (PARiH) framework to guide questions for the interviews, to ensure that their data collection process was complete, and to classify emerging findings. The data collection methods included focus group discussions with nurses, in-depth interviews with key informants, document reviews and journal writing. Coding the documents and maintaining a journal allowed the researchers to note linkages between data contained within the documents and data presented by the participants. Artifacts included assessment tools, Best Practice Spotlight Organization, logos, and marketing materials, patient and staff educational materials, posters, and event invitations. As part of the data collection process, researchers noted their observations while they were in the field (hospital setting). During team meetings, team members discussed their perspectives and interpretations to identify where their findings converged and diverged. For member checking, researchers shared the findings with the participants, who reported that the findings were consistent with their experiences.

Research results were presented as a journey made by the participants, described through six stages or phases of their journey: the early journey, shifting sands, gaining traction, reinvesting in the journey, a new vehicle on the road, and moving forward. Supported by quotes and phrases from the data sets, the researchers elaborated on these stages. The fall prevention guidelines for the three hospitals were informally started during a two-year process of continuous quality improvement (Boblin et al., 2013). Case study research proved to be beneficial to

understand the process of implementing the Registered Nurses Association of Ontario's Prevention of Falls and Fall Injuries in the Older Adult in three acute-care hospitals in Ontario. Understanding this process informed the subsequent implementation of BPG.

The fourth case study by nurse researchers comes from Walshe et al. (2004). They examined the literature to determine the appropriateness of case studies as a research strategy in palliative care. The authors describe case study is a research methodology that focuses on a particular case (individual, a group or an organization) and uses a variety of methods to explore complex phenomena within the context of the case or cases. Walshe et al. (2004) elaborate that case studies have been used intermittently in palliative care research, but the literature review indicates that the case study research methodology is not used much in comparison to other methods of quantitative and qualitative research designs. Thus, "a focus on other methodologies and the relative invisibility of case study in palliative care research mean[s] that there is a danger of overlooking what could be a valuable research strategy within palliative care" (Walshe et al., 2004, p. 677).

Case studies are appropriate to study complex social situations or interventions. Palliative care is complex, patient-focused, context-dependent and multi-professional. To study the dynamics and complex nature of dying requires robust methods that can be used to examine and expose that complexity. Using a range of data collection methods is the key to capturing complexity. Elaborating further, the authors describe that in the case study research, using more than one data source allows researchers to assess the shifting needs of dying patients. It also makes it possible to capture different perspectives and changing interpretations of outcomes (Walshe et al., 2004).

Walshe et al. (2004) state that the flexibility of the case study strategy allowed many researchers to look not just at the processes, but also at structures and outcomes. They assert that case study methodology is sufficiently flexible to respond to issues where clinicians' decisions are intuitive, tentative and variable. Case studies can be helpful in answering the "why" questions. Walshe et al. (2004) emphasize the importance of writing a research report in a narrative that explores and explains complex situations.

Walshe et al. (2004) summarize that case studies have the ability to deal with complex, context-dependent situations and flexibly address multiple perspectives. Palliative care is a complex mix that involves health and social services, and voluntary and statutory agencies. The care is provided by constantly shifting environments, which often shape themselves to take account of local historical, political and organizational issues. Case studies can be used to help providers and other stakeholders to recognize and take account of these issues, making them a powerful tool to improve services.

The fifth article is by Van Raak, Paulus, Cuijpers, and te Velde (2008). These researchers are from multidisciplinary teams: medicine, public health, and policy development. They followed Yin's (1994) methodology to research the "Palliative Care Network Region Arthem" from 2001 to 2004 (p.771). Their study's purpose was to identify the network characteristics and conditions that enabled or hindered cooperation among participants. Van Raak et al. (2008) collected the data through participants' interviews and reviews of the documents related to the palliative care network in the Arthem region. In the analysis section, the researchers describe how they used an explanation-building strategy to determine if cooperation in the network took place. Van Raak et al. (2008) then identified routines which they expressed were the observable actions of the actual performance. Also by looking at the artifacts which included guidelines,

checklists, and protocols related to the topic the authors classified similarities and differences between network routines. The authors, based on their analysis, describe three coherent topics. These are “working in a (multidisciplinary) team, cooperation with others inside or outside the organization, and care delivery inside or outside the organization” (p. 772).

Van Raak et al. (2008) continued data analysis and looked for convergence or divergence between artifacts and routines. Then the authors assessed whether the assumption about the role of convergence and divergence in the change or stability of routines helped them to understand the problem of cooperation in the network of palliative care providers. To support their analysis of the convergence or divergence, Van Raak et al. (2008) used quotes from participants’ interviews.

In the results section, Van Raak et al. (2008) briefly describe the historical perspective about the development of the “Palliative Care Network Region Arthem” (p.772) and about the participating organizations: a general hospital, hospice, home care agency and nursing home. The researchers’ analysis revealed that the hospice, nursing home, and home care agency artifacts and routines converged but in the hospital, they diverged. In this research the case study methodology allowed the researchers to examine a complex phenomenon. Examining this phenomenon may have been difficult in other research designs.

The sixth article is also by a multidisciplinary team (Sussman et al., 2012). This study aimed to explore if it was possible to identify a set of modifiable health system factors associated with palliative care outcomes for a population. These factors included less acute care use and more home deaths. The authors used a comparative multiple case study approach with four Canadian health care regions which were purposefully selected as single cases, representing the units of analysis. In this study, the palliative care delivery system within each region in the years

2003 and 2004 were the phenomena of interest. The researchers searched the literature but could not find any framework to examine palliative care systems. Therefore, based on the empirical literature the researchers developed a framework for their study and, using the Delphi method, they shared the framework with experts including health services researchers, palliative care nurses, and physicians. Based on the feedback, Sussman et al. (2012) modified the framework before using it for their research. Their data collection was through in-depth, semi-structured interviews with key informants; a self-administered survey with key informants; and structured detailed reviews of relevant programs and the system planning documents. The researchers triangulated data through quantitative and qualitative approaches and looked for convergence of evidence. Data triangulation increased the credibility of their research (Sussman et al., 2012).

The conceptual framework provided the researchers with a structure for a systematic analysis of qualitative and quantitative data. They used a two-steps-of-data analysis process. In the first step, they built an understanding of the relationships among the factors within each case or region. This, they state, was within-case analysis. In the second step, the researchers did a cross-case comparison. For qualitative data analysis, they coded the data and extracted themes and categories. For the quantitative data of survey forms, the researchers used descriptive analysis and calculated frequencies and percentages. The researchers presented their data through tables, graphs and writing themes. The researchers exemplify how a phenomenon of interest could be compared in different cases. In their research, they compared palliative care in four regions and revealed that the delivery of quality care between the regions was discriminated due to overall palliative care planning and needs assessment; standardized patient assessments; 24/7 palliative care team access; advanced practice nursing presence; and designated roles for the provision of palliative care services. Thus, this case study informs health system planners on the

important features to be incorporated into evolving palliative care systems (Sussman et al., 2012).

In summary, a case study allows a researcher to explore a phenomenon in its real setting without manipulation. It also allows for multiple perspectives from different participants and for various methods of data collection. Furthermore, it provides an opportunity to describe participants' perspectives and interpret those using theoretical propositions. Previous reviews are evidence that case study research can examine the complex phenomenon. Having such references enhanced my confidence in using the case study research design. What follows is a description of the case study methodology that I used to describe access to palliative care in Pakistan, which is an LMIC.

Case Study to Describe Access to Palliative Care in Pakistan

I followed the case study methodology suggested by Robert Yin (2014). He defines case study as “an empirical inquiry that investigates a contemporary phenomenon (the “case”) in depth and within its real-world context, especially when the boundaries between phenomenon and context may not be clearly evident” (p. 16). A single case can be selected or multiple cases are identified so that they can be compared (Creswell, 2013).

In a case study research design usually, the main focus of the inquiry is on a case that could be more concrete or less concrete (Yin, 2018). Individuals, small groups, organizations, and projects are the more concrete examples of the cases. Communities, relationships, decisions, and partnerships are the less concrete examples of the cases. The unit of analysis of the case study is the “case” (Yin, 2018, p. 288). Once the case is defined, bounding the case becomes important (Yin, 2018). It is “the distinction between the conditions that fall within as opposed to outside of the case in a case study. Such as the time period, social groups, organizations,

geographic locations, or other relevant features understanding that the boundaries can be fuzzy” (Yin, 2018, p. 286). However, avoiding undesired confusion between the unit of analysis and unit of data collection is required (Yin, 2018). This case study focuses on access to palliative care in Pakistan as a ‘case’. The case is bounded by the organization Bait-ul-Sukoon cancer hospital.

According to Yin (2018), a case study can be descriptive, explanatory and exploratory. A descriptive case study describes a phenomenon (the “case”) in its real-world context. It is explanatory shedding light on causal factors leading to particular events and explains how and why some events occurred or did not occur. It is also exploratory used to identify research questions and procedures to be used in subsequent research that will not necessarily follow a case study methodology (Yin, 2018). In this research on access to palliative care in Pakistan, I used a descriptive case study research design. A descriptive case study is focused and detailed with propositions and questions about a phenomenon are carefully scrutinized and articulated at the outset. These measures help to specify the boundaries of the case and contribute significantly to the rigor of the case study (Yin, 2018).

Yin (2018) requires case study researchers to provide an outline and a format for the narrative of the findings. The researcher formulates a research plan that guides the researcher in the process of collecting, analyzing and interpreting observations. Case study protocol requires four sections: (1) an overview of the case study which includes research objectives, case study issues, and relevant readings about the topic being investigated; (2) case study questions clearly linked and informed by propositions from literature; (3) data collection procedures; and (4) a guide for how the case study will be reported (Yin, 2014). These items appear in the following order: an overview of the case study, case study questions, data collection procedures, data analysis, report writing, and rigor.

Overview of the case study.

Facing a terminal illness has been identified as a stressful and fearful experience that affects all the aspects of life. In HICs, access to palliative care has improved (Johnson, 2015; Mishelmovich, Arber, & Odelius, 2016) but in LMICs palliative care is not accessible to all who are in need. These people may have unmet care needs mainly in the areas of pain and symptom control, emotional support, and spending time alone or with their loved one (Macaden, 2014; Mulji & Sachwani, 2017; Shah, Kayamba, Peek Jr, & Heimbürger, 2019; Teo, Krishnan, & Lee, 2019; Virdun, Luckett, Lorenz, Davidson, & Phillips, 2017).

Research objective.

The aim of this study was to describe how people accessed palliative care through the Bait-ul-Sukoon Cancer Hospital and Hospice, the research setting (and bounded case) selected for this research.

Research setting.

This research was from a clinical setting: the Bait- ul-Sukoon Cancer Hospital and Hospice, Karachi, Pakistan. Bait- ul-Sukoon Cancer Hospital originated in 1999 in a house where underprivileged terminally ill cancer patients were provided with hospice care. Eventually, it was funded by philanthropists, and in 2009 a hospital was built. This cancer hospital is able to accommodate 45 adult inpatient admissions. Bait-ul-Sukoon means House of Peace & Contentment. Its mandate is to help prevent cancer and provide services to underprivileged members of the community who have cancer. The hospital's mission is to focus on prevention, early detection, curative and palliative care for patients in a way that maintains dignity and promotes comfort (Bait-ul-Sukoon Cancer Hospital, 2015).

Case study questions.

This case study examines access to palliative care in Pakistan. This is done through examining multiple data sources at Bait- ul-Sukoon Cancer Hospital. Research questions were:

- 1) How do study participants describe their experience of barriers and facilitators to accessing palliative care?
- 2) How does the Bait-ul- Sukoon Cancer Hospital contribute to the facilitation of access to palliative care?
- 3) How do an individual's social determinants of health influence access to palliative care?

These research questions overlap and are not mutually exclusive. Therefore, while examining the data to find the facilitators to access, barriers were also presented.

Theoretical propositions.

Yin (2014; 2018) suggests that prior to conducting a case study, researchers should conduct a thorough literature review and thoughtfully pose a research question, objectives and propositions. Yin (2018) asserts that the study questions and study propositions help to identify the relevant information to be collected about the case. Without such questions and propositions, the researcher might be tempted to cover “everything” (p.29) about the case. The more a case study contains specific questions and propositions, the more it will stay within feasible limits (Yin, 2018). Thus, in line with Yin's guidelines, the previous chapter examined literature surrounding the history of, need for, and approaches for improving cancer patients' access to palliative care, with a special focus on LMICs. As Yin (2018) advocates, the literature review not only helped me to determine what is known about the topic but also assisted me to develop more insight about the research (Yin, 2018). Theoretical propositions were derived from the literature

and from my professional experience (Baxter & Jack, 2008). These theoretical propositions are presented in table one. This table also includes the sources from which these propositions were derived. Full references to these sources are included in the reference list. Many of the theoretical propositions were derived from sustainable development goal (SDG) 3.8, which is to “achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.” A full description of this goal is presented in Appendix C.

Table 1 *Propositions are related to LMICs including Pakistan.*

Propositions for this study	Source
<p>Social determinants of health influence access to palliative care. Palliative care is not accessible to all who are in need resulting in a late diagnosis of cancer in Pakistan and other LMICs. Those with high income have access to opioids pain medicines, while those with low income suffer. Cultural challenges may exist in terms of the person’s knowledge of his/her diagnosis. Individuals may be unwilling to get treatment because they do not want to take away their family’s resources (financial as well as time) for themselves if access to healthcare depends on the ability to pay. Individuals may first approach traditional healers and use alternative therapy. Then these individuals come to hospitals for treatment. This results in late diagnosis and treatment.</p>	Professional experience and literature: (Aehlert, 2011; Campbell & Amin, 2014; Donkor et al., 2015; Ginsburg, 2013; Hannon et al., 2016; Harding & Higginson, 2005; Jayasinghe, 2015; Krakauer et al., 2015; Pace et al., 2015; Punjwani et al., 2015; Moazam, 2000; Reutter & Kushner, 2010; Silbermann et al., 2012; Sloan & Gelband, 2007; Talpur et al., 2011; Tfayli et al., 2010; WHO, 2017a).
<p>Cancer pain management is not adequate. opioids are inaccessible in part because cancer pain is perceived as part of the disease. Also, access to opioids is obstructed by strict regulations and controls. Access to opioids is also dependent on income status; those with high income have access to opioids pain medicines, while those with low income do not have access. Thus, they suffer. Moreover, there is a lack of palliative care emphasis at the national policy level.</p>	Professional experience and literature: (Abbas et al., 2004; Aljawi & Harford, 2012; Cazap et al., 2015; Cleary et al., 2013; Gelband et al., 2016; Hannon et al., 2016; Kar, Subitha, & Iswarya, 2015; Khan, 2012; Krakauer et al., 2015; Lebaron, Beck, Maurer, Black, & Palat, 2014; Pastrana et al., 2010; Punjwani et al., 2015; Rattani, 2015; Reville & Foxwell, 2014; Stjernswärd, 2007; Story et al., 2012; United Nations

	Office on Drug and Crime, 2017; Vranken et al., 2014; Wu & Clark, 2013; WHO, 1996a; WHO, 2017d; Yusuf, 2013).
Health care providers lack palliative care education. This influences on cancer care and symptom management.	Professional experience and literature: (Hannon et al., 2016; Khan, 2012; LeBaron et al., 2014; Pastrana et al., 2010; Punjwani et al., 2015; Stjernsward, 2007; Yusuf, 2013)
Policy level change is required for improving access to palliative care. Reducing barriers and improving access to opioids require policy reform at the governmental level with a set of action plans being formulated and concurrently implemented and aimed at different levels of social, education, and economic policy change as severe suffering exists. The WHO and researchers recommend that a public health strategy is to be implemented to address the issue of palliative care.	Professional experience and literature: (Dempers, & Gott, 2017; Frieden et al., 2008; Hannon et al., 2016; Larjow, Papavasiliou, Payne, Scholten, & Radbruch, 2016; Lucas, 2002; Sepúlveda et al., 2002; Stjernsward, 2007; Stjernsward, Colleau, & Ventafridda, 1996; WHO, 1996a).

Case study data.

In a case study, Yin (2018) suggests using multiple sources of data. Common sources include documentation, archival records, interviews, observations and physical artifacts (Yin, 2018). However, it is not required that all of these data collection sources be used in one case study. Instead, any of these combinations can be used depending upon the phenomenon being investigated. In addition to these descriptions, Yin (2014) suggests that case study research is largely reflective work. My reflection in this case study helped me to raise questions about the experiences and the unstructured observations that I was making. Also, the physical artifacts; posters displayed at various locations at Bait-ul-Sukoon Cancer Hospital, and the in-depth individual interviews of patients, family members, and healthcare providers, deepened my analysis in this research as will be noted in the findings.

Sample and sampling for the interviews.

Writing about sample size in qualitative research, Vasileiou, Barnett, Thorpe, and Young (2018) state that experts argue that there is no straightforward answer to the question of ‘how many’. Samples in qualitative research are to be large enough to allow the unfolding of a new and richly textured understanding of the phenomenon under study, but they should be small enough so that they provide the deep, case-oriented analysis of qualitative data (Vasileiou et al., 2018). Qualitative samples are purposive. This is opposed to probability sampling employed in quantitative research. Instead qualitative research samples select ‘information-rich’ cases (Vasileiou et al., 2018). Using a purposive sampling methodology, four patients, three family members, two registered nurses (RNs), two physicians and a pharmacist at the Bait-ul- Sukoon Cancer Hospital were included in this research. These study participants included patients, those seeking to find help with their deteriorating health, family members who accompanied them, and the main professionals that participated in their care. The case was a bounded case (Bait-ul-Sukoon), a descriptive case study, and the sample includes those who were best able to inform the research questions (Yin, 2018).

Inclusion criteria.

Adults (18 years and above) enrolled in the study were male and female patients who were diagnosed with cancer and were admitted for palliative care at Bait-ul- Sukoon Cancer Hospital. The family members of the patients were those who were staying with the patients while they were hospitalized. Healthcare providers were those who had a minimum of one year of experience of working at Bait-ul- Sukoon Cancer Hospital. The selection of these healthcare providers was based on their experience and designation as health care providers. Spoken

language was another criterion that I followed. I enrolled individuals who could speak English or Urdu (national language in Pakistan).

Exclusion criteria.

In the exclusion criteria, I planned to exclude those patients at Bait-ul-Sukoon hospital who were children and those adults who had a diagnosis other than cancer. However, Bait-ul-Sukoon admits only adult patients for cancer care so this exclusion criteria was not used . If a person was too ill to be able to be interviewed he/she was excluded from the study.

Interviews.

Patients, families, and healthcare providers who agreed to participate in this study were interviewed face-to-face and individually. Prior to the interview I obtained their individual informed consent, explained to the individuals that their participation in the study was voluntary and that they were under no obligation to participate. They also received an explanation that they could choose not to answer any of the questions included in the interview, or could opt to withdraw from the study. Each person who agreed to participate was informed that his/her participation may not have individual benefits but the findings from this study may benefit others in their situation and society in general. Knowledge gained from this research may contribute to improving palliative care education, practice, and research. Also, it may have benefits at the policy level for improving systems. However, the individual's decision about whether or not to participate in the study did not influence his or her status as a patient receiving care. As well, participation did not affect the family members of patients at Bait-ul-Sukoon. Health care providers' participation in this study did not influence their employment status. Individuals' interviews were conducted based on a person's availability. These interviews were in the morning and evening shifts during weekdays and weekends. Interviews occurred at the time and

at a space provided by the hospital administration or at the patient's bedside as agreed upon by the participant. Among the healthcare providers, three (two physicians and a registered nurse) accepted to be interviewed in a separate setting. One registered nurse wanted to be interviewed while he was at the nursing station and the pharmacist wanted to be interviewed in the waiting area in the outpatient clinic designated for the patients and their family members. As the researcher, I accepted the desire of the participants when they selected the place for their interviews. However, at the time of the pharmacist's interview, the entire waiting area was vacant as the interview was in the evening of a weekend and the outpatient clinics were not operating. Still, I selected a corner to minimize the disturbance from the noise if it occurred. Similarly, for interviewing the registered nurse, a corner at the nursing station was selected to minimize the disruption if it was to occur.

Among the three family members, one person who was the daughter of a female patient agreed to be interviewed in a separate room that was equipped with a table and chairs /a couch. The other person who was also a daughter of another female patient wanted to be interviewed at her mother's bedside in her presence, and the third participant, who was the wife of a male patient, was interviewed in the presence of her younger daughter, who was about 12 years of age, while they both were in the visitors' lounge in the hospital setting. To interview the participants in a separate room, the door in the interview room was closed for privacy. For the interview at the individual patient's bedside, the curtains were drawn. A family member, a patient's daughter who wanted to be interviewed in the presence of her mother at her bedside, was sitting on a couch, which is provided at each bedside. For the patients, as they desired, all four were interviewed at their bedsides. While in the hospital, one attendant stays with the patient around the clock. Thus, all four patients were interviewed in the presence of their family members as an

attendant. It was interesting to note that the patients who participated and were interviewed, were not hesitant to talk in the presence of their family members. Similarly, the family member (a patient's daughter) who participated in the study was not reluctant to be interviewed in the presence of her mother.

An unstructured interview guide with some open-ended questions to begin the conversation was used to guide the interviews (See Appendix I 1a; I 2a; and I 3a). Interviews with patients, their family members and healthcare personnel were conducted in the Urdu language. An Urdu version of the interview guide was used (Appendix I 1b; I 2b, and I 3b). These conversational questions were asked in an unbiased, friendly, non-threatening way and without any coercion (Yin, 2014). The approximate time for an interview ranged between 18 – 90 minutes. While a participant was talking, the person was allowed to speak without interruption or any time limit. This allowed the participants to elaborate on their descriptions. Out of the twelve interviews, eleven were audio recorded. Among the patients, one of the participants agreed to participate in the research, but she did not want to be audio recorded. She allowed me to take notes during the interview. I recorded her interview through note-taking. I also wrote field notes in a notebook during the interviews, which allowed me to check with the participant to ensure that all the points that the participant wanted to talk about were covered. Each participant was also invited to add to the interview data if needed. Two of my participants needed a break during their interview which is elaborated on later under the section on ethical consideration.

For confidentiality and anonymity, each participant was assigned a code number. Codes with a 'P' indicates the participant is a patient whereas 'FM' indicates the person is a family member and 'HCP' indicates the participant is a healthcare provider. The names of these

participants are listed in a grid and access to this information is limited to me as a researcher and my research supervisors; both nursing professors. Audio recorded interview data is saved on a computer that is password protected. The entire electronic data is saved in a folder on a computer secured through the University of Alberta secured server. This folder is accessible to me and the supervisors. A copy of the hard data is saved in a cabinet, which is locked and its key is with me.

Pilot testing.

Prior to actual data collection, I pilot tested the Urdu and English versions of the interview guide. This pilot testing was with a colleague who volunteered to be interviewed. The purpose of pilot testing the interview guides was to determine that the questions in the interview guide were appropriate to achieve the aim of the study and to determine if the questions in the interview guides were understandable to potential participants. The pilot testing (Yin, 2018) also aimed to refine the interview guide if it was needed. However, no refinement of the tool was required. The data from the pilot test was not used in this case study.

Observations.

Unstructured observations focused on the physical appearance of the environment and the institution's capacity for services for in-patients, daycare, and outpatients. Observations noted treatment modalities (e.g., chemotherapy, radiation therapy, surgery, and other services). The guide that was used for the observation is appended (Appendix J). Observations included how patients and families navigated care processes, how people enter the facility, and who they speak with first.

Organizational records.

I planned to observe hospital records for information about the number of patients, types of cancer, and age, sex of people accessing services as well as documents of policy and

procedures for providing palliative care services (Appendix K). However, I did not have full access to this information. The information that was accessible I describe in the finding sections of this dissertation.

Artifacts.

Institutional artifact included posters used as educational material for patients and their family members and they were included in the dataset (Appendix L).

Reflective journal.

I maintained a reflective journal during the research process. This journal provided me a place as a researcher to document my feelings during the interview process and to reflect on the interpersonal exchange with participants, and my own experiences with palliative care. I did not have restrictions on writing reflections; rather, I documented my feelings, awareness, and reflections about the data and data collection process while engaged in the research.

Ethical considerations.

As mentioned earlier, this case study examined access to palliative care in Pakistan. This was through examining multiple data sources at Bait- ul-Sukoon Cancer Hospital. Institutional approval was obtained and was documented in a letter jointly signed by the Medical Director and the Administrator, Bait- ul-Sukoon Cancer Hospital (Appendix D). This research was approved by the Research Ethics Board 1, the University of Alberta with a study ID: Pro00079346 (Appendix E).

To communicate and recruit the participants, a poster was prepared, printed and was given to the hospital administration to be posted at various locations at Bait- ul-Sukoon Cancer Hospital. This poster included a brief description of the study, as well as title, purpose, and contact number for the principal investigator (Appendix F). An information letter was also

prepared for sharing with the individuals. This letter included the study title, name and contact details of the investigators; principal investigator and the research supervisors. Also, information about the study background, purpose, study procedure, benefits and risk, information that the participation in the study is voluntary, assurance for the individual's confidentiality and anonymity and freedom to withdraw from the study was included in the information letter in English and in Urdu (Appendix G 1a, G 1b, G 2a, G 2b, and G 3a, G3b) with the purpose to allow individuals to make an informed decision about participating in the study.

I had planned for the nursing staff at the hospital to approach patients and family members and provide them with a letter of information (Appendix G 1a, G 1b, and G 2a, G 2b), and for the health care providers to be approached by the person-in-charge of the unit, who was planning to give them the information letter (Appendix G 3a, G 3b). However, the nursing personnel, including the unit in-charge, excused themselves from this additional responsibility to their existing assignment. However, they permitted me to approach the individuals and invite them to participate in the study. I started this process with greetings, self-introduction as a PhD student and a brief description of the research. In this process of recruitment, those who did not want to participate or refused to know more about my study, were thanked and no further interaction occurred. Those who wanted to know more about this research were provided an information letter and were given an opportunity to ask questions. A number of patients and family members did not read the letter but wanted me to read it to them. This occurred because either the person did not want to read by himself/herself but to listen while it was read, or those individuals did not know how to read either Urdu or English but could understand spoken Urdu. After going through the information letter those who decided to participate were provided with a consent form to read or I read for them to obtain their individual informed consent (Appendix H

a, H b). A male patient who was a potential participant, after understanding the information in the letter, agreed to participate in the study. However, when it came to signing the consent form, he declined to participate and I respected his decision if a person was too ill to be able to be interviewed . A female patient who was a potential participant, after learning about the research details and reading the participant's information sheet agreed to participate. However, when she was provided the consent form for her signature, she told me to hold it because she first wanted to consult her husband and obtain his permission for her to participate in the research. This female, with her mobile phone in her hands, stepped out of the ward to talk to her husband. Upon her return, the female said that her husband agreed for her to participate in the study, but she will not sign the consent form. Also, she did not permit me to record her voice using audio recording during the interview. I noted the participant as informed verbal consent and recorded her interview through note-taking. Both verbal informed consent and note-taking were included in the research proposal as approved by the Research Ethics Board.

As I envisioned, there were individuals who were vulnerable due to low energy or other reasons. They were provided breaks during the interviews. One of the patient participants had his interview paused twice. First, it was when staff from the food service came to serve him lunch and the nursing staff came to change his wound dressing. Second, there needed to be a pause when the family members of another patient in the same ward came to this participant's bedside. Among the family members, a break during a participant's interview was necessary while she needed to respond to her mother (participant's mother) who was very sick, fragile and needed assistance to change position in the bed.

Although I had anticipated the need for a break during interviews with healthcare providers to attend to unit needs, among those who agreed to be interviewed, none of these

healthcare providers needed a break. Their interviews were scheduled based on their availability. Individuals were provided the option to review their own interview transcripts. It was explained that this review would provide the person an opportunity to check if the information that s/he provided was captured or not. It was also added that while reviewing, the individual could elaborate on his/her experience, or could ask to omit the parts of the transcript which did not represent what the person wanted to say. These reviews were also for maintaining the rigor in the research. Not all the participants agreed to review their interview transcripts but those who agreed to review confirmed that the experiences and perspectives that they shared through interviews were captured well and further elaboration was not needed.

Data transcription and management.

All electronic data was stored in the computer according to the ethical guidelines mentioned above. There was a separate folder for each data set: a folder for typed memos, reflections, and observations, and a separate folder for the interviews of family members, patients, and healthcare providers. Each participant's audio-recorded interview along with its transcripts in English was saved in the folder for these participants. To mitigate the cultural textual gap (Santos, Black, & Sandelowski, 2015), the interview guide was translated in the Urdu language as the interviews of patients, their family members and a few of the healthcare personnel occurred in Urdu, as expected. I as the researcher conducted all the interviews and transcribed them verbatim. The interviews that were in Urdu, I translated into English. These processes provided me with a good opportunity to become immersed in the data. The English version of the transcripts is saved in the specific folders as mentioned above. The hard data; a register in which I documented my notes of the interviews, reflections, and observations,

individuals' signed consent forms, and the printouts of the transcripts are saved in a cabinet with a lock and its key is with me.

One participant interview was backward translated from English into Urdu and then was forward translated from Urdu into English. This translation was done by two people (one did the backward and one did the forward translation). These individuals are experienced in interview translation and transcription in English and Urdu (the national language). Both the versions of Urdu and both the versions of English were compared to discover that no meaning was lost in the translation process. This process aimed to maintain the quality of research (Santos et al., 2015). These translators had signed a confidentiality form (Appendix M).

Data analysis.

Yin (2018) writes that case study data analysis consists of examining, categorizing, tabulating, testing or combining evidence to produce empirically based findings. The case study research data analysis depends largely on a researcher's own style of rigorous empirical thinking, along with the sufficient presentation of evidence and careful consideration of the alternatives. "One starting point for any analysis is to 'play' with the data" (Yin, 2018, p. 167). Four general strategies for analyzing case study data include relying on the theoretical propositions, working research data from the ground up, developing a case description and examining plausible rival explanations (Yin, 2018). Two of these strategies, theoretical propositions and examining the rival explanations were used in the data analysis process for this case study.

Data analysis occurred simultaneously with data gathering and involved reflexive analysis of the data. I initially read each transcript as a whole to get an overall impression of an individual's interview. To get a thorough understanding, I read the transcripts more than once. This study was guided by the theoretical propositions the study objectives and research questions

were driven from these propositions (Yin, 2018). I started the analysis by writing about each of the participants separately and shared the write-up with my supervisors. The supervisors also had access to audio-recorded interviews saved in the folder. The supervisors reviewed the write-up and provided their written feedback. Also, our discussion in regular meetings was intense and it further deepened my analysis. For each transcript, this process was continued multiple times. Seven transcripts that were reviewed through this process were of patients, family members, and healthcare providers. Two of the healthcare providers' interviews were in English. Thus, the research supervisors could double-check the transcriptions of these interviews. This process in addition to analysis enhanced the validity in the research. Through this analysis process, two main themes were developed with subthemes to describe the case. I was also attentive to identify the rival cases, data that is contrary to the propositions. Also, the linkages between the data were focused to see where the data were converging and diverging.

Case Study Report.

To make the case study an exemplar, for this report, I focused on the characteristics that Yin (2018) suggests: significance, complete, consider alternative perspective, description of the phenomenon, display sufficient evidence, and composed in an engaging manner. First, I was required to write about the significance of the topic. Access to palliative care in LMICs is significant as there is limited research in this area. Research on access to palliative care has the potential to influence education, practice and national policy. Second, this case study provided a description of the phenomenon, which is access to palliative care in LMICs. To make the case study exemplary, quotes from the participants and other evidence from data were used for presenting the findings. These provide enough information for the reader to reach an independent judgment regarding the merits of the analysis. They also present enough evidence so that the

reader can gain confidence that the investigator knew the subject well. A display of adequate evidence shows that the validity of the evidence is attended to. The fifth characteristic is that the case study is composed in an engaging manner that keeps readers' interest so that they continue reading. Accordingly, the findings chapters will unfold using the participants' descriptions of their experiences of access to palliative care. In addition to viewing these descriptions through the lens of the theoretical propositions, I also did further data analysis to determine what else the participants were telling me. For example, in the description of late diagnosis, I described how the failures in the existing healthcare system lead to this lateness. Participants' inaccessibility to palliative care is described through the suffering that they endured within existing systems. These descriptions are supported through the participants' quotes and artifacts, observations, and reflections reported later in the findings. Additionally, for reporting, I used an accurate, bias-free, and transparent tone in this writing.

Rigor.

In a case study research, the rigorous methodological path begins with a thorough literature review and careful and thoughtful posing of research questions or objectives (Yin, 2018). As mentioned earlier, this case study started with a literature search, presented in Chapter Two. Also, I was mindful of other criteria that Yin (2014) suggests for judging the quality and rigor of case study research. These are construct validity, internal validity, external validity, and reliability. There are different steps used for fulfilling these criteria. For construct validity, data were collected through multiple sources; individuals' interviews, unstructured observations, organizational records, artifacts and reflective journals. As the participants were the key informants, I shared the interview transcripts with participants for the individual's feedback. The participants were not only satisfied but they were happy to see that the transcript reflected what

they said in the interview. Internal validity was achieved during data analysis through matching patterns, building explanations, and addressing rival cases. External validity was demonstrated in the choice of research design, a single-case study. Reliability was established through the use of case study protocol, developing a case study database, and maintaining a chain of evidence. Reliability was demonstrated in the descriptions of the operations of this study, so that data collection procedures could be repeated, with the same results (Yin, 2018). Yin (2018) also identifies trustworthiness, credibility, conformability and data dependability as criteria for maintaining rigor in the research (Yin, 2018). Describing these criteria of rigor, Lincoln and Guba (1985) posit that in order to evaluate a research study, it is important to determine how trustworthy it is. Trustworthiness involves establishing credibility, transferability, dependability, and confirmability. These criteria are the reference points for the rigor of this research. Collecting multiple types of data provides data triangulation and thus increases the validity of the findings, leading to more reliable results (Yin, 2018). As previously mentioned, as a researcher I maintained a reflective journal throughout the research process, to record my emerging awareness, position in the field, and challenges encountered in the field and how I overcame these. Quality in research was maintained by following the criteria suggested by Yin (2018). Accordingly, for construct validity, multiple sources of evidence, as mentioned above, were used.

Credibility.

Credibility provided confidence in the “truth” of the findings. Techniques used for establishing credibility included prolonged engagement and persistent observation in the research field during morning and evening on weekdays and on weekends and public holidays. My connection in the research site started in March 2017 as I contacted the Medical Director, Bait-ul-Sukoon Cancer Hospital to obtain permission for this research. After the detailed discussion with the Medical Director and with the Hospital Administrator my request was approved and

permission granted through a letter jointly signed by the Medical Director and the Administrator, Bait-ul-Sukoon Cancer Hospital. They were informed about the research process including my candidacy and the approval of the Research Ethics Board University of Alberta. Receiving ethics clearance on April 6, 2018, I contacted the Medical Director and the Hospital Administrator. My data collection started April 6, 2018 and was completed by April 5, 2019. Credibility also was enhanced through data triangulation, peer debriefing, negative case analysis, and member-checking.

Prolonged engagement.

After obtaining ethical approval for this research I spent sufficient time in the field to learn about and understand the phenomenon of access to palliative care. I learned from the perspectives of patients, their families, and healthcare providers.

Persistent observation.

The observations were intended to identify which characteristics and elements in the situation were most relevant to the phenomenon being studied. Prolonged engagement provided the scope and persistent observation provided depth to the research.

Triangulation.

Triangulation involves using multiple data sources in an investigation to produce understanding. This was demonstrated through in-depth interviews with patients, family and healthcare providers as well as unstructured observation and artifacts. Some of these data were collected simultaneously, others sequentially, depending on the circumstances of each participant. The resulting data from these sources were all included in data analysis.

Triangulation also occurred through the research supervisors reviewing the entire process of

research and analysis and asking thought-provoking questions. This process enhanced the quality of the research.

Peer debriefing.

Peer debriefing was a regular process during which the supervisors meaningfully posed questions to provoke my critical thinking. This process allowed me to become aware of my beliefs about the data and its analysis.

Member checks.

The study participants were invited to review their interview transcripts. Not all agreed and were available to review their interview transcript, but a few of the participants agreed and reviewed their transcripts. The purpose of these member checks was to provide the research participants with an opportunity to correct errors and challenge interpretations perceived as wrong. It was also to provide the participants with an opportunity to volunteer additional information, which they may have thought of when reviewing their transcripts. Participants who agreed to check the findings reported that the information that they provided was well captured. They were satisfied and did not feel a need to add more information.

Conclusion

This chapter provided a general description of the method of the case study, exemplars of studies that have used that method, and an overview of the present case study examining access to palliative care in Pakistan, an LMIC. This study is from Bait- ul-Sukoon Cancer Hospital, Karachi. Data collection included interviews of the patients, family members, and healthcare providers, unstructured observations, reflective notes, and artifacts. Data were analyzed using the theoretical propositions that were derived from the literature and professional experience.

Methods to honor ethical procedures have been outlined to show the ways in which rigor was attended.

Chapter Four: Findings: Setting Stage

As Paul Eldridge, an American poet, novelist, short story writer and teacher (May 5, 1888 – July 26, 1982) suggests, within the spider-web of facts, many truths are strangled (Brainy Quote, 2019). The experiences that study participants described have overlapping concerns like a spider-web. Those who agreed to participate in this study were very open in sharing their experiences. It was as if they wanted to share their burden and wanted someone to hear them out. Based on the analysis of their descriptions, I developed themes and sub-themes. The first theme is suffering with two sub-themes. One is healthcare providers' suffering and the other is patients' and their family members' suffering. The second theme is a late diagnosis with five sub-themes. These are culture and beliefs preventing individuals seeking medical healthcare, living in poverty, lack of knowledge, experiencing difficulty in accessing the healthcare system, failure of the healthcare system and lack of cancer prevention for the study's population. Prior to discussing themes and sub-themes, I describe my study setting; Bait-ul-Sukoon cancer hospital where I conducted my study. Thus, my findings are divided into three chapters. These are chapters four, five and six. Chapter four is setting the stage, in chapter five I present the theme suffering and in chapter six I describe the theme late diagnosis.

Descriptions of Healthcare Providers in the System

At Bait-ul-Sukoon cancer hospital and hospice, the setting selected for this research, the healthcare providers were physicians, nurses, and a pharmacist. The physicians and the pharmacist had five years of undergraduate education. For admission in the undergraduate program, the candidate should have passed the 12th-grade intermediate science (FSc) examination (medical group) or 13th grade (A level education) (medical group). To be qualified as a registered nurse, after matriculation (10th-grade schooling) three years Diploma in General

Nursing and one-year Diploma recognized as post-basic diploma which could be any specialized field is required. However, with the vision of BScN for entry to practice as a nurse, in 2020, General Nursing Diploma is being phased out. Those who are enrolled will complete their programs but no new admissions are accepted in this program in the country.

Bait-ul-Sukoon Cancer Hospital

Philanthropists fund Bait-ul-Sukoon cancer hospital to provide in-patient and outpatient services to people who cannot afford to pay for their treatment. However, these funds are limited. Therefore, services are not accessible for patients with leukemia and other types of blood cancers. Only patients with solid cancers can navigate care through outpatient clinics. These patients have breast cancer, cheek also called oral cancer and head-and-neck cancer, lung, liver, esophagus, stomach, rectum and cervical cancer. The hospital has three oncologists and a surgeon who specializes in breast surgery. Each patient is registered under the care of an oncologist who assesses the patient and suggests diagnostic tests and a treatment plan. Only a few of these diagnostic tests such as hemoglobin, blood counts, and chest x-rays, ultrasound and mammogram are available within the hospital. For tests like computed tomography scan (CT scan) and tissue examination as well as for surgery and radiation, Bait-ul-Sukoon collaborates with other hospitals. For patients with breast cancer, the hospital funds the entire cost of treatment. For other types of cancers, when surgery is needed patients are required to explore other resources or pay for their own surgery and Bait-ul-Sukoon funds their radiation, chemotherapy and supportive care. Bait-ul-Sukoon also serves as a hospice. Therefore, it provides palliative care to patients who are at the end-of-life and require comfort care. The hospice and palliative care make patients last days as comfortable as possible (Bait-ul-Sukoon, 2015).

Geographically Pakistan is divided into four provinces and one capital territory for local administration (as well as several federally administered tribal areas) (Briney, July 16, 2018). Bait-ul-Sukoon cancer hospital is in Karachi city, the capital of Sindh province. The remaining three provinces are Balochistan, Punjab, and Khyber-Pakhtunkhwa. However, individuals' access to Bait-ul-Sukoon cancer hospital is not limited based on which province or city they live in, rather the services at the hospital are open to all. None- the- less, the majority of patients who come to the hospital are from the province of Sindh. Since its inception in 1999 as a hospice, Bait-ul-Sukoon has handled 12,920 in-house patients and 39,780 patients through the outpatient department (Bait-ul-Sukoon, 2015). Each month on average, Bait-ul-Sukoon registers 230- 250 new or follow-up patients. In these patients, cancer of breast and cervix is common among females. In male patients cheek or oral, also described as head-and-neck cancer, and liver cancer is the most occurring diagnosis. In all the patients at Bait-ul-Sukoon cancer hospital, 70% are between 30- 50 years of age and 36, 38 and 41 are the most common age of these patients . About two to three percent of patients are in the age group of 70 years and above. The remaining 27% – 28% of patients are between the ages of 17 - < 30 years and >50 - < 70 years of age. “Among all who register at Bait-ul-Sukoon 10%, are at the stage where they receive cancer treatment and 90% come for hospice care” (HCP001). For most of the patients coming to Bait-ul-Sukoon, their education and literacy levels are low and their level of poverty is high. This profile is similar to most of the people in Pakistan (Sayed, & González, 2014).

Rana (June 21, 2016) reports that in Pakistan 9.4% of the population lives in urban areas and 54.6% is the rural population. From the urban population, 38.8% live in poverty and in the rural population, 54.6% live in acute poverty. Due to poverty, the majority of people do not go to private hospitals as they cannot afford to pay the cost of care there. They go to public hospitals,

philanthropic institutions or institutions that subsidize the cost. Patients and their family members or caretakers must come up with the amount remaining after the subsidy. Most of the patients coming to Bait-ul-Sukoon are in extreme poverty with a low or no income and very limited access to the resources required for fulfilling the basic necessities for life such as food, clean water, medical care, and education. When admitted to the hospital, services available free of cost for patients include bed and linen for patients' use, medical-surgical items for dressing and wound care, urinary catheterization, and drainage bags, and a regular diet for their meals. Patients who require tube feeding via nasal-gastric or gastrostomy, receive formula feed. The hospital also provides chemotherapy and medicines that are in the hospital formulary. When a patient requires a medicine, which is not available in the hospital formulary then the patient and the family must arrange for the medicine. For example, I observed that to treat maggots in the wound of a patient with oral cancer, the patient's family arranged the medicine from another hospital.

In conclusion, Bait-ul-Sukoon cancer hospital is a philanthropic institution and it provides cancer treatment and hospice care free of cost to the patients who come to Bait-ul-Sukoon. However, due to limited funds, the hospital cannot meet the needs of all the patients who need palliative care in Pakistan. What it provides is stated in the description of Bait-ul-Sukoon Cancer Hospital.

Participants' Description

In my study, I enrolled a total of 12 participants. These included four patients, three family members, and five healthcare providers. The healthcare providers included two nurses, one pharmacist, and two doctors. Their working experience was between three to nine years.

While a patient is hospitalized one family member is needed to stay present round the clock as an attendant to take care of the psychological and emotional needs of the patient. The attendant assists the patient in activities of daily living, such as, bathing or assisting the patient to bath, shifting the patient in and out of bed and assisting the patient with meals. These are the tasks that nurses cannot do because of low staffing in the hospital. There are two separate in-patients' floors to house male and female patients. On each floor, there are three wards each with the capacity to accommodate four to six patients and two rooms each for a patient who requires to be isolated. Each of these floors can accommodate 16 patients in a given shift. On each floor, one staff nurse; male nurse for the male patients and female nurse for female patients is assigned round the clock. There is a separate ward for daycare patients. These patients are admitted for chemotherapy, blood transfusion or for other procedures after which patients could be safely discharged home and are not needed to stay in the hospital. The ward for daycare patients is staffed by two nurses and the daycare ward operates on weekdays. On weekends and public holidays, this ward is closed. Family members who participated in my study were in different relationships; two of the participants were patients' daughters and one was a patient's wife. They were the family members of the patients with a diagnosis of breast cancer, cancer of the cervix, and oral cavity cancer.

Of the four patients who participated three were females and one was male. Two of the females had the diagnosis of breast cancer, and one had cancer of the lung and thoracic cavity. The male patient was diagnosed with oral cavity cancer. The female patients were 29, 32, and 50 years and the male was 44 years of age. All of these four patients presented at the late stage of their disease. Their conditions will be described in greater detail related to the themes of suffering in chapter five and late diagnosis in chapter six.

In what follows are the themes, and sub-themes. Theme one is suffering from two sub-themes (1) patients' and family members' suffering, and (2) healthcare providers' suffering. Patients' and family members' suffering is into five different sections; social suffering, financial suffering, physical suffering, suffering due to cancer pain and suffering due to resource constraints and corruption. Theme two is a late diagnosis with five sub-themes; (1) culture and beliefs, (2) poverty, (3) lack of knowledge, (4) failure of the healthcare system, and (5) lack of cancer prevention.

Chapter Five: Findings: Suffering

In this chapter, I describe theme one - suffering. Suffering has two subthemes: patients' and their family members' suffering and healthcare providers' suffering. The sub-theme of the healthcare providers' suffering is stand-alone but the sub-theme patients' and their family members' suffering are described in five sections. These are (1) social suffering, (2) financial suffering, (3) physical suffering, (4) suffering due to cancer pain, and (5) suffering due to resource constraints and corruption. I elaborate on this chapter.

The World Health Organization (WHO) describes palliative care as,

“an approach that improves the quality of life of patients and their families facing the problems associated with a 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, p. 84)

However, the patients and their family members who participated in my research were experiencing deep, intense and extreme suffering from cancer and its sequelae. These I describe in five sections that I mentioned above. However, the suffering I describe under these sections are not mutually exclusive but are interwoven like a spider web. Thus, what I describe under one section may simultaneously seem relevant to another section. I elaborate these with quotes from the participants' description of their experiences highlighting the need to relieve their misery as high and urgent.

Patients' and Family Members' Suffering

In most cases when a person comes to the clinic, particularly in Pakistan and other countries in the LMIC group, one or more family members accompany the person. Thus, it may

occur that the patient and the family members are informed about the diagnosis together. It is also possible to maintain his or her confidentiality or to prevent the family from distress, the patient tells the healthcare personnel not to reveal the diagnosis to the family members. It is also possible that the family members for protecting the patient from “trauma that occurs with the word cancer”³ (HCP001) may request the healthcare personnel to conceal the diagnosis from the patient. When families keep the cancer diagnosis secret from patients, sometimes the patients do know about their diagnosis to a certain extent because they are weak and sick but they go along with the family wishes, to not talk about cancer. Describing his experience of patients’ and family members’ reaction when cancer is diagnosed, a nurse participant said,

“It is very painful for the patients and their family members to hear the word cancer as a diagnosis. Hearing the word cancer, they go blurred and feel there is no light at the end of the tunnel. They are fearful that cancer is not curable, sickness is prolonged and painful, the person’s condition will deteriorate and the person will die shortly”⁴ (HCP001).

Perhaps these fears explain why families do not talk about the diagnosis of cancer, as if not talking about it will keep it far away and the patient may live longer.

The first thing patients and families think of with a cancer diagnosis is oozing wounds, unbearable pain, and suffering. These types of feelings and perceptions cause patients and their family to sink into the fear of uncertainties and death. Feelings of helplessness, hopelessness, and

³ Cancer ka lufz khaufzada kardayta hay

⁴ Lufz cancer mariz aur iis kay khandan kay liyah intihai taklif dehay hay. Cancer ka suntay hi oon ki ankhon kay samnay indhara chaa jata hay, oonhayn ummed ki koi kiran Nazar nahi aatty. Who kaufzada ho jatay hayn kayh cancer kubhi bhi na khatum honay wala merz hay. Merz bauhat lumba aur taklifday hay. Ab mariz teakh nahi hosakta. Mariz ki sahat roz baroz bigarti jay ghi aur woh (mariz) jald hi mer jayga

powerlessness are present as experiencing cancer is extremely painful. Describing her experience, a family member of a patient with breast cancer said,

“When the cancer was diagnosed our entire family was very much disturbed. We were in distress. We all were shocked. We were concerned about what will happen next. We were weeping and we could not stop it (weeping). We were just praying to God to heal our mother”⁵(FM001).

Elaborating on the suffering that comes with the word cancer a nurse participant said, “Cancer treatment is for a longer time...in most of the cases a combination of surgery, radiation, and chemotherapy is required”⁶ (HCP001). It is not only the combination of the methods of the treatment and their duration but cancer, when diagnosed, intensifies their sense of dread. It creates a fear which a patient describes as “fear of the unknown, fear of death...”⁷ (P002). Thus, when diagnosed with cancer individuals (patients/family members) start mourning right then and this intensifies their feelings of suffering. To minimize this panic, creating hope is needed but “in most of the cases when a patient reaches the doctor the patient is at the third or fourth stage of his/her cancer”⁸ (HCP001). In these stages, the prognosis is not good and the individuals suffer

⁵Jub pata chalay kay ami ko cancer hay to hamary to halat hi boori hogai. Hum bhauhat khufzada huway. Humayn tension hogaya. Hamara rona bund hi nahi horaha tha. Fikar hogai kay ab kiya hoga. Bus yahi dua hay kah hamari maa jaldi theak ho jay.

⁶ Cancer ki bimari aik lumbay arsay tak chalti hay... is bimari ka ilaj aksar operatiton, radiation aur chemotherapy tino say milkar karna hota hay.

⁷ Unjana say khauf.

⁸ Aksar jub mariz doctor kay pas pauhchata hay woh (mariz) cancer kay tisray ya chauthay stage per hota hay.

the sequelae of cancer. Among all the patients coming to Bait-ul-Sukoon, “80-90% are at the end-stage of their disease (life)” (HCP005). These patients’ cancer has metastasized, their condition worsens day by day and they remain fearful and very worried.

When a patient suffers the person’s entire family suffers and is in pain. This I witnessed while the family members shared their experiences and described their feelings. A few of them expressed these feelings through weeping, others were extremely sad, depressed, and fearful. They were surrounded by uncertainties. For example, I observed that a participant (FM 002) was holding her mother’s hand, and was repeatedly looking at her. Giving the impression as if she (the participant) was saying to her mother that we (the family) need you (mother). This participant said that,

“Now her (participant’s mother) disease is at the 4th stage of the disease (cancer). The doctors have informed us that the disease is at the stage where no further treatment is possible. We should be ready as anything can occur to my mother at any time. No one can say about her lifespan. It could be six months, more or less”⁹ (FM002).

This participant’s mother was referred from a public hospital where the mother’s treatment for cancer started. The participant explained that her mother received five cycles of chemotherapy and between 27-33 cycles of radiation. After these cycles of treatment, the family noted that the mother was developing the symptoms of weakness; shivering and looking pale. They believed their mother needed a blood transfusion or some other immediate care so they

⁹ Ab ami ki bimary 4th stage per hay. Doctors nay hamay batay hay kahy iis stage per mazid koi treatment mumkin nahi hay. Ami ko kabhi bhi kuch bhi hosakta hay aur hamayn iis baath kayliya tayar rehna hoga. Yah koi nahi kahasakta kay iin ki zindgi kitnee hay. Yah chay mehinay, ya iis say ziyada ya kum bhi hosaktee hay.

rushed their mother to the public hospital. Although her cycles of chemotherapy and radiation were completed in January 2017, her visits for follow-ups, labs and blood transfusion continued. In September 2017 the family noted that the mother was developing swelling in one of her legs. Initially, the family related the swelling to their mother's past history of a road traffic accident that required correction through surgery (pinning and plating of the bone). Later they recognized that something serious was happening. Therefore, they first consulted an orthopedic doctor who did an assessment including bone x-rays and identified that there was no problem with her bone operated on earlier. Next, the family consulted the doctors at the public hospital. Diagnostic tests revealed a relapse of cancer. This family member's mother is an example of someone who experienced continual suffering. As she had received chemotherapy and radiation these could not be repeated when cancer relapsed. For the correction of her abnormal labs, she was provided with blood and blood products (plasma), intravenous fluids and medicines. This process continued for about seven months (September 2017 to March 2018). In April 2018 the family was informed that there was no further treatment for her disease and she was referred to Bait-ul-Sukoon cancer hospital and hospice. Here, the doctors alerted the family that the disease was at the stage where no further treatment was possible. The family should be ready as at any time anything could occur to their mother. The participant's mother was at a stage where end-of-life care was needed. Therefore, she was referred to Bait-ul-Sukoon. Describing his experience in palliative care a physician said, "...working in a palliative care setup has a 99% mortality rate" (HCP005). Unfortunately, I found this statement to be very reflective of what was in my data. When cancer is diagnosed individuals (patients and their families) are fearful the cancer is not treatable and death will occur fast.

Next, I describe the patients' and family members' experiences of sorrow and despair sectioned into five difficult and desperate sections. These are (1) social suffering, (2) financial suffering, (3) physical suffering, (4) suffering due to cancer pain, and (5) suffering due to resource constraints and corruption.

Social suffering.

Social connection is necessary for human survival but participants described cancer endangered these relations. Among the healthcare providers, a pharmacist (HCP002) described the social suffering of a female patient who came to the clinic accompanied by her husband. The female was diagnosed with breast cancer. Hearing the word cancer provoked her husband's anxiety and fear to a level where he was in extreme anger and became violent. Envisioning what was coming with his wife's diagnosis of cancer he immediately broke his relationships with the wife and divorced her. "... this is your problem handle that yourself..." (HCP002). He (the husband) left her in the hospital and went away. She (the woman) was in shock, completely lost, and had an "emotional breakdown for what she is going to face. Who is going to hold on?" (HCP002). She needed time and courage to share this information with her family members and friends in their social circle and to arrange how to deal with the change in her circumstances. Since she was divorced she could not live with her husband. In the immediate phase, the administration at Bait-ul-Sukoon cancer hospital admitted the woman to provide her accommodation. The participant (the pharmacist HCP002) could not add further as she was not aware of what happened next with this female patient. A physician described a similar experience. He said, "When cancer is diagnosed.... there are people who do not want to hear that

(cancer) and they do not want to accept that as a fact, they go aggressive”¹⁰(HCP004). Their aggression may turn towards patients as described above by the pharmacist (HCP002). These types of extreme reactions can also be directed towards the healthcare providers putting them in an unsafe zone for working. This I will elaborate on when I describe healthcare providers’ suffering. When cancer is diagnosed an individual’s reaction could be to such an extreme that the person wants to harm himself even though attempting suicide. This I base on my personal experience of dealing with patients when they were diagnosed with cancer. Thus, hearing the cancer diagnosis can be fearful, brutal, unforgiving especially when they (the patients/family members) know that there is nothing that can be done to get rid of cancer.

A patient from Mirpurkhas, a city in the province of Sindh, narrates the suffering and experience she observed of a fellow patient when both admitted to the same unit. The participant said,

“...a patient who was also from another city. As she was diagnosed with breast cancer, her husband left her and removed her from the home. The patient’s mother brought her (the patient) to Karachi as she (the mother) could not see her daughter suffering because being diagnosed with cancer she was immediately removed from the home. This patient was under treatment here (Bait-ul-Sukoon) but then, later on, the patient’s mother also left her because her son (patient’s brother) did not allow his mother to continue the support. While the patient was hospitalized her daughter was living with her. She had two daughters one was at home with her father (patient’s husband) and the other one was here

¹⁰ Jub patachalta hay kay cancer hay ho, to bhauhat say log woh hayn, jo yeh (cancer) sunna hi nahi chahtay. Woh iis hakikat ko mantay hi nahi hayn. Woh bauhat aggressive ho jatay hayn.

(in hospital) with her mother. As she (patient's daughter) did not have a place to live so she was also living in the hospital..."¹¹ (P002).

This participant also described that the patient's mother was feeling distressed for abandoning her daughter. The mother was afraid that since she was living with her son if she did not follow his instructions and not discontinue her support to her daughter (the patient), the son might not allow her (the mother) to live with him. Thus, the mother may be homeless. Most of the time it is customary that when married, a woman moves into the house of her husband, has children and raises them. Among the children, a daughter when she grows, gets married, moves in with her husband. Whereas a son lives with his parents after being married. When the married son with his wife and children lives with his parents, it is called a joint family system. However, it may occur that the son, his wife, and children may live in a separate house, called a nuclear family system. The mother of the patient that the participant described above is living with her son and he is financially supporting her needs of daily living. Thus, even though the mother wanted to be with her daughter to care for her, she could not disregard her son's wishes to discontinue the support that she was extending to her daughter. This put the mother and the patient in an uncomfortable position, where the mother was forced to choose her own survival over caring for her daughter. The son, through the people in his social gathering, believed that

¹¹ ... aik patient jo dusray shaher say aii thea oos kay shauhar ko jaysay hi pata chala kay iis ki biwi ko cancer hay oos kay shauhar nay foran hi oosay (aurat ko) ghar say bahir nikal diya. Patient ki maa say beti ki yah taklif bardasht nahi hooi kay cancer ki wajah say oos ki beti kay shauhar nay oosay ghar say nikal diya hay. Patient ki ami oosay (patient ko) Karachi lay kar aii. Oos patient ka yahan (Bait-ul-Sukoon) mayn ilaj ho raha tha laykin baad mayn oos kay baytay (patient kay bhai) nay appni ami ko ijazat nahi di kay woh (ami) beti ki madad karay patient ki ami apni beti ko chaur kar chali gai. Oos patient ki do betyan thi aik ghar par iis kay walid kay sath thee. Dusri yahan appni ami kay saath thea. Chunkay yahan in ka koi ghar nahi tha beti apni ami kay sath hospital mayn rehty thea...

cancer was a contagious disease. Therefore, he was afraid that while providing care to the patient (his sister), his mother might get cancer and he would not be able to support the mother. His fear of considering cancer as a contagious disease reflects Pakistan society's perception of cancer and highlights the need to educate society about cancer and palliative care. Also, this participant's (P002) narration speaks of patients' and family members' pain in living with social suffering.

The participants' descriptions indicate that patients' and their family members' suffering are inseparable. Also, these social pressures cause psychological distress. This is noted when the pharmacist (HCP002) described her observation of a patient admitted at Bait-ul-Sukoon cancer hospital. This patient had breast cancer which had metastasized to her lungs and brain and as a result, the patient was critically ill. Her husband was experiencing emotional pain about his wife's condition, but his family did not want him to continue support to his wife. While the husband was with his wife during her hospitalization, his mother or sister would come to see her (the patient, man's wife) and tried to pressure him (the husband) to leave his wife and not to waste his time and other resources for his wife who was dying.

He (the husband) was double-minded; if she is going to die why I am investing so much in her. The fears that come with a diagnosis of cancer in these participants kill love and emotions. Why? Because cancer is not just within the body but shows itself here in the whole social system. It becomes so much and the families suffer (HCP002).

Financial suffering.

Patients and their family members experience financial suffering when they pay to travel to the healthcare setting, or for medical investigations and treatment. It is depicted in the description from a family member (daughter) of a patient with cervical cancer. The participant said, "Managing transportation was the most challenging. We were required to take a private

transport. The cost of transportation was PKR 25,000 – 30,000 [CAN \$ 278- 334] a month which is the salary that I earn in a month working full time”¹² (FM002). Experiencing hardship due to transportation is also highlighted by the healthcare providers as the pharmacist said, “They (patients) do not have any means of transportation. They come in buses. They come in, on top of cars. They come in taxis and trains and its pathetic” (HCP002). The financial burden due to the heavy cost of transportation is what the participant described. Thus, individuals risk their lives by traveling in heavy loaded vehicles. This participant (HCP002) described people sitting on the roof of the vehicles. This may sound unreal but to a certain extent, it is the reality in Pakistan and other countries in LMICs.

A patient with breast cancer shared her financial suffering by explaining that for her breast surgery, she was required to pay “PKR 500,000 – 600,000 rupees” (P002). This amount equals 5,555 – 6,666 CAN \$. Another patient (P004) said he was required to pay PKR 800,000 rupees [CAN \$ 8,888] for his surgery for oral cancer. The participant (patient) said,

“When the doctor told about the fee (for the surgery), that amount we could not afford.

They were talking the amount in Lacs (means amount to be paid for the treatment is huge and that the patient could not afford). They said if you want to get the surgery done in a private hospital then it will cost you about 8 Lac rupees (PKR 800,000). There is a doctor, (the participant mentions the name of the doctor here), he also practices in another hospital so he said that if you get it (surgery) done there (the other hospital) then it will cost you 5 Lac rupees (PKR 500,000). As we could not afford this amount of money we

¹² Transportation manage karna hamaray liya sub se ziyada mushkil tha. Hamayn private transportation layni perti thea aur is ka kharcha 25 – 30 hazar rupay hota tha jo mayri full time kam karkay per aik mehinay ki tankhowa hay.

(patient and the family) canceled from there and we planned that we will get the treatment from here (at Bait-ul-Sukoon hospital)”¹³ (P004).

For both, the patients (P002 and P004) as the amount of money required for surgery was staggering in relation to their financial standing and thus they could not arrange to pay for the cost of their surgery. While describing their experiences, both these participants (patients) appeared distressed. The female patient (P002) was diagnosed with breast cancer. To her, Bait-ul-Sukoon hospital funded her surgery performed at a collaborating hospital, but the other patient (P004) was with a diagnosis of oral cancer. Bait-ul-Sukoon could not fund this patient because hospital funds are limited and for surgery, its funds are dedicated to patients with breast cancer, as mentioned in chapter four description of Bait-ul-Sukoon Cancer Hospital. This participant’s (P004) surgery was pending until the funds are arranged by the patient and the family or until Bait-ul-Sukoon arranges it through their funds. Until then this patient (P004) was receiving comfort care; hydration through intravenous infusion and medicine for pain management. As a healthcare provider said,

The reason for their (patients) coming to Bait-ul-Sukoon Cancer Hospital is that they cannot afford the cost of the treatment/care in other hospitals that they started with. Other patients who come are those who required hospice care. As the goal of tertiary care hospitals is different than hospice care. These patients are either referred here or they come through exploration, come to know about Bait- ul-Sukoon Hospital and are being

¹³ Doctor nay hamayn operation ka kharcha bataya who lakhon mayn thaa aur hum iitna afford nahi karsaktay thay. Takriban aath lakh ka kharcha bataya. Doctor --- nay kaha kay woh dusray private hospital mayn bhi behatay (practice) hayn agar hum wahan operation karwayn gay to panch lakh ka kharcha hoga. Magar chunkay hum itana afford nahi karsaktay hum nay wahan say cancel karwya aur iilaj kay liyan yahan (Bait-ul-Sukoon) dakhil ho gay hay.

admitted here. Because the name of this institution is Bait-ul-Sukoon Cancer Hospital and Hospice. Comfort care is the goal of hospice and the patients requiring hospice care are mostly those who do not have money to pay for their care. Also, these patients know that there is no use for them to be going from one to another hospital. There is no treatment for their disease. They come to Bait- ul- Sukoon and are admitted for hospice care¹⁴ (HCP001).

This participant describes the financial barriers for individuals' access to care. It is a terrible pathos they face, no surgery, no treatment; they can only wait to die in palliative care.

Physical suffering.

An example of the severity of physical suffering is evident in my observations and analysis of the interview of the family member of a patient with oral cancer. One day while going through the stairways in the hospital my sense of smell was triggered with a very strong odor. My clinical experience indicated this was a wound of mouth cancer. I followed this odor and reached the ward for male hospice patients. It is a four-bed unit; two at the right hand and two at the left-hand entrance to the unit. I noted that the odor I followed was from the tumor of a patient who was lying down supine in his bed with his eyes closed and his half of the face was covered with a piece of cloth. While looking at the covered face I observed that beneath the cloth there

¹⁴ Patients ki Bait-ul-Sukoon mayn aanay ki wajah yah hay kayh woh iilaj ka kharcha bardasht nahi kar saktay. Dusray patients woh hayn jin to hospice care is zaroorat hoti hay. In marizon ko ya to refer kiya jata hay ya phir woh khud hi malomat kartay hayn tau Bait-ul-Sukoon kay baray mayn ptaa chalta hay aur woh yahan dakhil hotay hayn. Kiyunkay Bait-ul-Sukoon ka pura naam Bait-ul-Sukoon cancer hospital and hospice hay. Hospice care ka goal hay comfort care aur jiin ko hospice care ki zaroorat hoti hay oonkay pass apnay iilaj kay liya paysay nahi. Iiskay alawa yah patients jantay hayn kay oonka aik hospital say dusri hospital mayn janay ka koi faida nahi hay. Iin ki bimari ka koin iilaj nahi hay. Yahy log hosptice care kay liya Bait-ul-Sukoon mayn dakhil hotay hayn.

appeared to be a big tumor. Although I wanted to invite this patient as my research participant, I did not, because I assessed that due to the size of his oral cancer he would not be able to talk. I moved towards another patient in the same ward and as he accepted the invitation to participate in my research and I included him in the research. While I was interviewing this patient, I noted that a woman and two young girls anxiously rushed towards this patient. It was as if they were hiding from someone or something scary. The woman explained that the staff nurse was there to change her husband's wound dressing but it was very painful for her to look at her husband's wound and see him suffering. She wanted to talk to me and express her feelings but as I was in the middle of interviewing the patient so I could not talk to this woman. Thus, for reassurance, I said to this lady that "*Allah behtar karay ga*" (God is great. He may bless you). I also told her that I am a researcher and was busy with a patient, but would meet her later. While the woman was present, I stopped the interview that I was conducting before she came in.

I paused the interview as the woman and her daughter were at my participant's bedside waiting for the dressing to be changed, I asked this woman for and received her permission to allow me to observe her husband's wound while the staff changes his wound dressing. The dressing nurse also consented for me to be present there while he changed the wound dressing, (the nurse would have already asked the patient for his consent for me to be present for the dressing change). As the nurse removed the piece of cloth from the patient's face, a huge tumor at the patient's left lower lip that appeared like a heavy rock was seen. The tumor was almost covering his mouth limiting the opening of his mouth and at the lower side due to heaviness, it was extending below his chin. At his cheek, there was a big hole and through this hole, I could see inside of his oral cavity; tongue, teeth and internal of his jaw. Looking at the tumor it was quite evident that it was very heavy in weight and holding this weight was tiring, suffocating,

and exhausting for the patient. At the outside, the tumor was black looking like necrosis of tissues but at the inside, the tumor was ulcerated, bleeding and was oozing with secretions of distinct odor. In the inner side of the tumor were the small white bodies of maggots. The nurse asked the attendant to provide the medicine to be applied to the wound. The woman who was the patient's wife remained standing at the distance but among the two young girls, one, the elder daughter of this patient, moved to her father's bedside and from the drawer at his bedside cupboard, she took out the medicine and she assisted the nurse to apply the medicine to treat the maggots in the wound. Although I admired the daughter's bravery, I also witnessed the misery of the patient and the family members who were present. The second young girl who was caring for her father, also bore the burden of witnessing the distress of her father. He (the father; patient) throughout the procedure was laying still without any reaction. I was wondering why? Was he not feeling any pain or he was feeling it but because he had gone through so much pain and suffering that he stopped expressing it? It could also be possible that he had accepted pain as part of his life. He was quiet and non-reactive/non-expressive like a mannequin but in reality, to my analysis, he was suffering in silence. Maggot infestation is an extremely distressing problem. The sight, smell and stigma can lead to the patients being very disturbed. The person may feel rejected by the family, healthcare providers and others in the society. It is also possible that the sight of maggots could frighten the patient and the caregivers. So it is difficult to find the best way to support people with maggots in their wounds. The nurses have little time to care for such patients.

While looking at the nurse changing the dressing, I did not see any expressions on his face. He was just focused on the task of changing the wound dressing. I wondered if the nurse doing such a difficult and distasteful yet very necessary dressing was experiencing distress and if

so, I wondered how he managed it. Witnessing such suffering of patients and their family members could cause the nurse distress. Working in such clinical settings where advanced cancer is present with almost every patient, witnessing so much of misery or pain yet remaining present and performing what needed to be done, requires lots of endurance and patience. The professional way the nurses managed such a disturbing task was admirable.

Once the dressing was changed the woman and her younger daughter moved away from my participant's bedside and with his permission, I continued the interview (P004). After this interview, I looked for the wife of the patient with the wound that I described above, but I did not find the woman until I moved downstairs. The woman was sitting in the visitors' lounge because after the visiting hours only one attendant could stay with the patient. Her elder daughter was present in the ward as an attendant.

When I invited the woman (wife of the man with oral cancer I described above) to participate in my research, she immediately asked for money. Once she understood I was a researcher, she agreed to participate (FM003). In describing her husband's disease she talked about his habit of chewing ghutkka (a sweetened mixture of chewing tobacco, betel nut, and palm nut). The participant said, "I don't know since when. We are married for 19 years. Since then I see him (her husband) chewing ghutkka"¹⁵(FM003), a habit he continued after their marriage. Although she wanted him to discontinue chewing this substance, this did not occur. The participant explained that her husband worked on a small scale shoe factory as a shoemaker. In order to meet the expenses of the family, he brought work home in addition to working in the

¹⁵ Mujay sahi say maloom nahi hay, laykin hamari shadi ko oonis saal ho gay hayn tub say mayn iin ko ghutkka khatay howay dikhti hoon.

factory. Thus, he worked day and night. To suppress his desire for food so that he could concentrate and remain focused on his work he was used to chewing ‘ghutka’. Other participants who talked about ‘ghutka’ rationalized people use of ‘ghutka’ and other such substances to relieve stress, for a boost in energy to work and to suppress their hunger due to these individuals’ unaffordability of food but the easy accessibility and availability of these substances at a low cost. As one of the physicians said,

“It (betel nuts and ghutka¹⁶) is the cheapest thing and the most amazing part you can find it in every nook and corner of the streets. You won’t find the police, you won’t find a doctor, you won’t find anything which is important to life but you will find a cabin of paan, cabin of chalia everywhere. So it’s so commonly available, it is cheap and there was no awareness about it’s negative effects. These things contribute to people starting these types of habits” (HCP005).

Thus, among the people who use these substances, most of them are from low socio-economic backgrounds. These individuals experience the short-term relief of the feeling of hunger suppression and an energy boost; they are often unaware of the dangers of using these substances explaining their continued use.

¹⁶ It has been reported that these products are consumed for perceived beneficial effects, such as mouth freshening, aid in digestion, germ-killing, astringency, mood enhancement, tension relief, and oral cleaning. *Gutkha* is sweet in taste, and children consider it to be a form of candy. Many people believe that *gutkha* is a mouth freshener, but its pleasant taste and sweetness aggregate microbes, causing damage to teeth. The use of *gutkha* is difficult to control in most countries where it is widespread, and its extensive use leads to oral cancer. Over three decades ago, a tobacco industry emerged in India producing *gutkha*, which consists of slaked lime, areca nut, chewing tobacco, spices, and catechu packed in tins or pouches (Niaz et al., 2017).

The participant (FM003) described her husband's oral cancer as starting below his lip as a small tubercle that could be noted by anyone who saw him. Even when people told him that it is a sign of cancer he did not accept that it was an early sign of cancer. It is unclear if he did not accept that it might be cancer due to disbelief, denial, and the cost of getting a diagnosis or if he felt he had no other options. Regardless of the reasons, he did not pay any attention to it. However, as the growth increased he went to Jinnah Postgraduate Medical Centre, a public hospital where he was diagnosed with cancer. After hearing the diagnosis of cancer, the entire family was emotionally upset and was crying. One would wonder what could be the reasons that the participant's husband or even his family did not pay any attention initially when the growth was small even though people who are connected to them were telling this could be cancer. He might have had a great fear of it being cancer, as participants in my research expressed that contracting cancer in Pakistan leaves people with little hope of survival. Consequently, in the initial stage of the disease, he avoided seeking medical attention, but this avoidance did not help him. He went to a public hospital funded by the government of Pakistan to provide free of cost services to the patients. As the hospital has limited funds it cannot provide all the services that are required by the patients, leaving patients and their families to arrange these services on their own. This participant's (FM003) husband received diagnostic services like Magnetic Resonance Imaging (MRI), a bed for in-patient admission, and chemotherapy. But he needed a medicine which was not available in the hospital. Therefore, the family had to buy medicine from a pharmacy. The participant and her husband could not afford the cost, therefore the participant's sister-in-law (her husband's sister) provided money to pay the cost of medicine. Such details at one point identify the presence of the social support system but simultaneously indicates the pressure on the immediate and extended family members when an individual is sick and suffers.

I not only witnessed but have also experienced it. When patients and families are unable to arrange the cost of treatment, they do not receive the treatment.

Even though the participant's husband was under treatment at Jinnah hospital for two and a half years, he did not recover from cancer. Instead, his condition worsened. I am describing it here, but this is what the participant said, "At [the public hospital] they did not take care of him. The care over there is almost absent"¹⁷ (FM003). Providing an account of her experience the participant said,

"...even when the stretcher was getting dirty and if we say to the staff there to please clean it but they would respond 'this is it if you like fine otherwise put (the patient) on the floor.' They were not at all caring. What should I say? I can just say that may Allah guide them so they can provide better services to their patients. I pray to God to please give them the doctors and nurses (humbleness) so they provide better services to the patients who are in need"¹⁸ (FM003).

This description indicates a lack of resources at this public hospital affecting the provision of care. The participant claimed that her husband was not provided with the correct treatment and his case was mismanaged. The participant's description of her husband's disease process demonstrated evidence of the ordeal that her husband and the entire family were going

¹⁷ Wahan (sarkari hospital) iin (aurat kay shohar) ka sahi khayal nahi rakha gaya. Balkay wahan to khyal rakha hi nahi jata tha.

¹⁸ ... balkay jub hum nay staff say kaha kay stretcher ganda hay please iis ko saaf kardayn oonka jawab hota yahi hay. Chahiya to iistamal karo warna mariz ko zameen par lita do. Woh (staff) bilkul bhi care nahi karta tha. Aab mayn kiya bataoon. Mayn sirf itna kah sakti hun kay Allah iin ko hidayat day takay woh marizon ka sahi khayal rakh sakayn. Mayn Allah say dua karti hunk kay iin kay dil may reham payda kar takay yah log iin ka khayal rakhayn jiin marizoon ko iin ki bauhat zaroorat hay.

through. Accordingly, when the participant's husband was earning, the participant did not need to work. Instead, she was fulfilling her familial roles and household responsibilities that included taking care of the family. However, when her husband was sick he was not able to continue his employment. Therefore, for financial reasons, the participant looked for a job and she was employed at a medicine packing company. Her working hours were 12 hours (0800- 2000 hours) and the time for her round trip travel to work was about 90- 120 minutes. Thus, she was not available at home to take care of her children. Also, she could not accompany her husband during his treatment at the public hospital. So the family came together to support both the ill father and the mother who must now work. The elder daughter, who at that time was around 16 years of age stayed as an attendant with her father while he was hospitalized. Also, while the father was at home the daughter provided the care which included cleaning and dressing the wound, and assisting with activities of daily living, such as feeding and giving medicine. The illness that was caused by consuming 'ghutka' so that he (the participant's husband) could work, however, in the end, caused him and his family to suffer physically, financially and psychologically. All of this suffering is connected like a spider web.

When the mother (the participant) went to work, her 11-year-old daughter was afraid to stay home alone. The participant said,

“As we are sharing the house (with participant's brother's family), my brother's kids, as they are young, when they go out of the home for something or the other they are not

used to locking the door properly (when they leave them home). So there was a threat; what if someone enters the home...”¹⁹(FM003).

Thus, the participant was fearful of her younger daughter having to stay home alone. To be with her daughter, the participant left her employment. Financially the family started surviving on the aid and support from the members of the extended family, friends, and neighbors. The elder daughter continued providing care as an attendant to her father while he was at the public hospital and when he was home. Once, while being hospitalized her father fainted, the family called the on-duty doctor. When he came to attend the patient the doctor was upset at the attendant (participant’s elder daughter) for not properly cleaning the wound which resulted in the development of maggots in his (patient’s) wound. “They (maggots) were so big in size...”²⁰ (FM003). The participant added, “My daughter removed these maggots from his wound. About 300 (numerous) maggots that were removed...”²¹(FM003). The 16-year-old daughter experienced the hardship of having to clean a wound that would be considered by many to be disgusting and then received recriminations from the doctor because she had not done it properly. Likely, she was doing her best in challenging circumstances. The participant explained that her daughter was cleaning the wound from its outer side by using Dettol, an antiseptic. She

¹⁹ Hum log mayray bhai kay saath rahtay hayn. Meray bhai kay buthcay chotay hayn. Jub woh ghar say bahir jatay hayn ghar ka darwaza khula chor kar jatay hayn. Chaunkay darwaza khula hota hay kissi kay bhi ghar mayn aanay ka khatra laga rehta hay. Iis liya mayn dari rahty thea (kyun kay meri beti ghar mayn akayli thea).

²⁰ Woh (kiray) bauhat baray thay (here the participant through her indexed figure shows the size which estimated to be 4-5 cm).

²¹ Meri beti nay takriban teen so say ziyada kiray (apnay walid kay zakham say) nikalay thay.

had no idea that the inside of the wound was to be cleaned. I wondered who was responsible for such an outcome.

“The doctor said (to her daughter) that you did not clean the wound properly; you did not take care of it properly. We were cleaning the wound from outside we did not know about cleaning the inside of the wound. My daughter was used to clean the outer layer of the wound but the maggots were inside the wound...”²² (FM003).

Handing over treatments to the patient or the family members requires teaching, demonstration and return demonstration of care. It seems like either the daughter misunderstood, or the teaching was missed in this scenario. Also when the patient came for the follow-up appointments it is unclear why his wound was not being assessed, Who is to be held responsible for the deterioration of his condition? The healthcare team members, being in a privileged position, shifted the responsibilities onto the family and the patient, who then were accused of not doing the treatment correctly. How ethical was this act?

As I analyze the situation the participant’s husband was receiving care at a public hospital but its quality was questionable. Looking at wounds filled with maggots is painful even for me not related to the patient and a nurse accustomed to seeing unpleasant things. I was disturbed to an extent that it affected my nerves, my rest, sleep pattern, and my appetite - it depressed me. It took me a few days to get out of the depression. Not that I had never seen maggots. I had seen maggots also in a living human body. Many years back when a young person lost in a plane

²² Doctor nay meri beti ko danta. Kaha kay tum nay zakhum ko sahi say saaf nahi kiya. Hum (meri beti) zakhum ko sahi say saaf kar rahay thay. Meri beti bahar say zakhum saaf kaar rahi thee. Woh (beti) to bahir say zakhum saaf kar rahi thee. Maggar zakhum kay andar kiray per gay thay.

crash and then was found with multiple injuries, he wheeled to the operation theater for correction of these injuries. Whereas this participant's (FM003) husband was under treatment at a recognized hospital, yet he developed maggots in his wound. Who is to be held responsible - family or healthcare providers? I wondered what could be the reasons that the patient (participant's husband) could not feel maggots moving on his body. Were his nerves damaged so that he did not feel maggots present in his body? It could be possible that he lost interest in his life thus he started neglecting himself. Whatever was the reason, the maggots were feeding on his flesh and were visible through a hole in his right cheek.

As the patient's oral cancer condition deteriorated at the public hospital, he was referred to Biat-ul-Sukoon Cancer Hospital. Once there, the family learned that there was nothing much that could be done, rather hospice care was possible and would be provided. The family was also informed that the patient's condition was poor and he could die at any time. The patient's wife (the participant) was shocked and upset after getting such news. She needed her husband to be alive financially as well as emotionally. The participant would be loaded with so many responsibilities if her husband died, as there would be no one to share them. She believed she would lose the support from her in-laws as she may feel they have no further responsibility towards her and her children. Listening to her anxiety as she described the change in the social dynamics that would occur if her husband died revealed her anxiety about whether she would be competent to handle the challenges before her. What this participant described is that the physical, emotional and social suffering is embedded deeply within each other such that these are inseparable.

When this family came to Biat-ul-Sukoon the family learned that according to the hospital policy only a male attendant could stay with a male patient during the night shift. Since

the family did not have a male child, other family members were required to provide this service. Male members from the participant's in-law's family were taking turns for the night shift to stay as an attendant. The same contribution was expected from the male members of the participant's mother's family. This, on one hand, highlights that although the culture is supportive, individuals are required to contribute their resources- time, energy, and finances to list a few. But on the other hand, these contributions may require compromising oneself or the person's individual necessities for living.

Suffering due to cancer pain.

Most of the patients who come to Bait-ul-Sukoon are at a stage where their disease could not be cured. Therefore, the focus of their treatment was on palliative care for pain management and comfort care. A patient with oral cancer described his pain, "I feel heaves in my teeth" (P004). He was experiencing sharp and sudden pain. When he received the medicine some of his pain was relieved, but he was not pain-free. He had to tolerate the pain. Healthcare providers explained that in hospice care a patient's pain management was of the utmost importance and was the priority. Doctors and nurses assessed pain and liaised with the pharmacists about pain control. However, healthcare providers explained that a patient's pain management was their biggest challenge because most of these patients need "morphine sulfate" (HCP001) and their pain could not be adequately managed with other types of analgesics, but for a long time "morphine is not available throughout Pakistan..." (HCP005). To manage pain the healthcare providers administered tramadol (a synthetic opioid for pain relief for mild to moderate pain) in adjunct with sedatives like midazolam to sedate their patients. Thus, sedation was used to manage pain due to a lack of analgesics. However, prior to heavily dosing the patient, the physician thoroughly explained to the patients' family members about the effects of tramadol; it

will induce sedation and will cause nausea. The purpose of pain management is to improve the patients' quality of life - sedation defeats the purpose due to side effects including nausea, which can be unbearable. As a physician describes that, "At times it happens that patient gets more sedated and feels nauseated..."²³ (HCP004). "...So at times we get the request from the attendant, and at times the patient himself also comes in refusal phase (does not want to take sedatives)"²⁴ (HCP004). This indicates that the patient and the family need to choose the discomfort of severe nausea or pain and when the patient's nausea is intolerable they opt for suffering pain.

Although the WHO recommends opioids with or without non-opioids and adjuvant therapies, opioids are not available for patients even when they experience moderate and severe pain. Based on my observations in the field, experience as a nurse in Pakistan and the descriptions from the healthcare providers who participated in my study, the processes for obtaining morphine are cumbersome. A hospital must be licensed by the narcotic control agency in the country. Licensed hospitals are provided with a limited stock of narcotics and are required to secure these drugs under strict control, such as locking the medicine in a safe with double doors each with a separate key. Additionally, when morphine is used, the healthcare team needs to maintain the evidence that the drug was used for the patients and there was not any pilferage of the drug. A registered nurse or a physician who administers the drug saves the empty ampule or the vial in the narcotic cupboard and documents the patients' information in a narcotic record. The information includes the patient's name, medical record number, diagnosis, the amount of

²³ At times (kabhi kabhi) aysaa hota hay kay patient bauhat ziyada sedate ho jata hay aur iis kay saath oosay nausea bhi hota hay...

²⁴ Iis liya patients aur iis kay attendants hamayn (tramadol daynay ki) mana karday tay hayn.

the drug administered, name and designation of the person who administered and the witness. The registered nurse sends the empty ampules and morphine record sheet to the pharmacy. The pharmacist saves these in order to procure the next consignment of morphine. Failing to maintain the proper documentation, or not saving the empty ampules, or lapsing in other processes of narcotic control protocol, may result in the hospital being disqualified from receiving narcotics which are already short in supply but are much needed for cancer pain management. Thus, the healthcare providers dealing with narcotics are held responsible and the hospital administration monitors their performance. Describing her experience the pharmacist who participated in the study said,

“We have to keep a very strict check. We have to maintain our inventories very well, and we need to have the correct patient record and we have to take down the consumption record and have to have a written record and a physical record and a system record (record in a computer) just to, you know, very stringent control over that. You know those controlled items because if something happens we will, I would be responsible if it is misused” (HCP002).

The pharmacist seemed overwhelmed with the accountability of administering opioids as it required so much evidence to support that the drug was used for patients and was not stolen for drug trafficking or for trading-it-off illegally.

The pharmacist said, “... it (morphine) is very difficult to acquire.” (HCP002) and it is not available in the hospital. Therefore, till the morphine consignment is received, morphine is deleted from the Bait-ul-Sukoon formulary. The participant said, “... for now it (morphine) is off the formulary because we do not want the doctors to keep prescribing it when we do not have it” (HCP002). The healthcare providers’ descriptions indicated that although morphine was required

for pain management, it was not available. Although, none of the participants offered the exact reasons for the non-availability of the drug, what they described indicates that either the government does not provide the required substance to the pharmaceutical companies, or the companies, to raise their profit for providing morphine for the hospital formulary, have reduced drug production and supply. Whatever the reasons, the physician was troubled that the unavailability of morphine caused patients to suffer. “Especially when they are terminally ill, the last stage, stage four cancer patients. It’s troubling them a lot” (HCP005). The physician said, “I have seen patients dying due to unavailability of morphine” (HCP005) because their severe pain is not controlled by medicine other than morphine, yet, it is not available.

Although opioids was unavailable in the hospital for cancer pain management it could be obtained through drug dealers who trade it via illegal channels. Families desperate to relieve their loved ones’ suffering took risks and identified and used illegal routes, to obtain morphine. This is depicted in the description of a physician. He said,

“A female patient... had breast cancer. Her cancer has now severely metastasized to her bones. We repeated the bone scan and not a single bone is left unaffected. She is having pain throughout her bones. We tried all the other pain control medicine but nothing is working. She is in a need of morphine but it is not available. Her husband said he is trying to arrange it through the drug dealers to keep his wife pain free. So if you do not provide morphine legally people will try to get it through illegal sources” (HCP005).

Cancer pain is a bitter experience not only for patients but also for the patients’ relatives, healthcare providers and others who witness patients in cancer pain. Morphine is required for cancer pain management. In LMICs, which includes Pakistan, morphine is not available for all

who need it for pain management. However, why do these country's medical centers not have access to morphine, yet opioids can be obtained easily illegally.

Suffering due to resource constraints and corruption.

The provision of palliative care requires an immense amount of resources. These include accessing the healthcare providers, healthcare facilities and diagnostic services, care and treatment. However, the accessibility of the required resources is hampered due to the low availability of these resources. Additionally, many of the resources that are available are obstructed by the individual gatekeepers in the healthcare system. When this occurs participants described it as corruption in the system. This is what a participant described and I will expand on it shortly in this section.

When patients are on chemotherapy and radiation their bone marrow gets affected and they suffer the symptoms of low blood counts (low hemoglobin, white blood cells or platelets). Their energy which is already compromised due to disease process reduces further with low hemoglobin. Thus, they require blood products, which must be arranged by the family members who either donate their own blood or they buy blood. Low white blood counts also add to the patients' susceptibility to infection. Patients' misery increases when their nutritional intake which is already compromised due to severe nausea and vomiting, gets further compromised when they cannot take food orally but need enteral feeding. However, enteral feeding is not always easily available. This is depicted in the description of a physician. He said,

“...The other thing is that palliative patients required few palliative procedures and for that the patients go through a lot of hassle. For example, we need to get a gastrostomy. If you go to a private hospital then it will be costly for the patients but if you go to a government (public) hospital, as the burden is huge, there is a very long queue.

Gastrostomy, tracheotomy, jejunostomy, endoscopy. Most of these procedures are required for patients requiring palliative care. We (Bait-ul-Sukoon) cannot perform these. So the patient's survival period, which is the palliative period and which I understand is to improve the quality of life in what is remaining in the life of an individual (patient) is affected. In fact, it gets difficult because we cannot perform what they need"²⁵ (HCP004).

Insufficiency of the required resources leading to delays in accessing care was asserted by most of the participants. Thus, they advocated for an increase in access to palliative care. This is depicted in a participant's description: "In Pakistan (for palliative care) the required resources are almost not available at all"²⁶ (P004). In Pakistan and other countries in LMICs where there is not a balance between demand and supply of healthcare resources, individuals must wait long periods of time before they can access these resources. As a patient said, "Wherever, you go you have to wait in the queue..."²⁷ (P004). The participant described that waiting as not only due to lack of resources but also due to corruption in the system. He said,

²⁵ Aur yah kay palliative patients ko palliative procedures ki zaroorat hoti hay jis kay liya patients ko bauhat say hassle say guzarana parta hay. For example oon ko gastrostomy ki zaroorat hoti hay. Iis kay liya agar woh (patients) private hospital mayn jayn to wahan ka kharcha bauhat ziyada hay. Laykin agar woh (patients) government hospital (public hospital) mayn jayan to wahan lumbi linay lagee hoti hayn. Gastrostomy, tracheotomy, jejunostomy, endoscopy takriban yah saray who procedures hayn jiiin ki palliative patients ko zaroorat hoti hay. Hum yahan (Bait-ul-Sukoon hospital mayn) yah procedures nahi karsaktay. Iis liyah patient ka survival period, jo kay palliative period hay, aur jo mayn samjta hun kay quality of life ko behtar bananay kay liya hay, woh hakikatan mazid mushkil ho jata hay kunkay hum oos (patient) kay liya woh nahi karsaktay jiiis ki oos ko zaroorat hay.

²⁶ Iis illaj kay liya (for palliative care) jiiin chizon ki zaroorat hay woh Pakistan mayn maujud nahi hayn.

²⁷ Aap kahin bhi jayn app ko aik lumby katar may intizar karna parta hay.

“...by the time he (a person) gets the turn he is on the verge of dying. He goes with a small problem and by the time his turn comes (he accesses the treatment) his disease spreads due to waiting in the queue for such a long time. So waiting in the long queue one spends half of his life. So what is that he will get? So how can (we) save ourselves? How can a person save this life? You just think over it...In our [public hospital] we have agents who cheat the people who are in need. The hospital staff are the agents. They trap the people....”²⁸(HCP004).

The participant added that,

“This (corruption) is for sure. This is what we note. We observe all that is going around. To whom should we say these things? Our government is also a thief. Our prime minister is not on the right path (to not be corrupt); our president is not on the right path, so how come our people would be on the right path. How would the country be on the right path? A person working as a peon to the person working as the president, all of them are taking bribes. So what will happen?”²⁹(HCP004).

²⁸ (Woh jo katar (line) mayn khara hay) jub tak oos ki bari atee hay woh marnay kay karib hota hay. Woh (shakhs) aik chutti sii taklif say (hospital) jatta hay aur jub tak oos ki baari atee hay oos ki bimari bauhat ziyada phayl jatee hay. Sirf iis liyah kay woh line mayn appnee bari ka intizar kar raha tha. Lumby lumby laeeno mayn intizar kartay howay iis ki adhi zindgi khatum ho jati hay. Oosay kiya mila? Hum apnee zindgi ko kiya bachayn? App khud hi sochayn. Hamay yahan (sarkari hospitals mayn) agents bathay howay hayn. Yeh wo log hayn jo oon logon ko cheat (dhoka dayana) kartay hayn jo zarooratmand hayn. Hospital mayn staff hayn jo agents hayn woh logo ko trap kartay hayn...

²⁹ Yakinan yeh corruption hay jo hum nay daykha hay. Hamaray ird gird yahi sub khuch ho raha hay. Laykeen hum yah sub kis ko batayn? Hamari government khud chaure hay. Hamaray mulk ka president, hamara wazir-e-aazam khud theak nahi hay. Woh (president, aur wazir-e-aazam) khud sahi rastay par nahi hayn tau hamaray laug kaysay sahi rastay par chalsaktay hayn? Hamara mulk kaysay sahi rastay par chal sakta hay? Jub peon say laykar president tak har koi rishwat layta hay to phir kiya hoga?

The participant said that for moving ahead in the line for consultation, investigation, getting a bed in the hospital, medical treatment and procedure, patients bribe these healthcare agents. Thus, bribing improves a few individuals' access to care and for others, it delays their access. Even, when bribing, the amount paid impacts on how fast the case or the patient's file is moved forward. Such experiences indicate that systems are rooted in corruption even when care is free in public hospitals. What the participant described about paying bribes to access care in public hospitals is supported through corruption in the system. In Pakistan, besides public hospitals, there is a system of private hospitals. However, to access a private hospital, people must pay, which maybe is more than the amount required to bribe in the public hospitals. All in all the cost of care is high in comparison to most people's financial standing. Such descriptions reveal that the reality is far from what the WHO promotes through a sustainable development goal 3.8 to "achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all" (WHO, 2017d).

In summary, the suffering that patients and their families suffer is extensive, but it may not be quantified. Suffering that patients and families suffer - physical, social, psychological, and financial all are intermingled such that they cannot be separated.

Healthcare Providers' Suffering

Healthcare providers suffer because of what they have to do, what they witness, and by the negative behavior of distraught people. A physician who participated in the study described how the patients' suffering emotionally affected him as a healthcare provider. The physician said,

“Sometimes we get so much attached to the patient, to their families, to their problems; some (patients) are so poor that they cannot even afford some basic drugs like Panadol. So that’s the bad part, the feeling I get working with them is not good.... We become emotionally attached to the patient especially those patients who come to us in an early stage of the disease. When these patients, instead of getting better, get worse day- by- day, we develop a bond with those types of patients because we are watching them getting worse day by day. We do not become directly emotional (emotionally attached) with a stage four patient; we become emotional with the patient whom we have personally seen getting worse day-by-day” (HCP005).

Such descriptions from the healthcare providers indicate deep emotional distress that may affect their own health and well-being.

While I interviewed the pharmacist, she appeared to be having deep feelings about patients’ suffering from cancer, based on her countenance when she related her experiences. I also observed feelings of unhappiness in the gestures and facial expressions of a few of the healthcare providers on duty. These care providers stated that working in palliative care was not a rewarding experience rather it made them feel unhappy and evoked moral distress. Participants elaborated that they became emotionally attached to their patients and witnessing patients suffering deeply depressed the care providers. Recalling vividly about a patient a physician said,

“I recall we had a patient. Throughout his life, that patient struggled a lot and when he was getting sound (his socio-economic status was improving) his marriage was being planned but suddenly before his marriage, he developed cancer of the colon. This was a difficult phase. All his family members were crying and all our healthcare providers were

very much upset. So we are attached with the patients and we feel down (emotionally disturbed)”³⁰(HCP004).

Describing how the healthcare providers suffer by witnessing patients’ suffering, as well as the lengths they must go to in providing care a physician participant said,

“If a patient is with cancer of the cheek, the patient’s wound gets so bad. It develops maggots. Those who come to us are full of maggots. These patients do not even know about it until they (the patients) see the maggots drop from their bodies on the floor, here and there. We have seen so many patients whom we needed to isolate in a separate room. We needed to seal the door through clothes because maggots were surrounding on the walls, bed, they spread all over. We receive patients in such conditions. We clean the patient, change the dressing, and apply the maggot oil (a medicine) through this care in most of the cases in four to five days the patient gets maggots free. Proper BID (twice a day) dressing morning and evening; our staff changes the dressing. It gets resolved”³¹ (HCP004).

³⁰ Mujay yaad hay meray paas aik patient thaa. Oosnay appni poori zindgi bauhat ziyada mahnat ki. Jub ooski zindigi behatar honay lagee oosay Ca colon hona shroo hagaya. Oos ki shadi honay wali thea laikin achanak hi shadii say pahalay oosay ca colon hogaya. Woh waqt bauhat mushkil thaa. Bauhat hi mushkil halat thay. Woh waqt oos ki family kay liya bauhat hi taklifdehay that. Oos kay saray ghar walay ro rahay thay aur hum sub bhi (hospital staff/healthcare providers) bauhat ziyada upset thay. Hum patient say bauhat attach hogay thay. Hum khud bhi bauhat low fee kar rahay tahay.

³¹ Agar koi patient ca cheek kay saath hay, patient ka wound itna kharab ho jata hay kay oos may maggots ho jatay hayn. Woh patients jo full of maggots kay saath attay hayn iin patients ko patta bhi nahi hota (kay oonkay zakhum mayn maggots hayn). Oonhayn to patta hi tub chalta hay jub maggots iin ki body say zamin per yahan wahan girtay hayn. Hum nay aaysay bauhat say patients daykhay hayn. Iin ko hamayn aik separate room mayn isolate karna parta hay. Hum oon kay room to kaproon say seal karday tay hayn. Kuyoon kay maggots itnay ziyada hotay hayn. Woh (maggots) pooray mayn phayl jatay hayn, bed per, diwaroon per, phayl jatay hay. Patient hamary pass iis condition mayn atta hay. Hum patient ko clean kartay hayn. Oos ki

It was shocking to hear how many wounds in the human body were full of maggots, which were dropping and crawling on the floor and on the walls in the patient's room and the healthcare providers had to put something under the door to block the maggots from entering the entire ward. One can only imagine how distressing that would be to healthcare providers who had to manage both the patient's discomfort, and ensure that the maggots did not spread to other patients.

Healthcare providers also suffer safety issues when they receive threats from patients and/or their families because they did not understand that nothing more can be done. Describing it a physician said,

“Sometimes we are threatened, we are abused, and we get harassed (by the patients' family members). They say you are doing nothing for our patients. Though we want we cannot; there is nothing that we can do because cancer has spread so much. We cannot give all the medicines that are required by the patient because his liver is involved, his kidneys are involved. If we give some medicine, that medicine would stay in the body. It will not be excreted. Therefore, we cannot do very much and their attendants think that we are sitting on a chair, doing nothing. They believe that if we start working we can save the patient but it is not the reality” (HCP005).

Some of the reasons family members had such reactions could be due to them not accepting that their loved one is at a stage where the prognosis is not good. I will elaborate on the

dressing change kartay hayn aur maggots oil apply kartay hayn. Iis tarha say char say panch roz mayn patients maggots free ho jata hay. Staff (nurses) ahee traha say din may do bar; morning, evening properly dressing kartay hay. Iis tarha say maggots khutum ho jatay hayn.

theme of late diagnosis. These reactions could also be based on family members' previous experiences of corruption that I mentioned earlier in this section.

Threats not only jeopardize the safety of healthcare providers and put them in danger, but it also adds to their stress and demotivates them from working. As a physician said, "Not in this hospital. At JPMC (Jinnah hospital) in an oncology ward, a patient's attendant took out his gun and pointed it on my forehead. He wanted that I see (attend) his patient first" (HCP005). The other physician said, "I regret to share that here (in Pakistan) there are people who get aggressive, they shout and scream. This is the reality"³² (HCP004). The healthcare providers' descriptions indicate that working in the palliative care setting, most of them experience emotional distress and they feel powerless when they cannot do much for their patients. These care providers also must safeguard themselves from being abused by patients' relatives who may become violent. These expressions of violence could be because family members cannot handle the stress related to the health condition of their loved one or that after facing corruption in public hospitals, they believe there is no help to be found, despite their best efforts. A healthcare provider said,

"The biggest challenge that we have is our safety. The most important thing is safety. I am not talking only about here (Bait-ul-Sukoon Hospital). I am talking overall about healthcare (in Pakistan). It is very common. Probably 20% of the attendants do not want to hear that the patient's condition is untreatable. It is when the cancer is diagnosed and it is at the advanced stage, there are people who do not want to hear that and they do not

³² Muajy intihai afsoos say kahna par raha hay kay yaha (Pakistan mayn) aysay log hayn jo bauhat jald hi agreesive ho jatay hayn. Woh shout aur scream kartay hayn. Yah aik haqiqat hay.

want to accept this as a fact. Consequently, we have to face the aggressive behavior (of the family members)”³³ (HCP004).

As mentioned earlier, when diagnosed with cancer, a majority of the patients are at the end-stage of their disease. Their disease cannot be cured, and palliative care is needed. Thus, when the family is informed about the patient’s diagnosis, family members who get violent often have an extreme reaction. These reactions can endanger them, the patients and the healthcare providers.

Physicians were the healthcare providers who most expressed their distress in the interviews. But I also witnessed the same distress in other healthcare providers through their expressions and gestures.

However, while the healthcare providers described their suffering, they also talked about what they are doing to improve their situation. They said they socialize with their own family, friends, and others in their social circle. Talking about its importance a physician said,

“... We have to continue with this work (provide palliative care services). If we ourselves get into this phase (remain depressed) then what is the fault of the person who is coming to us (for receiving services/care). It is us who have to take care of these patients and if we make any error then that individual patient will suffer (bear the consequences). Therefore, we need to forget these things, freshen up ourselves, and

³³ Sub say bara challenge hamari safety hay. Harami safety sub say ziyada aham hay. Mayn sirf yahan (Bait-ul-Sukoon hospital) ki baat nahi kar raha hun. Yeh har jaga common hay. Qarib 20% attendants aysay hayn jo yahay sunna hi nahi chahtay kay oon kay patient ki condition aissy hay kay woh theak nahi hosakta (bimari khutum nahi ho saktee). Aysa oos waqt hota hay jub cancer advance stage per diagnose hota hay. Aysay log hayn jo yah soonna hi nahi chahtay aur woh iis haqiqat ko accept hi nahi karnay chatay hayn. Yahi wajah hay kay Hamayn iin kay aggressive behavior ko face karna parta hay.

come back in the working situation. Moreover, most of the time this happens with us. It certainly happens”³⁴ (HCP004).

It is important that the suffering that the healthcare providers experience is recognized.

Recognizing that they are affected by what they experience and witness and then using strategies to address their feelings of suffering allows them to continue in their role as healthcare providers.

³⁴ Hamayn appna kaam continue rakhna hota hay. Agar hum khud hi iis phase (depression) mayn per jayn to oon logoon ka kya kasoore hay jo hamaray pass (illaj kay liya) aatay hay. Hum hi hayn jinhayn iin patients ka care karnay hota hay, oon ka khayal rakhna hota hay. Agar (depress rahaynay say) hum say koi galti ho joaygi to iis ka nuksan patient ko hoga. Iis liya Hamayn yah batayn bhool kar, khud ko refresh karkay dubara working condition mayn aana parta hay. Aur hamaray saath aisay aksar hota hay. Yaqeenon yah hota hay.

Chapter Six: Findings: Late diagnosis

A lack of access to appropriate health care due to cost, location, cultural and religious restrictions results in late diagnosis. A theme of late diagnosis is prominent in the descriptions of the participants from all the three groups: patients, family members, and healthcare providers. Late diagnosis means receiving the diagnosis of cancer at a very late stage when it has locally advanced or has metastasized, limiting treatment options. As seen in the preceding chapter, this results in extreme physical deterioration, pain, fatigue, and inability to work to support their families, resulting in increased emotional distress and financial burden. The theme, late diagnosis, includes five sub-themes that influence the ability of people with advanced cancer to access and receive appropriate care. It also influenced people's will and ability to access a proper cancer diagnosis. The late diagnosis makes treatment less likely to succeed and it reduces the person's chances of survival. The five subthemes that contribute to late diagnosis are culture and beliefs preventing individuals seeking medical healthcare; living in poverty; lack of knowledge; experiencing difficulty to access and failure of the healthcare system; and lack of cancer prevention for the study population.

Culture and Beliefs Preventing Individuals Seeking Medical Healthcare

Among the patients coming to Bait-ul-Sukoon, the majority come when they are at the end stage of their disease. This is evident through the description of a healthcare provider working as a registered nurse at Bait-ul-Sukoon. He said,

“If we are getting 100 patients then among these 3-4% patients are at the 1st stage of their disease. Others are at the advanced stage of their disease. Among the patients who come

(to Bait-ul-Sukoon Cancer Hospital), there are many who do not know that they have cancer....”³⁵ (HCP001).

Describing the reasons for individuals coming at an advanced stage of their disease the nurse said,

“...actually, in Pakistan, there are many systems: Unani medicine, homeopathy, dum durud (religious healers). Patients who have cancer are very depressed. Also, they have a lack of knowledge. In such a situation they accept whatever they are being told by others (e.g. neighbors and others in their surroundings). They just follow what others tell them as a guide to them. They are being told to go to this person or that person. Someone says to go to this ‘hakim’ (homeopath) or that religious healer and they just go there to seek care. In this way, they lose the time which is critical for diagnosis and treatment.

Important time is wasted. Therefore, they get late in reaching the doctor”³⁶ (HCP001).

In Pakistan, for many, it is a common occurrence that their cultural belief is to seek treatment from a homeopath or religious leader. Most of the time when a person goes to

³⁵ Agar haftay mayn so (100) cases atay hay to iin mayn say tin say char percent (3 -4%) first stage per aatay hayn. Baqi sub advance disease per aatay hayn. Patients jo hamaray pass (at Bait-ul-Sukoon) aatay hayn oon mayn say bauhat say woh hayn jo nahi jantay kayh oonhay cancer hay...

³⁶ ... assal mayn, hamaray Pakistan mayn bauhat say systems hayn; Unani wala system, aik homeopathic wala system hay, aur aik dum durud wala system hay. Jisko cancer hota hay woh bauhat depress ho jatay hayn. Oon ki knowledge bhi kum hoti hay. Iis waqat kissi nay kuch bhi bol diya yah (log) iis ko accept karlaytay hayn. Iis waqat agar kisi nay bola kahy hakim kay pass jana hay to woh point note karlaytay hayn aur hakim kay pass chalay jatay hayn. Aur iis tarha jo thora sa sahi waqat jo hota hay woh zaya ho jata hay. Iis kay baad jub woh doctor kay pass atay hayn to late ho jatay hayn.

homeopaths and religious healers, the person is engaged by these healers and is not allowed to take any allopathic treatment. Thus, the person's disease advances and enters the stage in which prognosis is not good. This is depicted in the nurse participant's quote as he said,

“When these patients go to a homeopath or religious healer, they [homeopath, spiritual healer] use their own treatment regime. They tell the patient to follow their [homeopathic, spiritual healing] regime and not to take any other treatment. They also instruct the patient to follow these instructions otherwise the regime will not provide the required results. This is how a patient's core time [to get timely treatment] is wasted and the disease gets to an advanced stage. Consequently, complications develop. [If cancer is detected at an early stage, chance of its adequate treatment are high and the person could be cured but] by the time the patient reaches the doctor, cancer is in the advanced stage and in most cases these patients come with metastases of their cancer. Metastasis of cancer to liver, bone or other parts of the body...”³⁷ (HCP001).

Sharing his experience of dealing with patients coming after they have been to traditional and spiritual healers, a physician participant said,

“People go to baba (traditional and spiritual healers). We also hear that the patients say that baba said this will heal in a year's time. So by the time the patient comes to us he has

³⁷ Jub yahay patients homeopathic, kisi ruhani banday kay pass jatay hayn to woh iin ko dum durudh karkay oos ko (mariz ko) mana kartay hayn abhi aap ko koi bhi goli nahi khani hay. Kissi doctor kay pass nahi jana hay aur kuch bhi nahi karnay hay. Samaj gay. Yah jo mera nuskha hay iisko istamal karna hay. Iis tarha mariz ka time zaya ho jata hay aur iisi arsay mayn merz bauhat phayl jata hay. Jub doctor kay paas aatay hayn to cancer bauhat phayl jata hay multiplication of cancer cell hota hay, aur mets ho jatay hayn. Ya to lungs mets, liver, bone, mets...

liver metastasis, bone metastasis and we cannot do anything for such patients”³⁸ (HCP 004).

Among the patients, there are individuals who come to the healthcare facility at an initial stage of their cancer. Thus, at the Bait-ul-Sukoon Cancer Hospital and Hospice, patients are provided care depending upon their cancer stage: first, second, third, or fourth. When they come at their initial stage, most patients receive a combination of surgery, radiation, and chemotherapy. At an advanced stage of the disease, hospice care is provided. So going to homeopaths and spiritual healers complicates the case. A physician emphasized that for serious health concerns, instead of listening to others and going to healers, individuals should approach the healthcare facility. But as we have seen in Chapter Five, approaching a health care facility is difficult and people wonder if they can afford the cost of the treatment. The other physician who participated in the study said,

“People go to healers, spiritual healers. I cannot say anything to somebody’s faith but for treatment, you go to the doctor. If your car gets stuck, you will go to a car mechanic. You will not go to a hairdresser for your car. So if there is some problem you should go to a doctor instead of going to a spiritual healer or an hakim baba” (HCP005).

Describing the barriers in accessing palliative care, a physician (HCP005) said that most of the healthcare facilities are in the main city, whereas many people live far away from these facilities. This participant also spoke about financial issues causing barriers in access to care. He said,

³⁸ Log baba kay paas jatay hayn. Hum bhi patients ko hay boltay howay suntay hayn kah baba nay kaha yah theak ho jay ga, aik saal mayn theak ho jay ga. Aksar jub mariz hamary pass atta hay to oosay metastasis ho jata hay, liver ka bone ka matastasis ho jata hay aur hum assay mariz kay liya kuch bhi nahi karsaktay.

“People assume healers are cheaper than private medicine but these healers may charge you [the person approaching the healer] something it may seem very small but in reality, it takes longer. Like, sacrifice a goat, sacrificing something in the name of God [so the amount for these things is quite high in comparison to these individuals’ financial standing]. When the patient comes to the doctor, the costs include the investigations as well as the medicines [so patient cannot afford to pay]. Here (at Bait-ul-Sukoon) everything is free” (HCP005).

Healthcare providers also talked about people using religion as an argument for their healthcare decision-making. Therefore, instead of going to a healthcare facility, people go to spiritual healers because they believe these healers will elicit divine intervention in spiritual and physical healing. A physician participant explained,

“What I believe is that the south Asian population, Indians, Pakistanis, and Bangolies, they have a very big place for religion in their life. We try to think of everything from a religious point of view. An act that we do, we see from the religious perspective; we check the act we are doing so it is not a sin” (HCP 005).

This participant (HCP 005) was concerned that people were using religion as a shield from facing reality. The participant said this approach is “religious immaturity”, “putting religion in everything” (HCP 005).

In contrast, a nursing staff member attributed late diagnosis among female patients to the cultural power dynamics in society and the implications to individuals’ decision-making processes. The nurse said,

“Women in the family play a role. They get very aggressive. They say (to the patient) whatever, we say you have to follow that. It is the woman in the home who has the

leadership. The one who is the head of the home, these are mostly mother-in-law, first these women they just hide the case. They say no male in the family should know about the disease. [This can occur when the problem is with a woman's reproductive organs like breast, the elder woman who the participant described as mother-in-law may hide it from the male members of the family considering that these are female issues and are not needed to be discussed with the male members in the family]. These heads of the family, here the mother-in-law have so much power that they use their own decision making. Consequently, by the time a patient reaches an oncologist the patient is at stage three or four of their disease"³⁹ (HCP 001).

In Pakistani culture, there is a head of the family and this is how the family relationships work. These heads are the decision-makers and gatekeepers through whom care is accessed. The head of the family influences individual family member's ability to go to a medical facility. In the above quote, the participant is referring to her mother-in-law who is the person in the family who holds the power and is the decision-maker. Her approval is needed for any action that is to occur in the family. However, power dynamics and decision-making processes in a family may depend upon the nature of the problem, family dynamics, female troubles, and how closely individuals hold to their cultural values and beliefs or allow them to shape their decisions.

³⁹ Khandan mayn aurtayn bauhat aggressive role karti hayn. Woh (mariz ko) kahiti hayn kah hum jo kahay tumhay wahi karna hay. Khandan ki woh (aurt) jo head of family hoti hay woh leadership role layti hayn, yah ziyadatar mother-in-law hoti hayn. Yah pahlay to kahti hayn kay ghar may kisi mard ko pata nahi chalna chahiya. Yah ghar ki bari, head of the family, mother-in-law bauhat hiziyada powerful hoti hayn. Yah apnay faisalay istamal karti hayn. Yahi wajah hay kah jub mariz oncologist kay paas pauhanchi hay woh stage three ya four mayn hoti hay.

When cancer is diagnosed late, the prognosis is poor and the person may die. This reinforces cultural views that cancer is a dangerous disease and will cause death. Therefore, people are fearful when cancer is diagnosed. Not only are women diagnosed at a late stage of their disease, but the same is also true for men. This was described earlier by a male participant, who was not paying attention to himself because he was busy with other priorities in his life, such as, providing for his family. This participant was 44 years of age. He had married when he was 20 and was the father of six children. His eldest son was about 22 years of age. The participant said, “After having the children, parents usually don’t pay attention to themselves. Their concentration is towards their children. They (parents) just remove their attention from themselves”⁴⁰ (P004).

Understanding an individual’s culture, values, and beliefs and their influence on the individual is not simple, but a complex phenomenon. This is depicted through the experience of a female patient with breast cancer that I narrate here. This woman is around 5.5 ft. in height, age around 33 years, married more than eight years, and she had conceived four times. First was a miscarriage at two months of gestation, the second was a normal delivery of a child who was five and a half years of age at the time of the interview. The mother breastfed this child. Her third pregnancy resulted in twins, a girl, and a boy. One twin was 1.5-kilogram necessitating admission in a hospital for incubation. As the mother was busy with both the twins, one at home and the other hospitalized, she did not breast-feed either of them. At the time of the interview, the children were two and a half years old. In the woman’s fourth pregnancy she needed to abort

⁴⁰ Bachu kay baad waldayn apni taraf tawaja hi nahi daytay. Oon ki (waldayn ki) saari tawaja appnay bachun ki taraf hi hoti hay.

so that she could be treated for right breast cancer that had started two and a half years ago as painless, hard and slippery nodules of about one inch in size. At the time of the interview, the size of her breast has increased such that it was dangling below her waist level and to support it she tied it with a bandage, even though the bandage caused her pain.

While I unfold her story it is noteworthy that when the nodules in her breast developed, she was aware of a problem, but did not inform anyone until the size of her breast enlarged such that the people around her, family members and neighbors noted and inquired about it. They inquired if it hurt or caused any pain, but the woman denied any pain. Also, these people and the participant herself thought that because she could not breast-feed her twins these nodules had developed, but because they were not painful they may resolve on their own. Therefore, she and her family believed there was no need to be worried. However, when she and people in her social circle noticed that her breast was increasing in size she was encouraged to see a doctor. Since her condition was worsening she visited different doctors in different clinics within her vicinity, who guided her to go to a hospital. The hospital she visited is funded and governed by a philanthropic foundation. Therefore, services were provided free of cost. After the initial assessment in the hospital, a biopsy was performed and surgery was advised but as she (the participant) was pregnant, her surgery could not be performed. The participant was advised to have an abortion. Although she aborted her fetus, she still delayed going to the hospital until one year later, after the mass in her breast ruptured. She explained that her delay in going for surgery was due to the financial costs of traveling from her home to the hospital in a day, was PRK 800 – 900 each time. This may cost her around PKR 15,000 [CAN\$167] in a month's time and she could not afford to bear these expenses. I noted a mismatch between her expressions and what she said. So I deepened my inquiry, which I will describe shortly. Once the woman noted the

ulcerating cancer wound in her breast, she went to the hospital that had previously recommended an abortion before surgery; but since the woman had delayed the process and her conditions are worsening, this hospital would no longer accept her for surgery. So she went to different hospitals. She mentioned two public hospitals, and the Karachi Institute of Radiotherapy and Nuclear Medicine [KIRAN], providing radiotherapy facilities, oncology, and chemotherapy services. None of these hospitals would accept her for treatment because her condition had deteriorated. She also went to a private hospital, which agreed to register her for surgery but as the cost of surgery was out of her reach, she did not admit herself there. Instead, the woman received treatment from a spiritual healer. Traveling to the spiritual healer cost her only the transportation PKR1,00 [CAN\$1] for two way travel, an amount she could afford. Although what she described remained her experience, I wondered, was this woman avoiding surgery and if yes, what were the reasons for her avoiding it? It was the participant's fear, which hindered her from going for surgery. She said, "I am very much fearful. I feel that if I go for surgery I will die"⁴¹(P003). This was one of the main reasons that she had been delaying her treatment.

Although the hospitals she visited prescribed surgery, she opted to avoid it. She said,

"[The spiritual healer told her] you will note that you will be cured without a surgery and then you should go and tell the doctors that you were telling me that this (disease) will not be cured but see I am alive, all well and standing in front of you"⁴² (P003).

⁴¹ Mujay bauhat dar lagta hay. Mujay lagta hay kah agar mera operation hoga to mayn mer jaoo gi.

⁴² (Baba nay kaha kah) tum dakho gi kay tum operation kay bagayr hi theak ho jao gi. Aur phir tum doctor kay paas jana au oos (doctor) ko kahana kah tum to kahtay thay yeh theak nahi hoga, dukho mayn zinda hun, theak hun aur tumharay samnay khari hun.

This woman was admitted to Bait-ul-Sukoon at the insistence of her family. When I visited her for this research she was receiving a blood transfusion to correct her anemia and her surgery was scheduled for the next day. But she was not ready for surgery. She said,

“Even now I think it (her breast) will be healed without any surgery. Even now I have planned that doctors have planned infusion for me [blood transfusion]. Tomorrow they will give me the last drip [one pint of blood transfusion]. I will go home”⁴³ (P003).

Although the participant’s mother (who was there as her attendant) interjected that surgery was needed, the participant said,

“I will go to he baba [the spiritual healer]”⁴⁴ (P003). She also said, “I don’t know why? But it is my mind that keeps thinking this way. I feel that if I don’t get the surgery done that would be better”⁴⁵ (P003).

Later in the evening, I noted that she was moving around on the floor out of her room. It could be because the blood transfusion had boosted her energy level, but I wondered was she using this as a strategy to show that she is fine and her surgery is not needed. Whatever was the reason, the next day when I visited the hospital I noted that her room was vacant. I inquired from the nursing staff about her and the nurse on the floor replied that the patient went home. She did not want to continue with the treatment. Her surgery was planned but she was not ready for

⁴³ Abhi bhi mayn samjhti hun kay yah (appni chati ki/ zakhum ki taraf ishar kiya) operation kay bagayr hi theak ho jaygi. Doctors mujhay yah (khun ki drip ki taraf ishara kiya) day rahay hayn. Kal mujahy akhri drip lagay gi aur phir mayn ghar chali jaoon gi.

⁴⁴ Mayn baba kay paas jaoon gee.

⁴⁵ Patta nahi kyun? laikin yah maray dimag mayn hay, aur mayn yah sochti rahti hun kayh agar mayn operation nahi karwaoon to behatar hay.

surgery. She went home, leaving against medical advice. I wondered why she opted to carry on with a tumor, which not only enlarged her breast but was oozing with a purulent discharge which she had described as: “it is like cloudy. It is something difficult to describe, dirty water. The smell from this fluid is so bad that no one can sit beside me”⁴⁶(P003). I wonder if even though she will die of the disease, her fear of dying during surgery was so frightening that she clung to the first healer who said she would be healed.

Accessing palliative care at times is connected to the individuals’ culture and beliefs. Approaching spiritual healers, consulting relatives and neighbors is customary. These practices although culturally acceptable, inhibit an early diagnosis and treatment. Obstructed by the cultural beliefs, the woman (P003) for her breast cancer rejected the treatment in the hospital to continue with her treatment by the spiritual healer as described in this chapter in the section above.

Living in Poverty

Poverty and the resulting lack of education and health literacy contributed to late diagnosis, and the inability to receive timely treatment. In Pakistan and other LMICs, it is a reality that people are concerned about the day-to-day survival of themselves and their families; and this may be more important than seeking treatment for an illness. This is depicted in the participants’ descriptions. Such was a young adult female participant, who was a family member describing the details of her mother’s illness. She explained that as her mother did not discuss her health with family members she (the participant) could not say exactly when her mother

⁴⁶ Yayh gadla sa hay. Yayh ganday pani ki tarha hay, iis ko sahi say batana mushkil hay. Iis mayn say itnee gandi badboo aati hay kah koi meray pass bayth hi nahi sakta hay.

began to have symptoms of cancer. The mother did not share her health issues because she wanted to protect her family and children from another stress, as they were already going through so much in their lives. They lost their father about 18- 20 years ago when the children were young. However, the person who died was not only the father of these children, but he was also the husband of the woman (participant's mother). What were the repercussions of his death on her (participant's mother)? Why did she not think about herself? It is because there were no social support networks, or time, or any option to put herself first. She needed to take care of her children and provide for them. She continued on and fulfilled the cultural roles of a woman, home-maker and mother. She also worked to earn a living for her family. Since she was not educated, the type of work that the mother could do was as a laborer. Her income was so low that she could barely meet the family needs and she did not want to spend money on her illness. Thus, she kept her health secret. This reflects how poverty influences access to medical care and ultimately palliative care.

The woman (participant's mother) maintained the secret of her illness because she was unwilling to take away the family resources, which already were not enough to fulfill family requirements and also to protect her children from stress. However, looking from another perspective, I wondered why the children did not note that their mother was not well. It could be possible that the children noticed the ill health of their mother. They noted that periodically their mother was suffering from high-grade fever. The participant who was the eldest daughter wanted her mother to take leaves from work so she could get some rest and treatment but her mother wanted to attend her job. When I explored what could be the reasons, the participant said her mother did not want to take leaves. After some reflection, I realized there were no paid leaves for sickness and there were no annual leaves. Likely the participant's mother did not want to take

leave without pay. A leave would further reduce the family income, which was already minimal in comparison to the needs of her family. Asking for leaves and being away from her job could result in a layoff from the job. Thus, although high-grade fever could have been an early sign, it was a missed opportunity resulting in a late diagnosis.

As I explored the history of this woman's illness, the participant's mother was visiting doctors for treatment of high-grade fever and she was prescribed medicines that temporarily resolved her fever. When the woman (participant's mother) was young and unmarried she was having a heavy vaginal discharge, the cause of which was not identified. If the vaginal discharge was watery, infected, pink or foul-smelling, and with pelvic pain, these are early warning signs of cervical cancer. If, as she says she has had this for a long time, it could have been identified by healthcare providers, who attended this woman during her five pregnancies and deliveries in a hospital. Access to this hospital for obstetric care and the birthing process of her children was possible because this facility was included in the employment package of the company where the woman's husband (participant's father) was working. With his death, these benefits were no longer available. About three to four years ago the problem of heavy vaginal discharge became unbearable. For its resolution, the participant's mother visited a doctor nearby who prescribed her Augmentin, an oral antibacterial. For some time the problem subsided but it reoccurred frequently and much time passed until she was diagnosed with cancer and treatment started. Thus, the culture, and her poverty, which contributed to long working hours, and the difficulty with family finances contributed to her delay in accessing health.

Elaborating on the financial constraints of the individuals, a physician participant said, "I have worked at [a public hospital] oncology [unit], I have also worked at [a private hospital] oncology [unit] and now I am working here [Bait-ul-Sukoon] in oncology

[unit]. I have seen the poor patients of [the public hospital], I have seen the rich patients of Aga Khan also. It [finance] does affect and it does affect a lot” (HCP 005).

The physician (HCP 005) listed educational background as a first and financial issue as the second major factor contributing to late diagnosis. Participants’ descriptions indicated that a person’s education level guides their decisions and approaches to health. Those who were not educated approached a spiritual healer before approaching a health facility. It is financial constraints that contributed to an individuals’ lack of education as their families could not afford schooling or higher education. Moreover, they may be required to enter the labor market while they were young to supplement their family income.

Talking about the importance of education a physician said,

“Educated people come to us in an early stage because they are aware that something is going bad and uneducated people come to us in the last stage. Sometimes the tumor is so large [that] we use the term, breast in a tumor because they come at so late-stage” (HCP005).

This is perhaps because these people have been through the healers and the other public hospitals or they have been obstructed due to cultural reasons. Therefore, they end up for treatment at a very late stage.

Not denying individuals’ responsibilities towards their own health, the government’s role in improving the health of the people in a country was highlighted by many participants from all the three groups: patients, family members, and healthcare providers. They talked about the need for poverty alleviation, improving access to health, including transportation, which is a huge barrier in accessing healthcare even when the treatment in the hospital is free. As a patient explained,

“There is so much poverty. People are so helpless. The government should think of giving services. Hospitals and schools are private and are getting too expensive.

Government hospitals are reducing in number. Our government should concentrate on improving the systems; they should improve the system in [a public hospital]⁴⁷ (P004).

Participants are anxious when they visualize the future of their next-generation being no better off than what they had and are experiencing. A male participant (P004) who due to his family circumstances, which included the low financial standing of his parents, could not attain education and as a result, his own financial condition prevents him from educating his children, creating him emotional distress. This participant was concerned that he could not afford the cost of his children’s schooling- tuition fees, books, transportation, uniform and other requirements of education. The participant felt so loaded with the responsibilities in his life that he was not at all able to see what was going on with himself. He said,

“My attention from myself has shifted away. I am required to take care of my kids, my wife, and my household. I am not spending a penny on me. It is not only not spending. In fact, I am not even looking at myself as what is happening to me. Having pain just keeps continuing to be in pain, having wound just keeps on continuing with the wound. So this is the situation I am in. Even now I was not in favor to come to the hospital. I was

⁴⁷ Iis kadar gurbat hay kay kya bataoo. Log ka koi pursanay haal hi nahi. Government ko chahiyah kay apnay logo ko sahoolat day. Huspatal, school, sub hi private hayn aur yah sub bauhat hi mayh gay hotay jarahay hayn. Government huspatal kum horahay hayn. Hamari government ko chahiyah kah woh iin chizoon (idaroon (school aur huspatalon)) per tawajah day. Oosay (government ko) chahiyah kah woh idaroon ko bahtar karay.

thinking of staying at home. My kids are young; they need me. It's my siblings and my father who pushed me to get treatment"⁴⁸ (P004).

Health and education are two of the main sectors for human development and these sectors need to be sufficiently budgeted, but in Pakistan, traditionally these two sectors are always on low budgets. Although each succeeding governments claim an increase in these budgets, it is not sufficient when compared to the rising population growth rate and inflation. Also, as Pakistan, the needs to secure the country's boundaries are significantly budgeted for through militarization. In the fiscal year 2017- 2018 the country was slated to increase its defense budget by seven percent (Gady, 2017). For the fiscal 2018-19 Pakistani Rs 1 trillion was outlaid related to the drying up of military hardware supplies caused by the steep cuts in the USA's reimbursements to Pakistan for expenses on the war on terror. As well the focus on developing tactical or battlefield nuclear weapons, primarily for use in potential hostilities with India, takes precedence over health and education (Syed, 2018). The need to spend more money to protect the borders of the country is high such that it supersedes the need for improving the health of the people.

For health as mentioned above, the budget does not meet the enormous needs of the people in the country, especially of those living in poverty. There is a less amount budgeted than

⁴⁸ Meri puri tawajah mujsay haat kar meray bachun ki taraf chali gae. Meri zimaydari thee kayh mayn appnay bachun ka khayal rakun, appni biwi ka, appnay ghar ka khayal rakhu. Khud par tau mayn aik paysa bhi nahi kharachta. Balakay, appni taraf to mayn daykha ti nahi hun. May yah to dakhta hi nahi hoon kayh maray saath kiya ho raha hay. Aggar dard hay to (dard) honay do, zakhum hay tau honay do. Hakikat mayn yah hay mery halat. Iis waqat bhi mayn nahi chahta tha kayh mayn huspatal may dikhil houn. Abhi bhi mayn ghar mayn hi rahna chahata tha. Abhi meray bachay bauhat chotay hayn. Oon ko meri zaroorat hay. Yehto meray bhan bhai hayn aur meray walid sahib hayn jonhon nay mujahay zabardasti yahan illaj kay liyah dakhil kiya hay.

the needed. Also, from the budgeted not all the amount much is engulfed through corruption. This is described by the participants in this study.

Lack of Knowledge

Analysis of the data indicates some participants are living with a lack of access to health education. Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Castle et al., 2019). The analysis of the data revealed that due to their lack of knowledge and low health literacy, participants frequently had a late diagnosis. This is depicted in the case that I narrate here. In Mirpur Khas, a city in the province of Sindh in Pakistan, a young woman around the age of 19 years felt some nodule in her left breast (P002). She visited a female doctor. The woman was assessed and an ultrasound was performed. The doctor informed the woman that the nodules were veins in the breast, which sometimes get congested. Once she (the young woman) was married congestion in the breast veins would be resolved. Hence, the woman considered the nodule normal and as a part of her body structure. Although, every month during menstruation she noticed that hardness and pain in her lump were increasing, once the menstruation cycle was over both the pain and hardness subsided. She considered it as a normal phenomenon and not to be worried about it. Gradually, she stopped noticing this bodily change and life went on. At the age of 21, she married and got busy with her new life. The phenomenon of pain and hardness remained constant but the woman stopped paying attention to it. Gradually she started feeling pain in her left breast starting from the front and radiating towards her left shoulder. She considered this pain related to her being busy with her household chores, taking care of the children who at the time of the interview were a seven-year-old and a five-year-old.

old. The woman was not examining if there was any hardness in her breast or not and her life was going on.

It was at around the age of 30 years that this woman delivered her third baby. After the delivery, the woman put her baby on her breast for the feeding. Feeding on the right breast was not a problem but from her left breast, the baby refused to be fed. She was worried about her baby not feeding. Therefore, she visited her obstetrician, who said to the mother “you are not feeding your baby properly”⁴⁹(P 002). The woman was not satisfied with the answer. She was an experienced mother of three children. Also, her newborn did not have any problem feeding on the mother’s right breast. Not being satisfied with the response from her obstetrician, the woman went to another obstetrician/gynecologist. This obstetrician performed an ultrasound of her breast and then informed the mother that there were some abnormalities requiring further assessment and investigation. Therefore, the obstetrician referred the mother to a doctor in Karachi.

The woman visited the doctor in Karachi and based on her assessment the woman was diagnosed with breast cancer for which surgery was required urgently. Without health care records it cannot be confirmed that the woman had breast cancer at this time. But the fact is that this problem with her breasts that occurred at the age of 19 persisted and remained undiagnosed and untreated until the woman reached the age of 30 years and her newborn refused to be fed by the affected breast. Why had she not been investigated further when her first ultrasound detected abnormalities? If the doctor did not have the expertise why she was not referred to another doctor for a second opinion? Above all when the woman noted that her symptoms did not subside why

⁴⁹ Tum isay (baby ko) sahi say dud nahi pila rahi ho.

did she not consult another doctor and get herself further investigated? Rather she continued suffering for more than ten years. Possible answers could be that the first doctor had suggested that the abnormality detected through ultrasound was a normal phenomenon for this individual. So, because she had sought answers in the past, she ignored subsequent symptoms believing that her symptoms were normal. In such cases, it is difficult to conclude what contributed to a delay in diagnosis without health records. Whatever was the reason there was a delay of 10 years before she was diagnosed with cancer (P002). At this time her cancer was advanced to the 2nd stage of the disease, meaning cancer had spread. While I inquired about the reason the participant had not consulted the doctors when nodules in her breast did not disappear, the woman responded,

“In Mirpur Khas, no one thinks/knows that cancer could be a problem. There was no concept of cancer as a disease.....When we came to Karachi, at Bait-ul-Sukoon we noted so many patients are admitted for cancer treatment. Now we know this disease is getting common”⁵⁰ (P002).

These descriptions indicate a gap in health literacy and call for the dire need of education to the masses for prevention and early detection. Since her experience with breast cancer, the participant guided and facilitated her younger sister who had developed a lump in her breast, also around the age of 19 years (about two and a half years ago at the time of my data collection), in having it removed. As a result, her sister did not require any further treatment beyond regular

⁵⁰ Mirpur khas mayn cancer kay baray mayn koi nahi janta tha. Kisi ko bhi pata nahi that kah cancer bhi koi bimari hay... jub hum yahan Karachi mayn Bait-ul-Sukoon aay to hum nay dekha kah yahan per cancer kay bauhat saray patients iilaj kay liyah dakhil hayn. Aab Hamay patta chala hay kah yah (cancer) bimari bauhat ziyada hay.

follow-ups. At the time of data collection, the sister had married and had a one and a half-year-old child. Also as a result of the participant's experience women, particularly young women, in the participant's extended families approached healthcare facilities for breast cancer screening. This suggests that improved health literacy can result in improved screening and treatment to prevent late diagnosis.

As I analyze the data from the healthcare providers and the patients it indicates that the individuals use ghutkka, paan, challia, and other substances so release their stress. The pharmacist who participated in the study said,

“It has become a trend that since they [individuals] are so stressed out, they are going to eat ghutkka so that they have something else to do and not think about it [the stress].

Once I asked a patient. I asked uncle, you are eating ghutkka even though you are, admitted to a hospital, you are sitting on a bed and you are here with an injury and you are still eating ‘ghutkka’ and he was like baji [sister], what should I do? I am so tense. Who is going to take care of my family? I think there are certain societal pressures on these people which cause them to divert to these things, to ‘ghutkka’ and ‘pan’, smoking, heroin and these cannabis” (HCP002).

It is hard to see addictive substances being used to assist the people to cope with the hard circumstances of living under the poverty line and in poverty. Yet this is the reality of their lives. The thinking is that these substances' euphoric effects help these individuals to cope with the stressors because their life is so difficult every day. But through using these substances they are at risk for and some are enduring with an already diagnosed cancer.

Experiencing Difficulty to Access and Failure of the Healthcare System

There were participants who although reached the healthcare facility at an early stage of their disease but due to being misdiagnosed they could not benefit from adequate healthcare treatment. This resulted in a late diagnosis of their disease. Here I paraphrase through the description of a female participant (P001). The participant was living in Naushahro, a district in the province of Sindh, Pakistan. The woman was in her mid-40s and the past four years she was suffering from the symptoms of chest pain and temperature for four years. She treated herself at home with medicines for relief of pain and fever. When she did not recover she went to a government healthcare setting in her district. There she was treated for tuberculosis, but her suffering continued. Not being satisfied with the treatment in Naushahro the woman went to several government healthcare settings in different cities, in Kotri, Nawabshah, and Ghambhat, all in the province of Sindh. The doctors focused on tuberculosis as her diagnosis. Based on her knowledge, the woman believed that a person with tuberculosis had a cough with sputum but she did not have any such complaint. She persistently provided this information to the doctors she visited but felt she was not heard, rather she was continuously being treated for tuberculosis. In Ghambhat after a chest x-ray, pleural effusion was noted. She was told she did not have tuberculosis but some other type of infection. Her anti-tuberculin treatment was discontinued, chest fluid was drained and she was prescribed some antibiotics. However, her diagnosis was not identified, her problem did not resolve and once again she developed the pleural effusion. Therefore, a thoracentesis was planned. This time her brother who is living in Karachi intervened and convinced the family that she (the participant) should come to Karachi for the treatment. The family agreed to the option. Reaching Karachi, the woman (participant) was taken to a private hospital. To pay the hospital bill support was provided through the patients' welfare system and

the participant's family. According to the welfare and zakat assistance program, patients who are in need of financial assistance and who fulfill the eligibility criteria for getting the assistance are supported for treatment at the hospital. At Aga Khan Hospital she (the participant) went through different diagnostic procedures including lung biopsy and thoracentesis, and she was diagnosed with lung cancer.

Before I describe her treatment I consider it worth elaborating on what the participant described her experience before she reached Karachi. Here I add that although funds are allocated to the province of Sindh and through these funds the healthcare settings in Naushahro, Kotri, Nawabshah, and Ghambhat are to be equipped with the required resources, even after four years of visiting healthcare facilities and consulting with doctors, she was not diagnosed properly. What could be the reasons for such happenings? Also, during the period of four years why for most of the time was, she was treated as having tuberculosis when for most of the cases duration of treatment for tuberculosis is shorter than a year. If she had tuberculosis then why was it not treated when she received its diagnosis and medication? Not complying with the treatment regime could have been a concern but it did not apply when looking at the participant's (P001) descriptions. Was there any issue with the potency of the medicine? Was this woman misdiagnosed or there were some other issues? It is also important to consider that it is morally, ethically and critically important that designated healthcare staff are properly educated, trained and competent in providing the required services. Also, the services provided should be of good quality.

Information about tuberculosis is known in the public domain that, supported through a number of organizations including the World Health Organization, in Sindh, Pakistan, has resulted in tuberculosis control programs being implemented. Thus, it is quite possible that being

engaged with these projects there is a heightened awareness among healthcare providers related to tuberculosis and as a result, everyone is seen as if they have tuberculosis. It could also be possible that healthcare personnel were inexperienced so they could not identify the disease, yet they still treated it.

As mentioned earlier that at Aga Khan Hospital the participant was diagnosed with lung cancer. Hearing the diagnosis the family was distressed. The participant was worried that she would die soon and when she died, she wondered what would happen to her children. The participant first had four daughters and then five sons. The eldest one was a daughter 26 years and the youngest was a son seven years of age. The participant's second-born daughter was married and the eldest daughter was engaged but was yet to be married. The participant was very concerned about her children as they were young and her eldest was yet to be married. It is very common in my data than worrying about family members remains more significant in comparison to concern for oneself.

If this woman had been diagnosed at the early stage of her disease would she had been in a better position than the one she is in at present? Would she have had a better prognosis? These are questions that remain unanswered given the prognosis of lung cancer is poor. However, this does not privilege the healthcare providers to rationalize them or misdiagnose their patients. Misdiagnosis suggests that attention could be paid to healthcare providers' education, as they are an integral part of healthcare systems. Other components that cause healthcare system failure include the unavailability of facilities for diagnosis and treatment. However, the presence of corruption described in the earlier sections suggests that even if the funds are provided, they are pilfered. Siphoning of public funds for private gains can occur at all levels of the health system while transferring/being transmitted through various layers of national and local government's

institutions on their way to the health facilities (Nishtar, n.d.). Theoretically within Pakistan's state health system, transfer of funds from the treasury to the Ministry of Health (MoH) and from the MoH to their own provider units as well as the fiscal transfers from the Provincial to their provider units and the Provincial to the District level, etc. could be possible conduits (Nishtar, n.d.). However, within provider units, siphoning of funds, pilferage and theft is known to occur at various levels. Political and bureaucratic leakage, fraud, abuse and corrupt practices are likely to occur as a result of poorly managed expenditure systems, lack of effective auditing and supervision, organizational deficiencies and poor fiscal controls over flow of public funds (Nishtar, n.d.).

About this female participant whom I described above (P001) at Aga Khan Hospital along with her diagnosis (lung cancer) her prognosis, treatment, and referral was discussed with the family. The family opted for the referral thus the participant was referred to a public hospital and from there she was referred to Bait-ul-Sukoon. At Bait-ul-Sukoon her blood tests and chest x-rays were done and the results were awaited. She was also planned for echocardiogram but as this service is not available at Bait-ul-Sukoon, the participant was to get it done from a hospital providing services at reduced rates and is affiliated with Bait-ul-Sukoon hospital. Based on the lab investigations her treatment was to be planned and until then she was provided with symptomatic treatment for pain management, and her intravenous line was maintained.

Failure of the healthcare system is also due to a gap in healthcare providers' knowledge about palliative care as it is not included in nursing and the medical curriculum. This is depicted in the responses by the healthcare providers in my research. A staff nurse said,

“I have not seen palliative care, hospice care in the nursing curriculum. I graduated in 2006 with a Diploma in General nursing. I have never seen it. I do not know (now).

Whereas, it should be there (in the curriculum). There should be one topic because all the patients who come to us (at Bait-ul-Sukoon) among those many go at the stage that palliative care is required. So most of our patients get to the stage where palliative care is needed...”⁵¹ (HCP001).

The need for inclusion of palliative care in the curriculum was also identified by the doctors who participated in my research. One of these doctors said,

“There in the MBBS (Bachelor degree of Medicine and Bachelor of Surgery) curriculum they just introduce palliative care as the terminology. It says a patient who is at the later stage of their disease is identified as palliative care. That’s it. At that stage (during MBBS education) we did not know much about palliative care. I just talk about myself. I would say I did not have much idea what palliative care is all about? So coming in this hospital (Bait-ul-Sukoon) I came to know what palliative care is all about. What are we required to do or not do?”⁵²(HCP004).

⁵¹ Maynay to nursing curriculum mayn palliative care, hospice care nahi daykha hay. Mayn 2006 mayn General Nursing Diploma may graduate kiya tha. Mayn nay kabhi nahi daykha. Abhi ka mujayh patta nahi hay. Yah (palliative care, hospice care) curriculum mayn hona lazmy hay. Kum az kum aik topic to (curriculum mayn) hona zaroori hay. Kiyoon kah hamary paas (Bait-ul-Sukoon mayn) jitney bhi mariz attay hayn oon mayn say bauhat say woh hayn jo oos stage mayn jatay hayn jub palliative care ki zaroor hoti hay. Lihaza hamaray bauhat say mariz iis stage per hotay hayn kah oon ko palliative care ki zaroorat hoti hay...

⁵² Wahan (MBBS curriculum mayn) woh sirf palliative care ki terminology batatay hayn. Sirf itna bata tayn hayn kah woh mariz jo cancer kay aakhri stage mayn hotay hayn oon ko palliative care ki zaroorat hoti hay. Buss (itna hi). Oos waqat (MBBS mayn) hum palliative care kay baray mayn ziyada nahi parhtay hayn. Agar mayn sirf apnay baray mayn baat karoon tau mayn kahun ga kahy mujhay palliative care kay baray mayn ziyada patta nahi tha. Mujahy nahi maloom that kah palliative care kiya hay? Mayn jub iis hospital (Bait-ul-Sukoon) mayn ayaa tau mujahay palliative care kay baray mayn patta challa. Mujahy patta challa kah (palliative care mayn) hamayn kiya karna chahiyah aur kiy nahi karnay chahiyah.

The other doctor who participated in this research describing the non-inclusion of palliative care in the medical curriculum said that at present palliative care is not included in the medical curriculum whereas, it should be in the curriculum. The participant said,

“I am a recent graduate. I graduated in 2016 and I haven’t learned palliative care, management of palliative patients. I started learning when I did my house job. Actually, my house job was in oncology. So I learned it during my house job. Then after my house job, I joined Aga Khan Hospital as an RMO (Resident Medical Officer). So I learned it over there also and now I am working at another oncological setting (Baitu-ul-Sukoon Cancer Hospital)”. (HCP005).

Describing the importance of including palliative care in the medical curriculum the participant said that if palliative care in the curriculum then the MBBS graduates will be more aware of palliative care this will impact their practice that they provide to the people. The participant said, “...we know what palliative treatment is? How to counsel the patient? We are confident about it because we know this. If they would be knowing they can treat their patients at their setups...” (HCP005).

Advocating about the need for inclusion of palliative care in the curriculum, a physician said,

“I think palliative care training is required because most of the people who join us, initially they do not seem to be understanding the situation. So if we get anxious then how would we be able to provide care to the one who is at the receiving end (patients, family members). Many times patients and their attendants ask you questions. You have multiple situations to handle at the same time. Post chemotherapy effects. At times patients suddenly expire. So emotionally, if we are not sound then we may not be able to

properly tackle the things. We ourselves will get upset. So first we need to prepare ourselves to face these situations. So emotionally we are to be very strong”⁵³(HCP004). Participants’ descriptions of the need for including palliative care into the curriculum of nursing and medicine are in-line with the literature and my professional experience as a healthcare provider in Pakistan.

Lack of Cancer Prevention for the Study Population

The prevalence of cancer could be controlled by focusing on prevention and early diagnosis. I described the need for early diagnosis earlier. In this section, I describe prevention. Among the research participants, the healthcare providers described the need for focusing on cancer prevention through a public awareness campaign. A staff nurse said,

“One thing that should be added when we do research... The rate of patients with different types of cancer is increasing we should increase the rate of the programs for protection from cancer. For example, when a person is diagnosed with cancer we should make a system that we should protect their relatives [who may also be exposed to the

⁵³ Maray khayal mayn palliative care ki training ki zaroorat hay. Kuyun kah bauhat say log (doctors) jo hamayn yahan joint kartay hayn oonko shirro shirro mayn samaj nahi atta kah (woh) kiya karayn. Tau agar hum khud hi parayshan hojayn gay to woh (mariz, aur oos kay rishataydar) jin ko zarrorat hay, hum oonka khayal kaysay rakh sakayn gahy. Aksaar mariz aur oos kay rishtaydar hum say bauhat say sawalat kartay hayn. Aap ko aik hi waqt mayn aik say ziyada kam karnay hotay hayn. Post chemotherapy ki effects (ka khayal rakhna hota hay). Kabhi mariz achaanak say expire ho jata hay (mer jata hay). Agar hum emotionally sound (zahni taur per mazboot) nahi hayn to hum iin tamam chizoon ka khayal kaysay rakh saktay hayn. Agar hum khud hi parayshan ho jayngay tau hum iin tamam (kam) ko sahi say hani karsaykayn gaay. Hum khud hi paraysahn ho jayn gaay. Iis liya pahlay hamayn apnay aap ko iin tamam batoo kay liya tayar karna hoga. Hamay zahni taur par majboot hona hoga.

same predisposing factors that the person diagnose cancer was exposed. Therefore, the disease occurred]”⁵⁴ (HCP001).

The pharmacist, who participated in the study, noted that family members accompanying patients with oral cancer are chewing substances causing oral cancer said,

“Attendants bringing them [the patients] they are also eating ghutkka and we are just so surprised. This is what you are chewing in your mouth, this is the reason why your patient is suffering what he is suffering today. So how can you consume the same thing that has brought your patient to this stage? But obviously, there is lack of, [taking a big sigh she says] lack of awareness in people” (HCP002).

The pharmacist asserted that the education provided is not sufficient given the burden of disease therefore, more is required first to minimize the prevalence and then to eradicate cancer.

She said,

“How much awareness needs to be spread. Even though you see lots of programs for breast cancer awareness and for ghutkka, chullia, and everything but in the end we are receiving those patients which is a surprising thing that after doing so much we are doing nothing. What is the end stage? They are your people they are poor and you have not just worn this [lab] coat and just having studies. Even though I am just a pharmacist and have not had as much authority as a doctor but I am a very crucial part of this triangle that needs to help the patient. I have the responsibility I have taken oath for this. So I feel for

⁵⁴ Aik baat jo mayn yahan par aur baatana chahon ga kay jub aap research... Jis rafter say mukhtalif kim kay cancer kay marizoon ki tadad baher rahi hay oosy tadad say cancer kay bacho kay program bhi bharnay chahiyen. Maslan jub aik shakhs ko cancer ka marza hota hay to oos kay rishataydaroon ko cancer (oon wajoochat say jis say mariz ko cancer howa hay) say bachana chahiyah.

these patients. I feel that what is my job? Have I not you know stood up and given awareness to people because prevention is better than cure no matter what?..” (HCP002). Not denying the importance of providing the curative care the pharmacist (HCP002) was very emotional and through her description, she reminded us that all healthcare providers have a duty for health promotion and disease prevention. Given the cases of late diagnosis that health care providers witnessed, they seemed frustrated that a lot of the suffering they witnessed could have been prevented if adequate health promotion and disease prevention programs existed and if these were effective.

A staff nurse (HCP003) explained why teens were consuming substances known to cause cancer said, “They are not aware of the consequences. They for short term effects, get shortly relieved [from stress] use these things. As they are addicted they use these things⁵⁵” (HCP003). Focusing on teens so as to save the future of the nation is much important and is also emphasized by a physician who says, “Teens due to their peer pressure develop habits. They think if my friend is doing this [consuming substances like ghutkka] then I should do it first thing” (HCP005). Thus, educating the masses is advocated to be one of the ways of controlling the prevalence of cancer. While I looked at the artifacts at Bait-ul-Sukoon, I noted posters are displayed in the visitors’ lounge providing the information about substances causing oral cancer so to avoid consuming these substances. Also, there are posters to teach about the importance of self-breast examination for early detection of cancer. These posters are culturally tailored.

⁵⁵ Woh nahi jantay kay iis kay kiya nuksanat hayn. Woh thoray arasay kayliya, is ko (appni parayshani) bholanay kay liya iin chizoon ka istamal kartay hayn. Chunkahy woh iin chizoo kay aadi ho jatay hayn (woh innhay chore nahi saktay).

Culturally acceptable language is used. However, as these posters are laminated in the visitors' lounge, visitors in the lounge can benefit through these posters. This was described by one of the family members who while pointing at the posters that are laminated on the walls in the visitors' lounge said, "It is mentioned in these posters that cigarette smoking, paan, chalia, and ghutkka cause cancer so refrain from getting into the habit of using these" ⁵⁶(FM 003). This indicates education is imparted through various channels yet these efforts are not sufficient and more is required to be done to overcome the burden of cancer.

A physician asserted that advocating for cancer control through policy-level change must include accessibility to substances that are known for causing cancer. When these substances are easily accessible their consumption will remain high causing cancer. In the participant's words "...it's so common availability, cheapness and no awareness about it [that using a substance can cause cancer]. Letting people starting these types of habits" (HCP 005).

In addition to working for prevention and control of cancer, improving access to care for the patients suffering from cancer is also highlighted as important. As a participant said, "... the need to know that cancer is such a huge thing and the patients are suffering so much. There is a lack of recognition of the fact that it is a huge need to be addressed (HCP002). Investing for the development of resources and building healthcare organizations for treatment and palliation for those living in extreme poverty are the things participants brought up as necessary. But it seems that in order to achieve the goal of improving the access for prevention, early detection, and treatment when disease occurred the pharmacist said,

⁵⁶ Yahan jo poster lagay howay hayn oon mayn likha hay kayh tambakoo noshi, paan, chaliat aur ghutkkay ki adaat nahi daliny chahiyah. Iis say cancer hojata hay.

“There is a responsibility that the government has, that nongovernmental organizations [NGOs] and other organizations have, the rich people [philanthropists] have. People forget that they have the duty. They forget that there are some patients who are going to die if they do not get the care” (HCP 002).

In summary, there is extreme suffering because of late diagnosis, and poor access to healthcare and all of these are interrelated like the strands of a spider-web. Understanding this web and strategizing for improving access is critically important for improving palliative care. Overworked healthcare professionals while they see the need to change many things to prevent the severe end-stage cancer they continually see, also need support from somewhere to at least give this information to health care at the government level.

Next is the discussion section with literature and theoretical propositions rooted in literature and some in personal experience (Baxter & Jack, 2008). Most of the theoretical propositions found from literature are derived from the sustainable development goal (SDG) 3.8 (World Health Organization, 2017d) which is to “achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.” This I mentioned earlier also in the methodology chapter of my dissertation. Propositions that guided my study include social determinants of health influence access to palliative care, cancer pain management is not adequate, health care providers lack palliative care education and policy level change is required for improving access to palliative care.

Chapter Seven: Discussion

In this chapter, I discuss the barriers and facilitators to accessing palliative care in Pakistan and the influence of individuals' social determinants of health on their access to palliative care. The findings have described the suffering of people due in a large part to the late diagnosis of cancer. However, late diagnosis is also related to cultural beliefs, the social stigma of having cancer, the financial (and social) burden of seeking treatment, lack of education about cancer prevention and detection, healthcare system inadequacies and corruption, and healthcare providers' knowledge deficits. Poverty underlies most of the suffering and is largely the reason for late diagnosis. This is in keeping with the theoretical propositions posed (Yin, 2014) to support this research project. The theoretical propositions that I used in this research are detailed in chapter three- methodology. As the theoretical propositions suggested, the participants' access to palliative care was influenced by their social determinants of health, their cancer pain management not being adequate, and health care providers lacking palliative care skills and education. Participants suggested that policy-level change was needed to meet palliative care needs, and enhance early diagnosis. Policy level change for poverty alleviation would improve the social determinants that cause obstructions in accessing palliative care and improve access to pain and symptom management (World Health Organization, 2018).

Barriers to accessing palliative care discussed in the upcoming section are lack of competency among healthcare providers, absence of palliative care in curricula, and system challenges. Under the section about the system, challenges include systematic poverty, absence of a public health approach, difficulties in accessing healthcare, lack of quality care, inaccessibility to pain management, and lack of integrity in the system. Facilitators mainly focus on philanthropy. The discussion also includes the role of Bait-u-Sukoon Cancer Hospital in the

provision of palliative care. Although the barriers and facilitators are sectioned for the description, they are interwoven. A barrier to one person could be a facilitator for another. For example, for some individuals living in poverty in a low-class society, their cultural values and beliefs about accessing healers, as well as the corruption that they faced when they did try to access palliative care services all obstructed their access to palliative care. Yet, for others, cultural values of philanthropy and cultural values of family-supporting one another facilitated their access to palliative care. All of these factors are interrelated and show how the participants through similar routes to seeking care were casualties of late diagnosis.

Barriers in Accessing Palliative Care

Barriers to accessing palliative care include missing the opportunity for an early diagnosis due to lack of information about cancer and early signs of cancer, lack of competency of healthcare providers in clinics and hospitals to identify the early signs of cancer, inefficiencies, and corruption in public health systems at primary, secondary and tertiary care levels. These barriers are caused in part by the government of Pakistan spending little on development in general and specifically on health and education (Ahmed & Shaikh, 2008; Khaliq & Ahmad, 2018) while spending much on defense to combat terrorism and the country's significant geopolitical position with neighboring countries (Anwar, Rafique, & Joiya, 2012; Datta, 2018; Raza, Shahbaz & Paramati, 2017). Fan, Liu, and Coyte (2018) researched the relationships between health and military expenditures in 197 countries using pooled cross-sectional time-series data between 2000- 2013. The researchers report that increased military expenditures reduce the capacity of government to direct expenditures to health. This poses a risk for population health and the well-being of the individuals. While looking at the type of nations

affected through such expenditures, Fan et al., (2018) report that it is the poorest of nations that are most sensitive to the negative effects of increased military expenditures.

One of the major objectives of any welfare state is to redistribute the government revenues to the public for improving their socio-economic conditions. In Pakistan, high military expenditures result in less funds being available for education, health, and other social expenditures (Jalil, Abbasi, & Bibi, 2016; Raza et al., 2017). Shahbaz and Shabbir (2012) looked at military spending and GDP throughout 1971 – 2009 and studied military spending and economic growth in Pakistan. These researchers report that due to persistent war threats and mutual mistrust between Pakistan and India, Pakistan has been spending extensively on defense. This spending is at the cost of economy-boosting programs and education in both countries. Hence, it is important that the governments of Pakistan and India initiate talks to develop a sense of confidence and trust in one another (Shahbaz & Shabbir, 2012). Majeed et al. (2019) assert that Pakistan has one of the worst ratios of palliative care services in the world. Except for a few institutions, palliative care is nonexistent in the country. Consequently, most patients die with untreated severe cancer pain due to inaccessibility to palliative care (Majeed et al., 2019).

Healthcare providers lack competency.

The participants in my study described that at an early stage of their disease they approached the healthcare facility but they did not receive a correct diagnosis; rather they were treated for other diseases. Hence, they were misdiagnosed and their cancer was diagnosed late. Sarangi, Mangaraj, Pattanayak, Kumar, and Mohanty (2017) describe that misdiagnosing patients may lead to poorer outcomes because of the adverse effects of inappropriate medication or incorrect treatment. Valente et al. (2016) describe the case of a woman who after insertion of her new dentures presented with an ulcerated lesion in her oral mucosa. She received many

treatment attempts, but her lesion did not cure. A biopsy was performed, and histo-pathologic examination revealed an ulcerated, invasive, poorly differentiated oral squamous cell carcinoma. The time from the patient's first contact with the prosthodontics because of the lesion until the appropriate diagnosis was established was approximately 6 months. Khaliq et al. (2019) explain that misdiagnosis results in a late referral of patients. The authors' systematic review suggests that initial misdiagnosis and inadequate examination by health practitioners are identified as the most common reasons associated with delays and failure to refer patients. Misdiagnosis could be due to the incompetence of healthcare personnel, insufficient resources and/or inefficient referral systems for healthcare.

It is not unusual to find unlicensed personnel practicing in healthcare facilities and this goes unrecognized until a serious incident occurs, it is publicized and actions are taken. For example, in a private hospital in Karachi, a nine-month-old female died due to an overdose of potassium chloride (Ahmed, 2019). For potassium, an oral route is preferred because it is easy and safe to administer and is readily absorbed from the gastrointestinal tract. However, for managing severe hypokalemia, oral and intravenous routes are needed but potassium solutions should never be given as an intravenous push (Garth, 2018) as was the case for the nine-month-old girl (Ahmed, 2019). This incident occurred in a private hospital in Karachi, Pakistan and root cause analysis revealed that this hospital was staffed with 70 untrained out of 165 nurses (Ahmed, 2019). While I relate this data with the healthcare providers in my study, the physicians and pharmacists had a minimum of a Bachelor's degree. Of the two nurse participants, one held a diploma in general nursing but the other did not reveal his educational background. In Pakistan, to work as a registered nurse a minimum of three years of general nursing diploma and one year of diploma in any specialization is required to be licensed by the Pakistan Nursing Council

(PNC), the regulatory body for nursing in the country. Established in 1948 the PNC is an autonomous professional body, constituted under the Pakistan Nursing Council Act (1952, 1973) (Pakistan Nursing Council, 2016). In this study, based on my observation and interaction and experience as an RN, it came to my attention that not all those practicing as staff nurses were qualified registered nurses (RNs). Yet these staff nurses were dealing with chemotherapy and other medicines which according to PNC guidelines could only be administered by RNs. When nurses are permitted to perform patient care duties that are not commensurate with their education and scope of practice, as prescribed by the applicable statutory body, this threatens patients' health and safety (Ahmed, 2019; Anwar et al., 2012; Lubbe & Roets, 2014). The statutory body for nursing in Pakistan is PNC and in its function it states that PNC maintains standards of education and practice. Based on my experience in hospitals and in nursing education which cumulates to more than three decades, PNC inspection focuses on nursing education institutions mainly and then periodically to maintain their affiliation with the PNC. However, its inspection to maintain the standards of practice in clinical settings requires strengthening.

Another example that the participants described depicts the opportunity for early diagnosis that was missed for a female participant in this study. She was diagnosed with tuberculosis, even though she repeatedly reminded her physicians that she had chest pain and dry cough but no sputum. Although not formally educated, this participant knew that the symptoms she was experiencing were not similar to what a patient with tuberculosis experiences, cough with sputum. Feeling that she was not heard, the participant traveled from one city to another to visit the doctors in different institutions in the public healthcare system. Despite all her efforts to find out what was wrong with her, she did not receive a correct diagnosis until she reached a

private University hospital in Karachi. Here she was diagnosed with lung cancer, which by this time had metastasized to her vital organs so no treatment was possible. However, Gali and Harsh (2018) report that the common presenting symptoms of lung cancer and pleural or pulmonary tuberculosis often are confusing, misleading, particularly in the middle-low-income group countries. Consequently, these patients are treated with antitubercular drugs which only taxes patients with multiple medications and also delays the diagnosis of lung cancer. Thus a careful analysis of history, a systematic and detailed clinical evaluation, appropriate investigations, and clinical expertise of the treating physician are crucial in establishing the diagnosis.

Kuhn (2002) reports that one of the most complex and challenging tasks facing physicians is the need to make a diagnosis. Many times a diagnosis is either incorrect or does not fully address the patient's problems. This can lead to both delayed and/or incorrect treatment, resulting in suboptimal care (Kuhn, 2002), and delay in referral to a specialist (Franco, Elghouche, Harris, & Kokoska, 2017). Aaronson et al. (2019) conducted a study to examine the key features and factors identified in missed cancer diagnosis malpractice claims filed related to primary care evaluate predictors of clinical and claim outcomes. Aaronson et al. (2019) performed a retrospective analysis of the Comparative Benchmarking System (CBS) database to identify all malpractice claims closed between 2005 and 2015 with a primary allegation of diagnostic error. Aaronson et al. (2019) stated that CBS is the world's largest malpractice claims database with detailed coding, containing >350,000 medical malpractice cases from >20 insurers and >400 hospitals. From this database, Aaronson et al. (2019) included all the 2155 cases that were categorized as occurring in the outpatient setting of care and identified a general medicine (internal medicine or family medicine) physician as the primary responsible party. Aaronson et al. (2019) report that from 2155 cases, missed cancer diagnoses represented 980 (46%). The

majority (76%) involved errors in clinical judgment, such as a failure or delay in ordering a diagnostic test (51%) or failure or delay in obtaining a consult or referral (37%). These factors were independently associated with higher-severity patient harm and the majority of these errors were of high severity (85%) (Aaronson, et al., 2019). Analyzing the data set of Coverys, a global insurer for medical liability (Cruz, 2017), Goodwin (2019) reports approximately 30% of the claims involved diagnostic error. Of these, claims involving cancer diagnosis were the most prevalent at 27%. These were related to the four key steps of the diagnostic process - history and physical, lab/diagnostic testing, management of referral, and patient follow-up. The author further adds that while diagnostic error may appear to be linked to a single clinician or perhaps two, some organizational systems and processes can aid in preventing similar future occurrences (Goodwin, 2019).

The importance of picking up the early signs of cancer was emphasized by the speakers at a scientific symposium on October 4, 2018, organized by Kharadar General Hospital, Karachi, Pakistan. In their oral presentations, the speakers discussed “Early Detection and Prevention of Oral Cancer in Pakistani Context” and “Early Detection of Breast Cancer.” These presentations were followed by a panel discussion. The panelist explained that most of the patients first visit a general physician. Therefore, general physicians need to know the early signs of cancer and then refer the patient to a specialist. The panelists also discussed the importance of training physicians to recognize the signs and symptoms of cancer.

Ginsburg et al. (2018) describe breast cancer disparities among women in LMICs and state that poor knowledge among health workers can cause delays. This contributes to misdiagnosis, false reassurance of patients and sometimes inappropriate treatment, such as antibiotics for presumed mastitis. Ginsburg et al. (2018) also adds that dysfunctional referral

pathways in fragmented health systems contribute to patients presenting at oncology centers at an advanced stage of cancers. Ginsburg et al. (2018) cite a study in Cameroon, a country in Central Africa and report that breast cancer patients in Cameroon had an average of four health worker interactions before being referred to definitive oncology services. Saju et al. (2019) researched the factors that impact the outcomes in testicular germ cell tumors in low–middle-income countries. Their study aimed to assess the demographic features, clinical manifestations, pathology, and outcomes of the patients treated at their center from 2001 to 2015. Data were extracted retrospectively from the case records. Saju et al. (2019) traced if the orchidectomy was through the scrotum or through a high inguinal route. They report that scrotal orchidectomy was an important predictor of an inferior overall survival and report that the surgeons who performed the orchidectomy were unaware of the importance of high inguinal orchidectomy in testicular cancers. The other factors that contributed to these surgeons in performing scrotal orchidectomy included surgeons misdiagnosing hydrocele or hematoma. Saju et al. (2019) add that patients who undergo scrotal orchidectomy are more likely to present late and with advanced disease, germ cell tumors because their referral by the treating doctors gets delayed. Late diagnosis can partially be attributed to healthcare providers' lack of competency and could be minimized through capacity building via education and training. I elaborate under the recommendation section of this study.

Absence of palliative care in curricula.

All the healthcare providers who participated in this study reported that palliative care was not included in their curricula. Researchers, however, advocate that palliative care must become recognized as a licensed medical specialty in every country, and all licensed general practitioners who provide palliative care should have the training to achieve basic competencies

(Knaul et al., 2018). Callaway et al., (2018) suggest that the deans of medicine, nursing, psychology, pharmacy, and social work schools, as well as education experts, and national and international pain and palliative care experts review existing curricula for undergraduate and postgraduate medical, nursing, social work, psychology, and pharmacy education and include the core competencies of palliative care into these curriculum. Callaway et al. (2018) also suggest that the curriculum should be adapted to be culturally appropriate and it should also be translated into a country's local language (Callaway et al., 2018). Providing an example, the authors state that in 1999 the International Palliative Care Initiative of Open Society Foundation brought together representatives from 25 countries from Central and Eastern Europe and the Soviet Union to seek their input on their country's need to develop palliative care initiatives. The International Palliative Care Initiative supported medical and nursing school faculty in Tajikistan to translate the American Association of Colleges of Nursing's "End of Life Nursing Education Consortium" curriculum into Russian. However, in Pakistan, palliative care is not included in nursing curriculum but knowing that it is needed, Kurji et al. (2019) advocate for the inclusion of palliative care in Pakistan nursing curricula. Acknowledging the importance of management of pain related to cancer Majeed (2018) emphasizes that pain management should be an essential part of medical education and every young doctor in Pakistan should learn the best practices available to manage their patient's pain. Jafree, Zakar, Fischer, and Zakar, (2015) assert the absence of palliative care and the non-existence of cultural competency in the present nursing curricula. Thus, Jafree et al. (2015) emphasize that training in cultural competency is important for a country like Pakistan, which has complex ethnic and provincial diversity. The authors further add that in the long run, this would also improve patient trust in nursing competency and their willingness to receive treatment. The inclusion of palliative care training for nurses and

other medical practitioners would reduce problems of the withdrawal of treatment and the pretense that practitioners are providing a cure when they are not (Jafree et al., 2015).

System challenges.

In this section, I explain the system challenges that obstruct access to palliative care. These include systemic poverty, absence of a public health approach, difficulties in accessing healthcare, lack of quality care, inaccessibility to pain management, and the lack of integrity in the system. In 2000, under the Devolution Plan of the Government of Pakistan, in all the 19 districts in the country, almost all the sectors including the health have been given comprehensive administrative as well as financial autonomy (Arshad, Iqbal, Waris, Ismail & Naseer, 2016). The healthcare system includes basic health units, rural health centers, referrals to hospitals and tertiary care hospitals (Arshad et al., 2016). Through the devolutions plan, improvement in all sectors is expected but as the participants in my study reported, they could not find basic healthcare and diagnostic services readily available in their vicinity. Pakistan has tried to improve the healthcare delivery system through the formulation of health policies, introducing public-private partnerships, developing basic health units, rural health centers and developing human resources and infrastructure (Kurji, Premani, & Mithani, 2016). Kurji et al. (2016) add that the healthcare system is not efficient and there are weaknesses. These weaknesses include poor governance, lack of access to health, unequal resources, poor quality of health information management system, bureaucratic power of the people involved in policymaking, corruption in the healthcare system, lack of monitoring in health policy and health planning, and lack of trained staff. The WHO also affirms the lack of healthcare services in countries like Pakistan (WHO, 2017c) which indicates similarities to the descriptions from Kurji et al. (2016). Thus, in Pakistan there is a need for provision of palliative care services,

improvement in the infrastructure of current health care system which includes healthcare delivery policies, palliative care models, trained staff to support patients and their families, multidisciplinary approach for pain management and provision of morphine (Kurji et al., 2019). Hence, the barriers in accessing healthcare services that the participants in my research described are also found in the literature cited above.

Sexual harassment, though not reported by any of the participants in this study, has been reported in the literature. Ahmed (2019) reported an outpatient department (OPD) in a hospital in Karachi, Pakistan was sealed because of an incident that occurred in this department. A 24- year old woman who went to the hospital for the treatment of her gum infection died due to being administered the wrong solution. The deceased's family alleged that the hospital staff raped and killed her. The five suspects of sexual assault included a physician and a surgeon specialized in ear, nose, and throat (ENT). A threat of sexual assault in the healthcare facility adds in obstruction to accessing health. Pape, Spuur, and Umo, (2016) surveyed the factors contributing to low participation in mammography screening in Papua New Guinea, an LMIC and found that environmental, political, social, financial, cultural and health factors attributed to the low participation of women in mammography screening. Among an estimated 4000 women who were screened, Pape et al. (2016) report that multiple factors contributed to the low participation of women in the screening program for breast cancer. Social factors (including sexual harassment) accounted for 77.6%. Among the other factors, similar to those reported by the participants in this study, were lack of transport and infrastructure for accessing health care making it both difficult and a financial burden (42.86%), and financial factors 40.54%. When there is a lack of finances, women gave priority to their families over themselves (Pape et al., 2016). These findings correspond to the findings from Ginsburg (2018) presented in chapter two,

the literature review. In the cultural factors, Pape et al. (2016) report that 50.03% of the participants in their study reported low participation in mammography screening attributed to not wanting to expose their body.

One of the challenges of the system that Qasim (2018) reports is the absence of a population-based cancer registry in Pakistan. Highlighting its importance, Qasim (2018) asserts that the registry is required for systematic reporting of incidences of cancer in the country. Without a registry, it is not possible to have cancer statistics. Making an estimation, Qasim (2018) states that each year around 300,000 new cancer patients are added to the existing pool of millions of cancer patients in the country. Thus, the need for palliative care is high but it is not available. Qasim (2018) adds that in the capital city of Pakistan, the federal government has been working to establish a cancer hospital. A proposal for the establishment of this hospital has been added in the federal budget for the last five years, yet this project has not been approved (Qasim, 2018). To meet the gap in care the Cancer Care Hospital and Research Centre is developing an institute of palliative care in the country. This institute is being developed under the guidance and supervision of world-renowned palliative care consultants and is envisioned to be one of its kind in the country. The institute has planned to provide state of the art palliative care services to more than 5000 cancer patients annually and provide a 100 bed treatment facility (Cancer Care Hospital & Research Centre. A Charitable Trust, n.d.).

Systemic poverty.

Poor people in all parts of the world live and die with little or no palliative care or pain relief. Staring into this access abyss, one sees the depth of extreme suffering in the cruel face of poverty and inequity (Knaul et al., 2018). In this study, the participants' descriptions of their life of poverty illuminated how the social determinants of health influence the individuals, their

families, and society. For example, one participant was very frustrated as he was envisioning that the lives of his children were not only no better than the life he spent by living in poverty, not being able to be educated in order to obtain a better paying job but since he was not able to afford treatment for cancer, this poverty was perpetuated by the need for his elder child (son) to enter in labor market at an early age. These experiences led participants to suggest there was a dire need for the government of Pakistan to take measures for the development of education, transportation, poverty elevation and provide access to health facilities with qualified healthcare personnel that could make an early diagnosis and treats people's healthcare concerns. However, Husseni and Ullah (2019) state that insufficient health budget, scarcity of resources and understaffing in hospitals have deteriorated the health system of Pakistan. Yet, Pakistan's defense expenditure has always been on an increase and the higher end (Raza, Shahbaz & Paramati, 2017), spending a huge amount on defense as an effort to maintain credibility results in high inflation, extreme poverty, unemployment, energy crises, debt burden, and many other major socio-economic issues. Also, spending can cause spiraling debt when the government must borrow to pay off loans, contributing to the poverty of the people (Haseeb, Bakar, Azam, Hassan & Hartani; 2014).

Mahmood, Yu, and Klasen (2019) report that the World Bank Development Report in 2013 indicates that 10.7% of the world's population lives on less than the US \$1.90 per day, which is the current poverty line, set by the World Bank. The report also states that in Pakistan 29% of the people live below the poverty line (Mahmood et al., 2019). Poverty is a major issue in Pakistan and it is badly disturbing the economy of the country (Abbas, Hassan, Asif, & Zainab, 2018). No poverty is one of the aims of the United Nations sustainable development goals targeted to be achieved by 2030. To attain this goal employing the strategies proven to be

successful in the past is a way forward. Page and Pande (2018) describe that historically poverty reduction relied on economic growth and the intentional redistribution of resources to the poor, either by the domestic state or foreign aid. However, these two strategies are not sufficient to achieve the sustainable development goal to end poverty. This requires that the states governing the world's poor need to be strengthened such that they are both accountable to the needs of the poor and have the capacity to meet those needs. This also requires the international development community to recalibrate the allocation of resources to increase accountability and state capacity. Page and Pande (2018) support this argument by comparing poverty in 1987 and 2013 by providing the figures that in 1987, 90 percent of the world's poor lived in low-income countries, while only 6.5 percent lived in middle-income countries. By 2013, over 60 percent of the world's poor lived in middle-income countries.

Absence of a public health approach.

Stjernswärd, Foley, and Ferris (2007) described the WHO's public health strategy for integrating palliative care into a country's health care system. This strategy includes guidelines for governments on how to prioritize and implement both national palliative care programs and national cancer control programs, making palliative care one of the four key pillars of comprehensive cancer control in the WHO's public health system. These pillars are “1) appropriate policies; 2) adequate drug availability 3) education of policymakers, health care workers, and the public; and 4) implementation of palliative care services at all levels throughout the society” (Stiensward et al., 2007, p. 486). However, despite substantial efforts related to the development of palliative care worldwide, there are still many countries, (mostly LMICs) that have not yet considered palliative care as a public health problem and do not include it in their health agenda, or integrate it into the country's national health policies (Sepúlveda, Marlin,

Yoshida, & Ullrich, 2002; WHO, 2018a; WHO, 2018b). In these countries, there are serious impediments to opioid availability, a key element to pain control (Knaul et al., 2018; WHO, 2018a; WHO, 2018b). The experiences of participants in this study illuminate the suffering that occurs when access to adequate pain control is not available. Participants' descriptions of the lack of diagnostic and health education about cancer underscore the need for a public health approach to healthcare. Other scholars have asserted that it is essential to promote a public health approach in which comprehensive palliative care programs are integrated into the existing health systems and are tailored to the specific cultural and social context of the target populations (Sallnow, Richardson, Murray & Kellehear, 2016; Sepúlveda et al., 2002). Clark and Graham (2011) describe that:

Palliative care remains poorly framed within evidence-based global policymaking and more needs to be done to demonstrate its role and efficacy, not only in relieving physical and psychological distress but also in promoting community cohesion and personal resilience. Such recognition is vital if the world's palliative care needs are to be met in an equitable and culturally sensitive manner (p.637).

Palliative care is both public health and a human rights issue (Clark & Graham, 2011; Clark, 2012; WHO, 2018). Insertion of palliative care into the public health system positions it within a framework of 'need', 'supply' and 'resource allocation'. Through this approach, several projects are now in operation in Africa and India, as well as in higher-income nations (Clark & Graham, 2011; Clark, 2012). Seeking recognition for palliative care within human rights legislation could be one step toward improving the situation faced by the participants in this study. The reality is that their needs for palliative care were not met. Rather, they were living in pain, distress, and were living with a compromised quality of life.

Difficulties in accessing healthcare.

Difficulty in accessing healthcare was described by most of the participants. These difficulties were often related to their distance from healthcare services costing them much for transportation. Therefore, even if there was no fee for services in the healthcare facilities participants shared their reluctance to visit healthcare. Panezai, Ahmad and Saqib, (2017) conducted a study to identify factors affecting access to primary healthcare services in Pakistan. They performed a gender-based analysis of data from 302 respondents and relating to accessibility they report that access to primary healthcare services is influenced by the inconvenient location of the healthcare facility, long distance between patients' homes and healthcare facilities, and lack of or inadequate availability of transport. They add that access to primary healthcare services are influenced by the insufficient supply of medicine to primary healthcare, unavailability of female doctors, and lack of human resources at health facilities, staff absenteeism, and poor infrastructure of the primary healthcare facilities. The authors assert that the affordability of care has a strong influence on access to primary healthcare services. This includes individuals' occupational status, women's household income, and husband's employment, non-affordability of drugs and having insurance. Socio-economic status of women, and lack of healthcare knowledge influence access to services. Additionally, the cultural norms requiring the permission of the husband and mother-in-law, and women not wanting to see a male healthcare provider also influences women's utilization of healthcare facilities. As well, inconvenient facility working hours, poor attitude and discriminatory behavior of health facility staff and poor quality of care have a strong influence on access to primary care at public facilities (Panezai, Ahmad, & Saqib, 2017). Similar findings are reported by Aziz and Hanif (2016) when

they analyzed the health system performance in the provision of primary health care in Pakistan's southern Punjab region.

Lack of quality care.

The World Health Organization, Organisation for Economic Co-operation and Development, and the World Bank (2018) define “quality of care is the degree to which health services for individuals and population increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (p.30). They further elaborate that quality care is aimed at health improvements rather than simply increasing services. Quality care should reflect the desires of key stakeholders, including service users and communities. The World Bank (2018) describes the span of quality care to include both curative and preventive care, and facility and community-based care for individuals and populations. This is particularly important in countries such as Pakistan facing an increasing burden of non-communicable diseases and whose health systems must provide services across the life-span. This includes reducing risk factors identified as causative agents for these non-communicable diseases which include cancer, screening for early diagnosis, management of individuals suffering from disease, and providing them with rehabilitation and palliative care when needed (Knaul et al., 2018; The World Health Organization, Organisation for Economic Co-operation and Development, and the World Bank, 2018).

The findings from my study highlight a clear gap between individuals’ need for managing their diagnosis, treatment and palliation and what they experience. Furthermore, the potency of medicine was lower than the patients required. I wonder if the radiation they received was accurately provided. Based on my professional experience I am aware that to ensure the full benefits of radiation with minimal impact on surrounding normal tissues careful planning, called

simulation, is necessary before beginning of radiation treatment. Accordingly, the radiation dose is calculated and treatment is designed and the patient is provided radiation. All of these processes require expertise and accuracy. If all the participants in my research were provided with the quality treatment or not is the point that I reflected upon.

Participants' descriptions indicated compromised quality of care and healthcare providers shifting their responsibility of patient care to family members of the patients. This positioned them at risk for complications. There was a poignant example in which a 16-year-old daughter was responsible for cleaning her father's wound, without adequate education about how to do this. When her father developed maggots in his wound the daughter was then blamed for the poor care. National Academies of Sciences, Engineering, and Medicine (2018) states that each year in LMICs overall between 5.7 and 8.4 million deaths are attributed to poor-quality care, and years of life lived with disability amount up to 107 million annually. In the overall deaths that occur in LMICs, up to 15% of these deaths occur due to poor-quality care. Hence, poor-quality care imposes costs of \$1.4 to \$1.6 trillion each year in lost productivity in LMICs.

Inaccessibility to pain management.

In advanced cancer, pain is highly prevalent and it requires aggressive management (Erol et al., 2018; Fallon et al., 2018). Most high-income countries have responded with effective interventions including the provision of morphine which is critically important for managing cancer-related pain management suggested by the WHO ladder for cancer-related pain management (Majeed, Nadeem, Khokhar, & Qaisar, 2019; WHO, 2018a). However, low- and-middle-income countries may have little or no access to pain relief or palliative care (Knaul et al., 2018). This is because "Of the 298.5 metric tons of morphine-equivalent opioids distributed in the world each year (an average from 2010- 2013), 287.7 metric tons are distributed to high-

income- countries... Only 0.1 metric tons, which is 0.03% of the total amount are distributed to low-income countries... In the poorest countries, a patient with life-threatening or life-limiting health conditions has access to only 10 mg morphine-equivalent opioids per year” (Knaul et al., 2018, p. 1397). It is very sad that such an inexpensive, essential, and effective intervention is denied to most patients in low-and middle-income countries and in particular to poor people. My participants’ inaccessibility to pain management caused extreme suffering in the cruel face of poverty and inequity. The same is reported is by Knaul et al. (2018).

The healthcare providers in my research explained that as morphine was not available, patients were managed with Tramadol which is a weak opioid medication and usually not recommended as primary medications for the treatment of severe pain that occurs in cancer (Majeed, Nadeem, Khokhar, & Qaisar, 2019). The healthcare providers in my study described that not having morphine, patients are sedated. This clinical practice conflicts with the philosophy of pain management which is to improve the quality of life and allows individuals to participate in the activities of daily living. Describing the experience of his mother enduring cancer pain Majeed (2018), who is also a medical doctor, asserts that it was hard for him to believe when he heard his mother’s oncologist saying that “--- no potent opioid pain reliever was available in Pakistan”. The only readily available options were Tramadol and Codeine. Majeed (2018) adds that the oncologist informed him that morphine was available in a few areas, but in an injectable form. The family was able to arrange a few ampules of morphine but finding the intravenous line was a problem. Also, given that morphine has a short half-life, it requires multiple doses a day to relieve pain and having to endure needle pricks so frequently made Majeed’s (2018) mother very uncomfortable. Majeed (2018) adds that he contacted one of his colleagues who is an oncologist and inquired from him about the availability of pain medications

in Pakistan for cancer patients, who said: “I see patients suffering from cancer pain in front of me every day, but I cannot do much about it. There are no medications. The available ones are not easily accessible. There is a lot of unnecessary misery, suffering, and pain. We can treat it effectively only if we can get pain medications.” Majeed (2018) further quotes his oncologist colleague “... And the irony is that I see people using heroin right outside the hospital, an illicit but potent opioid pain killer.” Sharing his own experience as a medical doctor Majeed (2018) adds that he had seen several cases of cancer and end-of-life care in the course of his training and work, but he did not think about treating pain. Also, he did not notice missing pain management in medical students’ curriculum and training. Thus, he emphasizes it needs to be included in the curriculum. Majeed (2018) also, asserts that in Pakistan, regulatory bodies are fearful of illicit use of morphine which causes a barrier in accessing it for cancer pain management. Government and regulatory agencies in the country must make these medications available to those who are suffering from severe cancer pain or are in an end-of-life care situation (Majeed, 2018; Saini & Bhatnagar, 2016). One of my participants explained that at times families went on the black-market to obtain morphine for their loved ones as it was not accessible in the hospital. This way the family members in addition to being heavily burdened financially they for obtaining the drugs illegally are vulnerable to being arrested by law enforcement agencies.

Lack of integrity in the system.

Integrity and accountability are fundamental to ensuring trust between the public and healthcare professionals. Physicians' integrity forms a foundation for patients' trust and fosters healthy therapeutic relationships that promote healing (Levinson, Ginsburg, Hafferty, & Lucey, 2014). Participants in my research were concerned about the lack of integrity in healthcare. For example, to move ahead in the line for diagnostic tests, physician’s consultation and/or for

treatment, participants described they were required to bribe the healthcare workers who were the gatekeepers in the healthcare system. The research participants in this study experienced this type of obstruction process as painful. Haroon (2014) describes corruption as one of the oldest and most prevalent social evil that has existed throughout the history of humankind and will remain a permanent reality. Corruption is the abuse of entrusted power for private gain (Cohen & Petkov, 2016). The adverse effects of corruption are not only financial, but there are also societal and human costs too, especially in low-income settings (Mackey, Vian & Kohler, 2018). Nasir (2018) reports that corruption is one of the most chronic issues all over the world especially in third world⁵⁷ countries like Pakistan. Nasir uses the term third world countries however the new designation by the WHO is High, low and middle income countries (WHO, 2017c). In these countries corruption flourishes because the government fails to strengthen the measures of good governance on a regular basis (Faisal, & Jafri, 2017). Khan, Ahmad, and Khan (2018) write about the politics of corruption and its impact on democracy in Pakistan (1988-1999). They also discuss the menace of corruption, favoritism, misuse of public office for personal gains as the daunting issues hindering the growth of Pakistan as a stable economic power (Khan et al., 2018). The participants in this research were victimized by corruption in the health system as Khan et al. (2018) identify. They specifically talked of their experiences of physicians working in public settings diverting patients to their private clinics where patients would need to pay more money

⁵⁷ The term “Third World countries” was first used during the Cold War. During the Cold War, the United States, Canada, South Korea, Japan, and Western European nations and allies were categorized as *First World countries*. *Second World countries* included China, Cuba, the Soviet Union and their allies. *Third World countries* typically had colonial pasts in Asia, Africa, Latin America and Oceania. In present time the use of the term “Third World” is being used less frequently because of the confusion about its definition (World Population Review, 2019). The WHO refers to these countries as LMIC.

for service. Javed, Liu, Mahmoudi, and Nawaz (2019) assert that in developing countries like Pakistan out-of-pocket expenditures also described as direct payments made by individuals to health care providers at the time of service use health care are 66.5%; while the world's average is 18.147%. Javed et al. (2019) add that the public sector health care system of Pakistan is producing a greater number of dissatisfied customers and the majority of the Pakistani population believes that the country's health care sector is corrupt. Hence, it is critically important that the correct measures are taken for improving the healthcare system. Failure to address this corruption will be continued to have catastrophic effects on the people's current health and future generations of Pakistanis. To overcome corruption Cohen and Petkov (2016) and Haroon (2014) suggest a multi-stakeholder approach and a united front against corruption in the health sector. Nasir (2018) suggests that it is the responsibility of every individual to work jointly with the government institutions to make Pakistan a corruption-free country. He advocates for people to be provided their rights (Nasir, 2018).

The research participants in this study indicated that people who are sick cannot do much about corruption. On paper, especially in public sectors, though there are systems for logging any complaints and for providing the feedback, in reality, these are not examined. Rather they have negative implications; adding to an obstruction in accessing care. Such as standing in a never-ending long queue described above in the findings chapter. My findings correspond to the findings from Haroon (2014) who state that Pakistan is overwhelmed by corruption in its health care system. Haroon (2014) reports that patients who sought care at hospitals faced corruption in order to get admitted to these hospitals. Data indicated that staff dealing with admission, laboratory staff dealing with the provision of blood to the patients, and pharmacy staff is the most corrupt. Seventy percent of respondents in Haroon's study claim that they have paid these

disciplines money as a bribe followed by twenty-four percent of respondents claiming that they have paid money as a bribe to the doctors. In addition, other participants reported being 'forced' to go to the physician's private practice. Those involved in corruption enjoy its benefit but those who face corruption like this are distressed. The participants in my research were feeling overwhelmed and it was painful for them to deal with corruption. Lewis (2006) interviewed public officials, business executives and the general public in 23 countries and reports that for the most part in these countries the population perceives a high level of corruption in health. It was as high as 95% in Pakistan, 92% in Sri Lanka, 85% in Tajikistan. These findings though are more than a decade old, correspond to how the participants in my research described their experiences of corruption that obstructed their access to health. Mostert, Sitaresmi, Njuguna, Beers, and Kaspers (2012) state that in many LMICs, corruption exists at all levels and affects the entire society. It is public knowledge that not only government, politics, courts, police, immigration, business, and universities, but also public hospitals can be affected by this phenomenon. Mostert et al. (2012) add that corruption is of three types. These are (i) bribery, illegal demand of extra money for public services; (ii) extortion, ordering gifts, and favors for public duties or using funds for private purposes; and (iii) nepotism, assignment of family or friends to civil services regardless of their capacities and effects on public welfare. In corruption, the common welfare is deliberately subordinated to personal welfare (Mostert et al., 2012). They add that:

Corruption is usually surrounded by secrecy, betrayal of trust, deception, suppression, exploitation, inequality, and disregard for consequences suffered by civilians. Corruptors influence definite decisions and camouflage their transactions by some kind of

justification. In many low-income nations, both an official and unofficial procedure exists for almost every activity of government-institutions. (p.325).

Mostert et al. (2012) further describe that corruption in medicine includes:

(i) health ministers and hospital administrators, who distort health policy, by demanding bribes and depleting health budgets or funds that should be used to construct clinics, buy medication or engage personnel; to (ii) medical suppliers who offer bribes; and (iii) doctors, nurses, and other health-care providers insisting on bribes from patients in public hospitals to supplement low government salaries. (p. 325).

Mostert et al. (2012) state that types of participants in corruption are corruptors, a partner in corruption and a victim of corruption. The authors also provide their roles, examples in these roles and the effects on patient care. These are as follows:

Types of participants	Roles	Examples	Effects on patient care
Corruptor	Perpetrator of corrupt act.	Doctors, nurses, pharmacists, and hospital administrators demanding bribes from patients. Doctors, receiving government salaries to staff public hospitals, work in private practices where they make more money. Doctors improperly refer to public hospital patients to their private practices and perform unnecessary medical interventions to maximize fee revenue. Afterward, these private patients receive preferential treatment in public hospitals, forcing the poor to wait.	Health-care providers grow rich at the expense of poor cancer patients. Poor cancer patients in public hospitals who cannot afford bribes or private practices are denied medical care of health-care providers in public hospitals. The climate of social injustice in public hospitals: poor and powerless patients are exploited and feel unsafe.
Partner in corruption	A person who deliberately offers bribes to receive	Pharmaceutical and medical device companies	Health-care providers and their

	<p>avored treatment and thereby harms the rights of others.</p>	<p>bribing doctors to only prescribe their expensive drugs or medical devices. Doctors subsequently do not offer patients alternative and cheaper options.</p>	<p>partners grow rich at the expense of poor cancer patients. Poor cancer patients receive no treatment because they cannot afford expensive drugs or medical devices.</p>
<p>Victim of corruption</p>	<p>Victim of corruption</p>	<p>Families are afraid of doctors, nurses, pharmacists, and hospital administrators insisting on bribes for taking care of their loved ones (patients).</p>	<p>The bad reputation of public hospitals, due to corruption and exploitation of the poor, causes a delay in health-seeking behavior. Cancer patients come with advanced stages of the disease and have a poorer prognosis. Dislike and distrust of health-care providers diminish adherence to treatment and evolves in poor health outcomes. Inadequate access to medical care and medicines for poor cancer patients results in abandonment of treatment and low survival rates.</p>

National Academies of Sciences, Engineering, and Medicine (2018) states that corruption is a complex and multifaceted challenge. Offenses range from smaller-scale acts by doctors and nurses who charge bribes or “informal payments” to larger-scale acts at the ministerial or hospital administrator-level by people in power siphon money or redirect resources away from those who need it for their own benefit. Approximately \$455 billion of the \$7.35 trillion spent on

health care annually worldwide is lost each year to fraud and corruption. Underfunding by the government, insufficient regulatory oversight, and lack of transparency in governance breed corruption and reduce the quality of healthcare (National Academies of Sciences, Engineering, and Medicine, 2018). Hussmann (2019) adds that corruption in health systems costs lives, not only by impeding access to life-saving treatments but also by killing people through the use of counterfeit or sub-standard drugs. Thus, corruption in the healthcare impedes equitable access to quality care, it violates basic human rights, and it undermines state legitimacy and trust in the health sector. Lack of resources may be perceived due to the underfunding of the health sector but in reality, in many situations, resources are pilfered through corruption. Access to quality care through diagnosis and treatment of cancer at an earlier stage also disappears where corruption is present. These situations described above were very distressing to the participants in my study and frequent as they sought treatment before they went to Bait-ul-Suksoon.

Facilitators in accessing palliative care

Given the above, improving access to palliative care is still possible through identifying and addressing barriers that obstruct access to palliative care with a view to working towards overcoming them. This study also adds that support through philanthropy improves access to palliative care as seen through the description of Bait-ul-Sukoon hospital. Harvey, Maclean, and Suddaby (2019) define philanthropy “as voluntary giving by households or corporate bodies to promote charitable causes, projects, and organizations or, alternatively, as voluntary action for the public good” (p.443). Harvey et al. (2019) further add that entrepreneurial philanthropy refers specifically to “the pursuit by entrepreneurs on a not-for-profit basis of big social objectives through an active investment of their economic, cultural, social and symbolic resources” (p. 442). In the book titled ‘*The ethics of giving philosophers’ perspectives on philanthropy*’ edited

by Paul Woodruff (2018), Woodruff writes that some human lives depend on philanthropy, and so does the quality of life for many others. Hence, philanthropy can be a matter of life and death, for both people and institutions (Woodruff, 2018). Fox (2017) in his book titled *Engines of culture: Philanthropy and art museums* states that in the 1950s and 1960s philanthropy became a focus of scholarship mainly because foundations made grants to study it. At the same time, many intellectuals were becoming skeptical about the assumptions of the centrist coalition that dominated decisions in government and the economy. Fox (2017) further adds that some intellectuals lost faith in the national welfare state which includes public subsidies. This entire process created alternatives for private philanthropy for hospitals, universities, foundations, and museums.

Countries generate income through tax collection and may budget this amount for the development of social sectors. However, Pakistan fails to generate and collect taxes. Therefore, the social sectors in the country rely on philanthropy (Baqir, 2019). The Pakistan Centre for Philanthropy (2016) conducted a study and reports that Pakistani give around 239.7 Billion PKR annually to charity in the form of monetary, in-kind or time. In a country, its government is responsible to provide the welfare state to its citizens but in Pakistan welfare is supported through charity by the people and with this, the country is recognized as one of the most charitable nations in the world (The Express Tribune, 2018). Hence, philanthropy precedes the welfare state and the institutions of philanthropy help people who need money, or housing, education or healthcare (Fox, 2017). But due to the complexity of the problems and the high need for philanthropy in the society, the philanthropists get overwhelmed. Hence, it is required that the government should invest more in the development sectors. For this, the government needs to set targets for tax collection and then to achieve those targets. However, as Cevik (2018)

asserts Pakistan's tax revenue remains low relative to comparator countries and the tax effort expected for the country's level of development. This creates significant challenges in providing the much-desired fiscal space to expand growth-enhancing expenditure on infrastructure, education, health care, and targeted social assistance. Blackman (2016) states that when it comes to charitable giving, it's well known that taxes matter and the relationship between taxes and giving is not simple. Research suggests people may even be willing to give money voluntarily to the government if the government gives them the chance to direct the money to a cause they approve (Blackman, 2016). As I reflect in Pakistan individuals have a lack of trust in the government that it will use the money on the welfare of the society and will not use it for the personal gains by those who are in power. Mehmood in his article titled "Why don't we pay taxes?" in Dawn news (2017, September 18) addresses the prime minister of Pakistan and states that "Please understand that to realize more taxes, you need to build trust with the people. Once you earn their trust, the apple (taxes) will automatically fall into your lap". Jones (2018) writes that we don't want billionaires' charity. We want them to pay their taxes. He adds that philanthropy is a dangerous substitution for progressive taxation. Philanthropy often is just to make rich people and major corporations look generous while they save far more money through exploiting loopholes and using tax havens. Hence, they have the means to legally avoid tax. Rather than philanthropy, the super-wealthy should give their money in the form of taxes to governments that know better how to spend it (Jones, 2018).

Bait-ul-Sukoon Cancer Hospital, site of this research study, is a philanthropic institution. Bait-ul-Sukoon provides free cancer treatment to those from less privileged areas and who cannot fund their treatment (Bait-ul-Sukoon, 2015). The Bait-ul-Sukoon Hospital and Hospice invites philanthropists to contribute through cash or cheque, sponsor a bed or a patient or donate

to support in building up for endowment funds or to support the medical staff payroll (Bait-ul-Sukoon, 2015). Providing multiple options for donations encourages individuals to contribute according to their affordability. Both small and big donations collectively have a huge impact and they make a difference (Serafin, 2018, (Mesothelioma Cancer Alliance, 2020; Smart Money Daily, n.d.; Talk About Giving, 2012). Given the philanthropic nature of the institution, the majority of the patients at Bait-ul-Sukoon are of low-income groups, who also make the majority of the people in Pakistan. These are people who are living day to day struggling to meet the basic necessities of life. Kassim-Lakha and Bennet (2013) write that it is through philanthropy, a strong giving and volunteering tradition rooted in religion, civic duty, and social responsibility in Pakistan, that individual donors, foundations, business corporations, and community and faith-based organizations have stepped in to support healthcare activities, including service delivery.

The Zakat⁵⁸ is the most common form of charity in Pakistan and is one of the five pillars of Islam that is deeply embedded in the religion (Kassim-Lakha & Bennet, 2013). It constitutes both private and voluntary donations by individuals and officially administered donations. The officially administered zakat is deducted at a rate of 2.5% per year on the value of financial assets of Muslims who authorize such deduction. In addition, there are individuals who give zakat privately because of religious sanctity and privacy (Kassim-Lakha, & Bennet, 2013). According to a Sharia definition of the religion of Islam, those who are needy⁵⁹ can receive zakat either routed through the charitable organization or given directly to the individuals (Amjad, & Ali, 2018; Kassim-Lakha, & Bennet, 2013). There are individuals or lower-middle-class families

⁵⁸ Obligatory Islamic poor tax of at least 2.5% per year on financial assets

⁵⁹ Owning less than 400 g of silver

that may be in a need of financial assistance, yet they might not qualify to receive the funds through zakat. These individuals may be supported through funds other than zakat through gifts and donations from more privileged individuals. The mode of delivery for these funds is the same - through a charitable organization or given directly to the individuals (Amjad, & Ali, 2018; Kassim-Lakha, & Bennet, 2013). Thus, the amount, patterns and forms of philanthropy remain poorly understood. However, in 2000 the first-ever national study of individual philanthropy in Pakistan revealed that individuals gave an estimated PKR 70 billion in cash, in-kind, and voluntary time (Kassim-Lakha, & Bennet, 2013). Philanthropy is necessary because of poverty, lack of funding for healthcare in Pakistan and corruption in health delivery. Ali and Maqsood (2018) state that in Pakistan nearly 98 percent of people give through cash, in-kind or time volunteered.

Role of Bait-ul-Sukoon Cancer Hospital

As mentioned in chapter one Bait-ul-Sukoon established in 1999 (Bait-ul-Sukoon, 2015) as a hospice for terminally ill cancer patients in 2009 (Bait-ul-Sukoon Cancer Hospital, n.d.) expanded as a cancer hospital and hospice in with the purpose to provide inpatients and diagnostic facilities of mammography, ultrasound radiography, pathological laboratory and in house pharmacy for a complete range of cancer treatment. Run by a trust (Bait-ul-Sukoon Cancer Hospital, n.d.) the hospital also provides family financial support (Bait-ul-Sukoon Cancer Hospital, n.d.). This way Bait-ul-Sukoon expands its services to improve the individuals' social determinants of health by connecting them to the philanthropists who desire to contribute through their wealth. At Bait-ul-Sukoon the goal of care is prevention, early detection, (Bait-ul-Sukoon Cancer Hospital, n.d.) treatment and hospice care. Patients who come to Bait-ul-Sukoon Cancer Hospital are referred here from other hospitals mainly for hospice care. Not all the

services required for diagnosis and treatment are provided at Bait-ul- Sukoon Cancer Hospital instead these services are provided in the institutions affiliated with Bait-ul- Sukoon Cancer Hospital. Such as breast surgeries and CT scans are performed in the institutions that are affiliated with Bait-ul- Sukoon Cancer Hospital for that ambulance service is provided for patients' two way transportation from Bait-ul-Sukoon to the affiliated institutions (Bait-ul-Sukoon Cancer Hospital, n.d.).

Bait-ul- Sukoon Cancer Hospital also recognizes itself as an institution for training and education (Bait-ul-Sukoon Cancer Hospital, n.d.). The institution website states that Bait-ul-Sukoon Cancer Hospital conducts a wide range of courses and training related to the caring of patients with cancer. During my data collection, I noted that medical students from other institutions were learning through being buddied and supervised by the oncologists at Bait-ul-Sukoon Cancer Hospital. Also, Bait-ul-Sukoon challenges doctorate and post-doctorate fellows to peruse their scientific interests and make a significant contribution to the prevention and treatment of cancer. My research at Bait-ul-Sukoon is evidence of their interest and contribution to generating new knowledge through the scholarship of research. The institution website also states that Bait-ul-Sukoon offers a range of Continuing Medical Education opportunities to the health-care providers for direct access to the latest advances in cancer medicine.

Locating the Findings With the Theoretical Propositions

The theoretical propositions that guided my research were invaluable. Each proposition was present in my findings and was accepted. For example, the findings indicate that palliative care is not accessible to all who are in need of it. This results in a late diagnosis of cancer. It is the individuals' social determinants of health that influence their access to palliative care. Individuals guided by their culture or when access is delayed, it is because they do not want to

take away their family resources and are unwilling to proceed with access to care when it is dependent on their ability to pay. The participants instead of accessing costly healthcare, approach a traditional healer or they use alternative therapies as suggested by the members in the surroundings. These are their relatives, friends, neighbors, and others. This I describe in findings under the chapter on suffering due to resource constraints and corruption, late diagnosis, and culture and beliefs preventing seeking medical health. This research also informs as in the proposition, that opioids are inaccessible in part because cancer pain is perceived as part of the disease. Also, access to opioids is obstructed by strict regulations and controls. Access to opioids is also dependent on income status; those with high income have access to opioids pain medicines, while those with low income do not have access. Thus, they suffer. Moreover, there is a lack of palliative care emphasis at the national policy level. This is described in findings under the chapter on suffering including healthcare providers' suffering.

Under lack of education describes the health care providers are deficient in palliative care education and its influence on cancer care and symptom management. Hence, a policy level change is required for improving access to palliative care. The WHO and researchers recommend that a public health strategy is to be implemented to address the issue of palliative care. This described under the section on public health strategy.

Summary of Discussion

In Pakistan cancer is considered a disease that has no cure and once diagnosed death will occur. Not that individuals without cancer will never die, but death due to cancer turns into stark reality because in most cases when diagnosed, patients are at an advanced stage of disease or are at the end of their lives. Consequently, the term cancer is understood as a bomb threat and is perceived as a certain death with no light at the end of the tunnel. Therefore, when diagnosed,

individuals and their families mourn that nothing could be done to save the person. This depicts the historic picture that hospice and palliative care has had in the past, but now palliative care may extend life. Also, palliative care is for all diseases or conditions of coming mortality. Palliative care also focuses on the public health approach which includes prevention, early detection, cancer treatment, and symptom management. But circumstances described above, show how Pakistan contributes and creates barriers to making palliative care accessible to all who are in need. Barriers discussed in this chapter are healthcare providers lack the competency to identify the early signs of cancer resulting in late diagnosis. One of the reasons for their incompetence is the absence of palliative care in the medical and nursing curriculum. Other obstructions included in the discussion are cultural and system challenges resulting in individuals trapped in poverty, and they find it difficult to access health and quality care. Often due to circumstances beyond their control, they fail to access cancer pain management and they suffer severe pain. Above all corruption was one of the main obstructions to accessing palliative care. Overcoming all these barriers is highly important in improving access to palliative care in Pakistan. In the country philanthropy though is rooted in religion and culture of giving by the rich to the needy is a facilitator in fulfilling their needs to some extent but this approach is not sufficient. Thus, more is to be invested in social development. This could be achieved through diverting budget priorities from the military to social and health service delivery development and controlling corruption which is the novel finding of this research.

Implications for Education, Practice, Research, and Policy

I used sustainable development goals (SDGs) as the framework to describe the implications of my research. In my research, I used SGD 3.8 as a theoretical proposition and the implications I describe under the section of education and training, healthcare delivery and

integration into national health systems, and practice. Implications about research and policy are also discussed in this section. I draw on the components from the framework Hannon et al. (2016) developed to overcome obstacles for effective treatment delivery and for the provision of palliative care in LMICs. They include education and training.

Education and Training

SDG 3 focuses on good health and wellbeing. In the provision of health and wellbeing healthcare providers play a critical role. Thus, they are to be well educated and prepared to provide the required services. However, the participants in my research asserted palliative care was not included in their curricula. This research also informs that delayed diagnosis was also attributed to the general physicians' lack of expertise in the identification of early signs of cancer resulting in the physicians treating their patients for other diseases. Therefore, providing sufficient training to healthcare professionals both before and after they begin practice is important to overcome a major obstacle to the provision of palliative care.

Systematic approaches are needed to train healthcare providers in the delivery of palliative care and pain management. Hanon et al. (2016) propose education and training opportunities from basic to advance levels as a way to improve palliative care delivery in LMICs and therefore one of the recommendations of this study is to adopt the proposal by Hanon et al. (2016). This is also greatly relevant to Pakistan an LMIC. The basic level could be the time before they enter into the practice, the middle level is the time when the healthcare providers are licensed by the statutory body. In Pakistan, the Pakistan Medical and Dental Council is the statutory body for doctors and for nurses Pakistan Nursing Council is the statutory body. The advanced level could be the time when these practitioners are to move forward in their field; nursing or medicine. A basic level the healthcare providers are to be educated and trained for

using basic diagnostic tests and equipment, gain awareness about the culture of the population they serve, build expertise in communication skills, and physical symptoms assessment skills, access to morphine which is a basic drug for palliative care. The healthcare providers should also be educated and trained to provide psychological, spiritual and bereavement support. At mid-level access to drugs as per the WHO pain ladder (Appendix A) for pain and symptom management, multidisciplinary approach to symptom management, home- and- hospital-based services with nursing support, access to specialist referral services, and undergraduate teaching. At the advanced level uses of physical and psychological screening tool, access to advanced pain and symptom management modalities, home-based services with clinician's support, specialists inpatient units, complex psychological and bereavement support, quality assurance systems, postgraduate and specialists training programs, and research (Hannon et al., 2016). For better outcomes of these training and education programs, it is required that the partnership should be built with the organizations that are established and they show a history of reliable outcomes (Rosa et al., 2018). In Pakistan, such institutions are yet to be built. It is also recommended that the Memorandums of Understanding should be developed with internationally recognized institutions and universities and through exchange programs those who may like to pursue their career in the field of palliative care could be trained and developed as specialists or experts. This training could be through different pedagogies including a blended learning approach which includes face-to-face and a-synchronized distance mode. These courses and programs could be from certificate to graduate-level programs. Accordingly, the duration of programs could be from four to six weeks short term, one-year diploma to a two years master program. The content of the program could be developed accordingly. Nigolian, Gantioque, and Dexheimer (2019) suggest that a recent focus on palliative care has led medical schools worldwide to grow their palliative

care curricula. Also to avoid both neglects of the topic and educational overload they suggested integrating basic palliative care competencies into each year of the medical school curriculum. It is also recommended that knowledge of the major ethical dilemmas in medicine, particularly those that arise at the beginning and end-of-life, knowledge about relieving pain and ameliorating the suffering of patients, as outcomes that all medical students should have achieved by graduation (Nigolian et al., 2019). Rosa (2018) emphasizes that nurses should be provided with palliative care nursing education. Palliative care is to support patients, families, and communities. This support is to be regarding advance care planning, pain and symptom management, and improved quality of life (Rosa, 2018). The participants in my research talked about them not getting the drugs for their patients' pain management. It is important that palliative care education prepares nurses to provide the evidence to policymakers and partner with them for the provision of drugs for pain management. For example, there could be those who advocate prioritizing the procurement of necessary medications in areas of critical shortages (Rosa, 2018). Additionally, there is a presenting need to educate nurses and physicians about pain management and administration of opioids and to not be fearful of patients getting dependent on these drugs when cancer pain management is the priority.

The participants in my research asserted the need to include palliative care in the medical and nursing curriculum but while I relate to the literature, my personal experience and reflection as researcher I also see the need of educational initiatives and partnership within the institutions in the country; Pakistan, in other countries in LIMCs and with international partners. Providing examples Hannon et al. (2016) write about a number of education programs in LMICs. A multidisciplinary master's course offered by the University of Cape Town in South Africa, a Postgraduate training for palliative care nurses and special clinical officers in Uganda, and a

master's program through collaboration between Hospice Africa Uganda and Makerere University in Kampala the capital city of Uganda. In India in the state of Karala, Hannon et al. (2016) state that there are several palliative care training programs for physicians and nurses, including one year residential or distance learning fellowships, an eight weeks certificate course on essentials of palliative care through the Indian Association of Palliative Care, and a four to six weeks residential training program through the WHO collaborating centers. This research supports the need for including palliative care education in the medical and nursing education and training while they are being trained for entry in the profession but also for continuing education at certificate, fellowship and graduate-level programs. The same is recommended by the WHO (2016a) advocating that training is needed at pre-service, continuous education and faculty levels.

It also needs to be recognized that individuals' health and social practices are guided by their culture and tradition. Accordingly, individuals often first approach traditional healers. These healers could be educated, partnered and a referral system could be developed. Traditional Healers could be integrating into the Health (Krah, de Kruijf, & Ragno, 2018). Green and Colucci (2020) give different perspectives about these healers; traditional healers have been successfully integrated into HIV care as educators and counselors since the 1990s, research and best practice guidance for working with these healers is scarce, the relationship between biomedical and indigenous forms of care has historically been tense, characterized by a belief that the two systems would not be able to work together due to their diametrically different understandings of illness (Green, & Colucci, 2020).

Healthcare Delivery and Integration into National Health System

Dempers and Gott (2017) conducted an integrative literature review and based on their thematic synthesis, identified three different paradigms of public health approach to palliative care. These were (1) health-promotion approach focused on empowerment at the community level, (2) a World Health Organization approach which focused on systems at the country level, and (3) a population-based approach that typically viewed palliative care issues from an epidemiological perspective. Accordingly, the population in general needs to be educated about cancer, its prevention, early detection, and curative and even end-of-life care. Also, it is a must that early diagnosis of cancer, provision of screening services such as mammography are offered at a subsidized cost. This research informs that the individuals who eat gutka have a reason for doing this. They must remain awake to be able to work longer hours, to suppress their desire for food and to fulfill their emotional needs. The practice of chewing gutka is discussed in the literature yet this is one of the areas that could be explored further. However, this research recommends that at-risk populations should be educated and examined to control this substance abuse. People should also be educated about the implications of using these substances.

My research reports that even if patients were receiving treatment, all did not find it effective. This questions the efficacy of drugs like chemotherapy and other treatment but it could also be the patient's poor health condition and the effects of late diagnosis. It is suggested that all the security checks for the provision of palliative care be employed. Quality checks are required for the efficacy of the entire treatment that the patients receive. This requires focusing on the efficacy of drugs like chemotherapy and other drugs. Similarly, other treatment regimens like radiation and adjunct therapies should also be of a quality appropriate to the type of cancer diagnosis. Access to morphine for pain is much needed. This requires changing healthcare

providers' assumptions about using morphine and not being fearful of patients' addiction to morphine. Murakami (n.d.) writes in a proverb that while pain is inevitable, suffering is optional. Yet my research informs that patients with cancer have severe unrelenting pain and suffer dreadfully or terribly. This requires policy level change to control illegal drug trafficking of opioids needed for control of cancer pain.

Implications for Nursing Practice

For the safety of their own and of their patients, it is important that nurses should work within their scope of practice. However, findings of the present research and also reported in the literature, indicate that nurses are deviating from their scope of practice. It is recommended that the statutory bodies for nursing should periodically audit the institutions and those nurses who do not comply with these requirements they should be charged a penalty, such as pay a heavy fee. Similarly, those institutions that allow or force nurses to perform the tasks that are not in the scope of their practice, these organizations and institutions should also face their legal implications. They should realize the importance of the scope of practice and its implications on human lives.

Implications for Research

In Pakistan the concept of palliative is still new and this field is yet to be recognized. The above section detailed pertaining to education and practice or healthcare delivery. Pertaining to scholarly inquiry there is a dearth of literature related to the field of palliative care generally in LMICs and particular to Pakistan. When I was searched literature, not much could be found in the context of Pakistan. Thus, I consider my research will add value and fill a portion of the gap present in the literature related mainly to Pakistan. Hannon et al. (2016) assert that evidence-based-medicine is a fundamental underpinning of high-quality care, and research has been

proposed as a fifth pillar in the WHO public health strategy for palliative care. These research findings will be disseminated through high-impact journals. Areas of palliative care research building on these findings must be in the field of education, practice, policy level. Similarly, research findings are to guide education, practice and policy level. It will also guide the need for future research. Consultations and partnerships with other scholars including both educational and health institutions would be helpful.

Implications for Policy

Policy level change is required in multiple areas. These are not in any sequential order rather all of these are much important. Hence, there is a need that social determinants of health should be used to assess the need for health information and access to health services. Programs for poverty alleviation are needed. Eradication of poverty is also a goal in SDGs. Also, providing universal healthcare included in SDG 3.0 would occur through policy development.

Corruption as above was voiced by most of the participants in my research. Corruption which is one of the core difficulties in obstructing access to quality care should be eradicated. Those who found guilty, or convicted should be arrested and legally charged; punished, jailed, pay the penalty. Similarly, there should be strict checks for monitoring the quality of care that is being provided. In case of the failure, the institutions and the professional failing to follow the standards should be charged and disciplined. It is the responsibility of the statutory bodies of medicine, nursing and regulating bodies to conduct audits in line with job descriptions based on the level of education and competency. It is also suggested that the policies should be instituted for the in-service programs and continuing education of healthcare professionals. In these continuing educations programs, health ethics courses must be developed and must be mandatory for refreshing health professionals. Education is also needed for the population for prevention

and screening for early detection. Given that the cost of health care is to be borne by the individuals resulting in them not giving priority to themselves but to other commitments such as their families Poverty is a major issue of Pakistan since its foundation and it is badly disturbing the economy of the country as described earlier in this chapter. Policies are needed to provide the financial cover for the cost of health and the government should fulfill this need. Whereas, as the participants in my research shared that at present public institutions are not sufficient and of those which are present many are inefficient, encircled with corruption and with questionable quality. Added to this is the need to fulfill the financial need for defense and military, therefore, fewer funds are invested in education and health. More allocation of a percentage of GDP on these components is required and should be focused on health. Strategies for improving GDP are also needed to enhance resources. Also, improve the relationships between countries would minimize the need for the budget for the military/army.

Policy level change to improve access to morphine, and controlling illegal trafficking of drugs is needed. Systems for procurement and release of opioids should be enhanced. Myths and threats that the administration of morphine may cause drug abuse should be overcome by including it in the basic curriculum in medicine and nursing and through a program of continuing education of these professionals. It is also required that the services that are offered should be of quality. Based on this study's findings, it is also suggested that the perspectives of those who are at the policy level should be obtained and should be explored as to why narcotics are not supplied. These policymakers' commitment should be obtained to make the system easy for obtaining opioids instead of making it difficult which at present is the situation.

Strengths and Limitations of the Study

Participants in my research were patients, family members, and healthcare providers. Thus, the perspectives of healthcare providers and the recipients of healthcare obtained were enriching. This research was guided through theoretical propositions found in the literature and in my personal experience (Baxter & Jack, 2008). Thus, it builds on what already exists in the literature. My personal experience in the field which includes both education and practice is more than three decades. Data collection in this research included observation, self-reflection, and interviews of the patients, family members, and the healthcare provider. Thus, this study provides a window to look into the unique experience of the research participants. Insights from their experiences were enriching; yet, it was very challenging for me to witness these human experiences. Bringing the emic and etic perspective was value-added, yet emotional too. Looking at the critical cases such as wounds filled with maggots, people needing care but could not access it, and witnessing individuals' physical, financial and emotional misery was very difficult for me to bear. It required that I obtain emotional help and support so as to remain working and focused and to come out of the depression caused by witnessing the state that many people live in and the few choices they have for accessing medical care. I discussed this with my supervisors and with my family, especially with my daughter who is a young adult and has her undergraduate background in human psychology. Her suggestion was that I needed to think of this research as an opportunity to give voice to those in need. Instead of being depressed I was to rise myself so I can defend these individuals and advocate for them. My supervisors encouraged me to note that the participants in my research gave their valuable input, they shared their difficult and disturbing experiences which was highly valuable and enriching. Their feedback always guided

me throughout the research process. It deepened my analysis. I see this research highly valuable not because I did it but because it really looking into the area much needed to be focused.

Pertaining to the limitations of my research, collecting data from one institution which is a philanthropic institution may be considered as a limitation. However, the descriptions of my participants indicated what they had experienced from other institutions including both public and private ones. A strong limitation I see was that I did not include the traditional healers to obtain their perspectives. Yet, now I see it as another study as these findings will inform that study. Another limitation is not including individuals of high income, or possibly personnel from the policy level. I see more research in the context of policy level will build on this research and extend it.

Conclusion

I used theoretical propositions to guide my research Yin (2014; 2018) and these theoretical propositions were derived from the literature and from my professional experience (Baxter & Jack, 2008). Many of the theoretical propositions were derived from SDG 3.8. My research indicates that though as indicated in SDG 3.8 yet in Pakistan all the people are not provided with universal health coverage including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines. This was illuminated through extreme suffering and late diagnosis. Some of this is already in the existing literature. However, witnessing these experiences through direct interaction with the participants and actual hearing of these participants was enriching. Thus, this study provides a unique window to look into the experiences of people seeking palliative care in Pakistan. The study shows what it is like to live these experiences that the participants in my study were living. They described healthcare system failures embedded in

corruption obstructing their access to health. This research also underscores that at present in Pakistan, military and defense are the focus in the budget priorities. This deprives the population of fulfilling the need for social development and the health of the people in the country which ruins the health and quality of life of the individuals. This results in individuals feeling emotionally distressed, viewing no or little betterment of their lives not only for themselves but also for their generations and after generations. These findings highlight the need for policy change by involving the stakeholders from social sectors, health, and education at the country level and through working with the WHO. Therefore, focusing on the public health approach and providing universal health coverage to all as stated in the SDGs is critically important for improving the access to palliative care in Pakistan.

This research also affirms Hannon et al. (2016) recommendations to overcome the obstacles for effective delivery of palliative care in LMICs. Where Hannon et al. (2016) assert that despite being declared a basic human right, access to adult and pediatric palliative care for millions of individuals remains difficult and at times insurmountable in LMICs. Given that the global cancer case prevalence is anticipated to be doubled over the next two decades it is urgent that palliative care be available to patients with cancer. Fifty percent of these cancers are expected to occur in LMICs, due to late diagnosis and insufficient access to appropriate treatment options for cancer care mortality is high. Hannon et al. (2016) add that in these countries, a multipronged public health approach is needed to fulfill the humane and ethical obligation to make palliative care universally available. This includes health policy that supports the integration of palliative care and investment in systems of health care delivery; changes in legislation and regulation that inappropriately restrict access to opioid medications for individuals with life-limiting illnesses; education and training of health professionals;

development of a methodologically rigorous data and research base specific to LMICs that encompasses health systems and clinical care; and shifts in societal and health professional attitudes to palliative and end-of-life care. International partnerships are valuable to achieve these goals, particularly in education and research, but leadership and health systems stewardship within LMICs are critical factors that will drive and implement change (Hannon et al., 2016).

Knowledge generated through this research will be disseminated through publications in scholarly journals and through presentations at seminars and conferences. I will work toward integrating the research findings into palliative care curricula to educate healthcare professionals. These findings form the basis for the development of a program of research following WHO standards and guidelines for research in LMICs funded through national and international funding agencies supporting palliative care.

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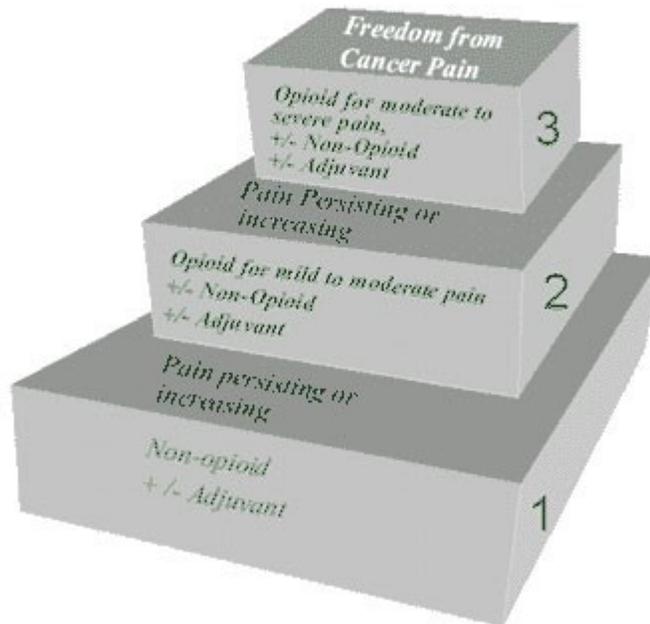
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Appendix A: World Health Organization's Pain Relief Ladder

WHO's Pain Relief Ladder



Source:

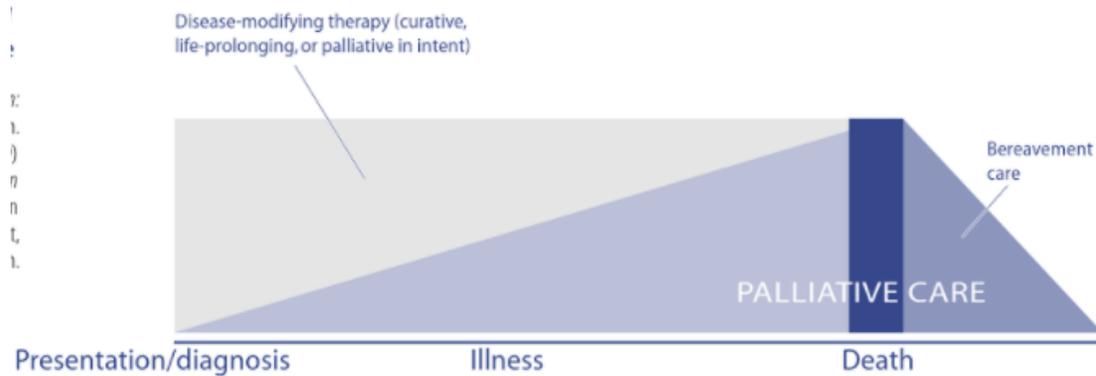
World Health Organization. (1996a). *Cancer Pain Relief: With a Guide to Opioid Availability*.

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<https://books.google.ca/books?hl=en&lr=&id=FhaII7PMHZcC&oi=fnd&pg=PR5&dq=world+health+organization+take+about+palliative+care&ots=th7jq5DU7d&sig=ZXM2EEoJ61EZI9j2YJXdwcHRrok#v=snippet&q=palliative%20care&f=false>

World Health Organization. (2018a). Cancer: WHO's cancer pain ladder for adults. Retrieved from <http://www.who.int/cancer/palliative/painladder/en/>

Appendix B: The WHO figure: The quality of Life Dimension of Palliative Care



Source:

World Health Organization. (2002). *National Cancer Control Programmes: Policies and management guidelines*. (2nded.). World Health Organization: Geneva. Retrieved from https://books.google.ca/books?hl=en&lr=&id=7VQ0DgAAQBAJ&oi=fnd&pg=PR11&dq=world+health+organization+take+about+palliative+care&ots=qfdBXjX9_F&sig=10N8FyhyIIAalmdJPaEE4Zmow#v=onepage&q=Pakistan&f=false

Appendix C: Sustainable Development Goal 3: Good Health and Wellbeing

SDG 3 “Ensure healthy lives and promote well-being for all of all ages”

The goals within a goal: Health targets for SDG 3

3.1 By 2030, reduce the global maternal mortality ratio to less than 70 per 100 000 live births.

3.2 By 2030, end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1000 live births and under-5 mortality to at least as low as 25 per 1000 live births.

3.3 By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases.

3.4 By 2030, reduce by one-third premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being.

3.5 Strengthen the prevention and treatment of substance abuse, including narcotic drug abuse and harmful use of alcohol.

3.6 By 2020, halve the number of global deaths and injuries from road traffic accidents.

3.7 By 2030, ensure universal access to sexual and reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes.

3.8 Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.

3.9 By 2030, substantially reduce the number of deaths and illnesses from hazardous chemicals and air, water and soil pollution and contamination.

3.a Strengthen the implementation of the WHO Framework Convention on Tobacco Control in all countries, as appropriate.

3.b Support the research and development of vaccines and medicines for the communicable and non-communicable diseases that primarily affect developing countries, provide access to affordable essential medicines and vaccines, in accordance with the Doha Declaration on the TRIPS Agreement and Public Health, which affirms the right of developing countries to use to the full the provisions in the Agreement on Trade-Related Aspects of Intellectual Property Rights regarding flexibilities to protect public health, and, in particular, provide access to medicines for all.

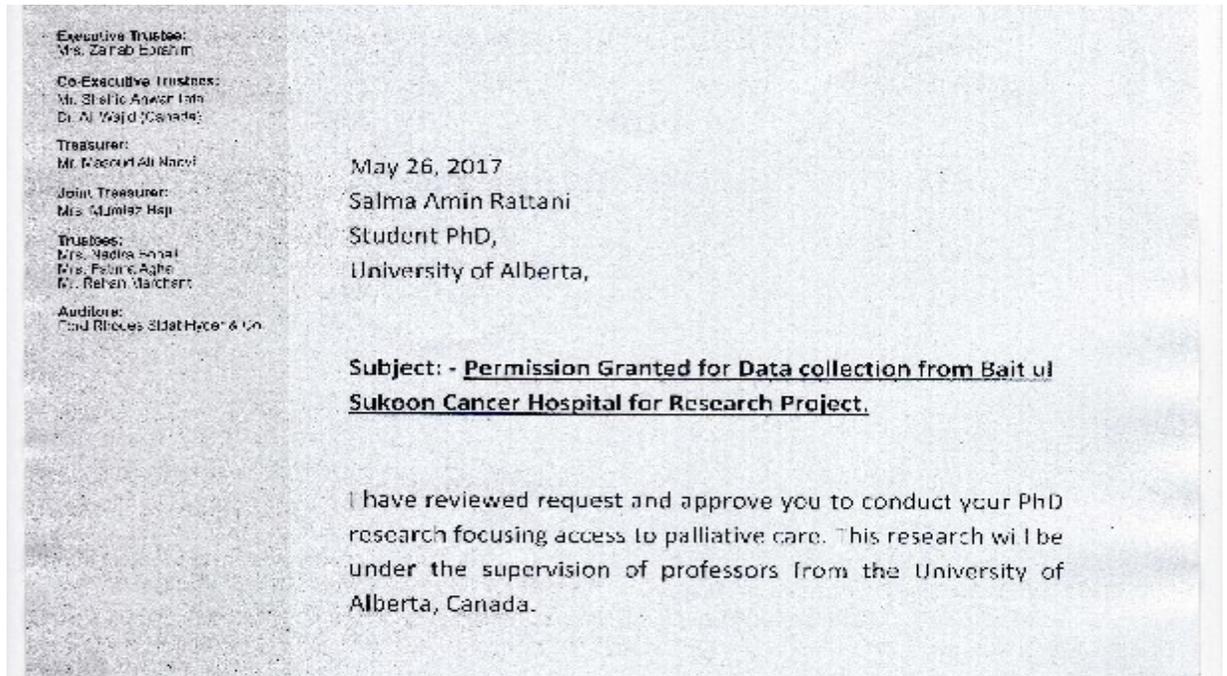
3.c Substantially increase health financing and the recruitment, development, training, and retention of the health workforce in developing countries, especially in the least developed countries and small island developing States.

3.d Strengthen the capacity of all countries, in particular developing countries, for early warning, risk reduction and management of national and global health risks.

Reference

World Health Organization (2017). Sustainable Development Goals.SDG 3: Ensure healthy lives and promote wellbeing for all at all ages. Retrieved from <http://www.who.int/sdg/targets/en/>

Appendix D: Permission Letter from Bait-ul-Sukoon Cancer Hospital



Appendix E: Approval by the Research Ethics Board 1, University of Alberta

Notification of Approval

Date: April 6, 2018

Study ID: Pro00079346

Principal
Investigator: Salma Rattani

Study
Supervisor: Brenda Cameron

Study Title: Case study describing access to palliative care in Pakistan

Approval
Expiry Date: April 5, 2019

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,
Anne Malena, PhD
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Ethics Application has been Approved

ID: [Pro00079346](#)
Title: Case study describing access to palliative care in Pakistan
Study Investigator: [Salma Rattani](#)

This is to inform you that the above study has been approved.

Description: Click on the link(s) above to navigate to the HERO workspace.

Please do not reply to this message. This is a system-generated email that cannot receive replies.

University of Alberta
Edmonton Alberta
Canada T6G 2E1

© 2008 University of Alberta

Appendix F: Recruitment of the Participants Information Poster

Background:

Salma Amin Rattani, in partial fulfillment of the requirements of the degree of Doctor of Philosophy, Faculty of Nursing, University of Alberta, is conducting research at Bait-ul-Sukoon Cancer Hospital. This research is under the supervision of professors Dr. Brenda Cameron and Dr. Sherry Dahlke from the University of Alberta.

Permission and approval:

The Medical Director and the Administrator Bait-ul-Sukoon Cancer Hospital have granted permission for data collection from Bait-ul-Sukoon Cancer Hospital for the research project. Also, the plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (7800) 492-2615. This office is independent of the researchers.

Study Title: A Case Study Describing Access to Palliative Care in Pakistan

Purpose: To learn from the experiences of the individual patient, family member, and health care providers at Bait- ul-Sukoon Cancer Hospital.

Methods for data collection:

- Observation in the field (please see the observation sheet attached to this poster).
- Interview with the individuals (patients, family members, and healthcare providers are invited for interview).
- Collection of information from the hospital such as the number of patients coming to the hospital and the type of services provided by the hospital.

Further information:

For information or to volunteer for this study please contact Salma Rattani

Email: rattani@ualberta.ca

Contact number (021) 34865256

Appendix G 1a: Information Letter for Patients

Study Title: A Case study describing access to palliative care in Pakistan

Research Investigator: Supervisors:

Salma Amin Rattani Professor Supervisor: Dr. Brenda Cameron and Dr. Sherry Dahlke,
Email rattani@ualberta.ca bcameron@ualberta.ca dahlke@ualberta.ca
Phone number +923452341738 1-888-492-8089 780-492-8232
Address Faculty of Nursing, Edmonton Clinic Health Academy
 11405-87 Avenue University of Alberta
 Edmonton Alberta, Canada T6G 1C9

Background

- You are invited to participate in a research project because you are a patient receiving palliative care services at Bait- ul-Sukoon Cancer Hospital
- We are interested in your experience of getting help from the doctor and nurses when you feel sick.
- This research is a student's (Salma Amin Rattani) project in partial fulfillment of the requirements of the degree of Doctor of Philosophy, Faculty of Nursing, University of Alberta. Salma is conducting this research under the supervision of professors Dr. Brenda Cameron and Dr. Sherry Dahlke from the University of Alberta.

Purpose

- The purpose of the research is to learn from the experiences of the individual patient, family member, and health care providers at Bait- ul-Sukoon Cancer Hospital.

Study Procedures

- If you agree to participate you will be interviewed by the researcher about your experiences related to your access to care and treatment. The researcher will gather information about your illness from the hospital record.
- The interview will take approximately 30 – 45 minutes and will occur in a private space to maintain your confidentiality. During the interview, if you feel tired, you can ask for a break or the interview could be rescheduled.
- It is also possible that while reviewing your interview notes, the need for more description is identified. In such a situation, you will be approached and requested to add to the description. Thus, it is possible that you may be interviewed more than once.
- If at any time you wish to discontinue your participation in this study you are free to do so.
- Your participation in this study will not influence the care you receive from the hospital staff.
- Your interview will be audio recorded. If you want to participate in the research but you do not want your interview to be audio recorded then the researcher will take your interview notes.
- Transcribed transcripts of the interviews will be shared with you and you may wish to elaborate on your experiences.
- These interview notes will be assigned a transcript number and your name will be concealed.
- Only, the researcher and her supervisors will see your transcribed data or interview notes.

- The findings from this research will be shared through the student's dissertation which will be submitted to the nursing graduate office, University of Alberta. This research will be presented at different forums and through publication in scientific journals.
- These presentations and publications will include the verbatim from your interviews but your individual identity will not be recognized as your name will be concealed and your interview transcripts will be assigned a code number.

Benefits

- Your participation in this research may provide you an opportunity to ventilate your feelings and concerns related to your health status. It is also possible that your participation in this study may not benefit you as an individual but the findings from this study may benefit society in general. Knowledge gained from this research may contribute to improving health care education, practice, and research. Also, it may benefit at the policy level for improving the systems.

Risk

- It is possible that talking about your experience will bring up negative feelings. You do not need to talk about anything that makes you feel uncomfortable.

Voluntary Participation

- You are under no obligation to participate in this study.
- Your participation in this study is completely voluntary and you are not obliged to answer any specific question even if you are participating in the study.
- You can opt-out from the study without any penalty and you can ask to have any collected data to be withdrawn from the database and it will not be included in the study.

Confidentiality & Anonymity

- Your personal identifier like name and medical record number will not be used. The researcher will encrypt the data and your anonymity will be maintained throughout the research process and disseminating the findings through research presentation and publication.
- Your interview recording will be saved on the primary researcher's computer which will be password protected. This computer will be in the custody of the researcher. Your interview will be translated into English and the interview transcript will be saved on the primary researcher's computer and in a folder in the primary researcher's computer and in the University of Alberta secured computer. This folder will be accessible to the student and the research supervisors.
- The entire data set will be secured for a minimum of five years following completion of the research project. After that this data will be destroyed by deleting these files from the computer.
- It is quite possible that the data collected for this study may be used for another research but this research will have to be approved by a research ethics board.

Freedom to withdraw

- You will have the right to withdraw from the study at any time within six weeks of your participation in the study. However, data withdrawal will not be possible after six weeks as thereafter, the data will be included in the analysis process.

Further Information

- If you have any further questions regarding this study, please do not hesitate to contact the researcher Salma Amin Rattani. Her contact details are provided in this form.
- “The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.”

G 1b اینڈکس
مریضوں کے لئے معلوماتی مراسلہ

تحقیق کا عنوان: پاکستان میں ، درد سے سکون پہنچانے کی نگہداشت تک رسائی کی وضاحت کے لئے کیس

اسٹڈی

محققہ: سلمہ امین رتانی

ای میل: rattani@ualberta.ca

فون نمبر: +923452341738

پروفیسر نگرہاں: ڈاکٹر برینڈا کیمرون اور ڈاکٹر شیری ڈھلکے

ای میل: bcameron@ualberta.ca اور dahlke@ualberta.ca

فون نمبر: 1-888-492-8089 اور 780-492-8232

پتہ: فیکلٹی آف نرسنگ، ایڈمنٹن کلینک ہیلتھ اکیڈمی،

11405-87 ایوینیو، یونیورسٹی آف البرٹا،

ایڈمنٹن، البرٹا، کینیڈا T6G 1C9

پس منظر:

- آپ کو ایک تحقیقی پروجیکٹ میں شرکت کرنے کی دعوت دی جارہی ہے کیونکہ آپ بیت السکون کینسر ہسپتال میں درد سے سکون پہنچانے کی نگہداشت حاصل کرنے والے مریض ہیں۔
- جب آپ بیماری محسوس کرتے ہیں تو ڈاکٹر اور نرسوں سے آپ کو جو مدد ملتی ہے ہم اس کے سلسلے میں آپ کے تجربات معلوم کرنے میں دلچسپی رکھتے ہیں۔
- یہ تحقیق ، فیکلٹی آف نرسنگ یونیورسٹی آف البرٹا، میں فلسفے کی ڈاکٹر کی سند کی جزوی ضروریات کے سلسلے میں ایک طالبہ (سلمہ امین رتانی) کا پروجیکٹ ہے۔ سلمہ یہ تحقیق یونیورسٹی آف البرٹا کی پروفیسر ڈاکٹر برینڈا کیمرون اور پروفیسر ڈاکٹر شیری ڈھلکے کی زیر نگرانی کر رہی ہیں۔

مقصد:

اس تحقیق کا مقصد بیت السکون کینسر ہسپتال میں مریض، اس کے اہل خانہ اور صحت مہیا کرنے والے افراد کے تجربات سے سمجھنا ہے۔

تحقیق کا طریقہ کار:

- اگر آپ اس تحقیق میں شرکت کے لئے رضامند ہوتے ہیں تو آپ کی نگہداشت اور علاج تک آپ کی رسائی سے متعلق آپ کے تجربات کے سلسلے میں اس تحقیق کی محققہ ایک انٹرویو کریں گی۔ محققہ ہسپتال کے ریکارڈ سے آپ کے بیماری کے متعلق معلومات حاصل کریں گی۔
- انٹرویو کا دورانیہ تقریباً تیس سے پینتالیس منٹ ہوگا اور اسکو آپ کی رازداری برقرار رکھنے کے لئے کسی نجی جگہ پر کیا جائے گا۔ انٹرویو کے دوران اگر آپ تھکاوٹ محسوس کریں تو آپ وقفے کے لئے کہہ سکتے ہیں یا انٹرویو کو کسی اور وقت کے لئے طے کر سکتے ہیں۔

- یہ بھی ممکن ہے کہ آپ کے انٹرویو کے نوٹس پر نظر ثانی کے وقت، مزید وضاحت کی ضرورت محسوس ہو۔ ایسی صورت میں آپ سے دوبارہ رابطہ کیا جائے گا اور آپ سے اس وضاحت کے اضافے کی درخواست کی جائیگی۔ چنانچہ یہ ممکن ہے کہ آپ کا انٹرویو ایک سے زائد مرتبہ کرنے کی ضرورت پیش آئے۔
- اگر کسی بھی موقع پر آپ اس تحقیق میں شرکت کو روکنا چاہیں تو آپ کو اس کی آزادی حاصل ہے۔
- اس تحقیق میں آپ کی شرکت، آپ کو ہسپتال کے عملے سے ملنے والی نگہداشت پر اثر انداز نہیں ہوگی۔
- آپ کے انٹرویو کو آڈیو ریکارڈ کیا جائے گا۔ اگر آپ تحقیق میں شرکت کرتے ہیں لیکن اپنا انٹرویو آڈیو ریکارڈ کرانا نہیں چاہتے تو محققہ آپ کے انٹرویو کے صرف نوٹس درج کرے گی۔
- انٹرویو ز کی نقول آپ کو فراہم کی جائیں گی اور آپ اپنے تجربات کی وضاحت کرسکتے ہیں۔
- انٹرویو نوٹس کو ایک نقل نمبر دیا جائے گا اور آپ کے نام کو خفیہ رکھا جائے گا۔
- صرف محققہ اور انکے سپروائزرز آپ سے حاصل معلومات یا انٹرویو نوٹس دیکھ سکیں گے۔
- تحقیق سے حاصل نتائج کو طالبہ کے مقالے کے ذریعے ایک دوسرے تک پہنچایا جائے گا جو نرسنگ گریجویٹ آفس، یونیورسٹی آف البرٹا میں پیش کیا جائے گا۔ یہ تحقیق مختلف مباحثوں اور سائنسی جریوں میں اشاعت کے ذریعے پیش کی جائیگی۔
- اس تحقیق کی نمائش اور اشاعتوں میں آپ کے انٹرویوز لفظ بہ لفظ شامل ہونگے مگر کہیں بھی آپ کی شناخت ظاہر نہیں ہوگی کیونکہ آپ کا نام خفیہ رکھا جائے گا اور آپ کے انٹرویو کی نقول کو ایک خفیہ نمبر دیا جائے گا۔

فوائد:

- اس تحقیق میں آپ کی شرکت آپ کو اپنی صحت کے درجے سے متعلق اپنے احساسات اور پریشانیوں کو سامنے لانے کا موقع فراہم کرسکتی ہے۔ یہ بھی ممکن ہے کہ اس تحقیق میں آپ کی شرکت آپ کو انفرادی طور پر تو کوئی فائدہ نہ پہنچائے لیکن اس کے نتائج عمومی طور پر معاشرے کو فائدہ پہنچاسکیں۔ اس تحقیق سے حاصل کردہ تعلیم صحت کی نگہداشت کی تعلیم، عمل اور تحقیق کو بہتر بنانے میں مددگار ثابت ہوسکتی ہے۔ اس کے علاوہ، یہ پالیسی کی سطح پر نظاموں کو بہتر بنانے میں بھی فائدہ مند ثابت ہوسکتی ہے۔

اندیشہ:

یہ ممکن ہے کہ آپ کے تجربات کے بارے میں بات کرتے وقت آپ کو منفی احساسات کا سامنا ہو۔ آپ کو اس چیز کے بارے میں بات کرنے کی ضرورت نہیں ہے جس سے آپ بے چینی یا بے اطمینانی محسوس کریں۔

رضاکارانہ شرکت:

- آپ اس تحقیق میں شرکت کرنے کے پابند نہیں ہیں۔
- اس تحقیق میں آپ کی شرکت مکمل طور پر رضاکارانہ ہے اور اگر آپ تحقیق میں شرکت کرتے ہیں اور کسی خاص سوال کا جواب نہ دینا چاہیں تو آپ اس کا جواب دینے کے پابند نہیں ہیں۔
- آپ کسی وقت بھی خود کو بغیر کسی جرمانے کے تحقیق سے علیحدہ کرسکتے ہیں اور آپ سے حاصل کردہ تمام معلوماتی مواد کو ڈیٹا بیس سے نکالنے کے لئے کہہ سکتے ہیں اور وہ تحقیق میں شامل نہیں کیا جائے گا۔ البتہ ایک بار جب معلوماتی مواد تجزیاتی عمل میں شامل ہو جائے تو اسکو نکالنا ممکن نہیں ہوگا۔

رازداری اور گمنامی:

- آپ کی ذاتی شناخت جیسے کہ نام اور میڈیکل ریکارڈ نمبر استعمال نہیں کیا جائے گا۔ تحقیق کے تمام تر عمل کے دوران اور تحقیقی نمائش اور اشاعت کے ذریعے اس کے نتائج پھیلانے کے دوران آپ کی گمنامی کو برقرار رکھا جائے گا۔ آپ کی انٹرویو ریکارڈنگ کو مرکزی محققہ کے کمپیوٹر پر پاس ورڈ کے ذریعے محفوظ کیا جائے گا۔ کمپیوٹر محققہ کی دسترس میں رہے گا۔ آپ کے انٹرویو کانگریزی میں ترجمہ کیا جائے گا (جس میں آپ کی شناخت ہٹادی جائے گی) اور اسکی ایک نقل کو مرکزی محققہ کے کمپیوٹر پر ایک فولڈر میں اور دوسری نقل یونیورسٹی آف البرٹا کے کمپیوٹر پر محفوظ کردی جائے گی۔ اس فولڈر تک صرف محققہ اور تحقیق سپروائزرز کو رسائی حاصل ہوگی۔

- تمام تر مواد تحقیق پروجیکٹ کے مکمل ہونے کے بعد پانچ سال کے لئے محفوظ رکھا جائے گا۔ اس کے بعد تمام مواد کو کمپیوٹر سے نکال کر ضائع کر دیا جائے گا۔ تحقیق کے تمام تر عمل کے دوران آپ کی شناخت کا خفیہ رکھا جائے گا۔
- اس بات کا بھی کچھ امکان ہے کہ اس تحقیق کے لئے حاصل کردہ مواد کسی اور تحقیق کے لئے بھی استعمال ہو لیکن اس کے لئے اسکا کسی ریسرچ ایٹھکس بورڈ سے منظور ہونا ضروری ہے۔

تحقیق سے دستبردار ہونے کی آزادی:

- آپ کو تحقیق کے دوران کسی بھی وقت اس سے دستبردار ہونے کا حق حاصل ہے۔ البتہ ایک بار جب معلوماتی مواد تجزیاتی عمل میں شامل ہو جائے تو اسکو نکالنا ممکن نہیں ہوگا۔

مزید معلومات:

اگر اس تحقیق کے بارے میں آپ کے ذہن میں کوئی سوال ہو تو اس تحقیق کی محققہ سلمہ امین رتانی سے رابطہ کرنے میں کوئی تردد نہیں کیجئے گا۔ ان سے رابطے کی تفصیلات فارم میں درج ہیں۔ اس تحقیق کے اخلاقی اصولوں کی پاسداری کے لئے، منصوبے پر یونیورسٹی آف البرٹا کے ریسرچ ایٹھکس بورڈ نے نظر ثانی کی ہے۔ شرکت کنندہ کے حقوق اور ضابطہ اخلاق کے متعلق کسی بھی سوال کے لئے ریسرچ ایٹھکس کے دفتر، فون (780) 492 2615 پر رابطہ کیجئے۔

Appendix G 2a: Information Letter for Family Members

Study Title: A Case study describing access to palliative care in Pakistan

Research Investigator: Supervisors:

Salma Amin Rattani Professor Supervisor: Dr. Brenda Cameron and Dr. Sherry Dahlke,

Email rattani@ualberta.ca

bcameron@ualberta.ca

dahlke@ualberta.ca

Phone number +923452341738

1-888-492-8089

780-492-8232

Address Faculty of Nursing, Edmonton Clinic Health Academy

11405-87 Avenue University of Alberta

Edmonton Alberta, Canada T6G 1C9

Background

- You are invited to participate in a research project because you are a family member of a patient receiving palliative care services at Bait- ul-Sukoon Cancer Hospital.
- This research is a student's (Salma Amin Rattani) project in partial fulfillment of the requirements of the degree of Doctor of Philosophy, Faculty of Nursing, University of Alberta. Salma is conducting this research under the supervision of professors Dr. Brenda Cameron and Dr. Sherry Dahlke from the University of Alberta.

Purpose

- The purpose of the research is to learn from the experiences of the individual patient, family member, and health care providers at Bait- ul-Sukoon Cancer Hospital.

Study Procedures

- If you agree to participate you will be interviewed by the researcher about your experiences related to the access to care and treatment.
- The interview will take approximately 30 – 45 minutes and will occur in a private space to maintain your confidentiality. During the interview, if you feel tired, you can ask for a break or the interview could be rescheduled.
- It is also possible that while reviewing your interview notes, the need for more description is identified. In such a situation, you will be approached and requested to add to the description. Thus, it is possible that you may be interviewed more than once.
- If at any time you wish to discontinue your participation in this study you are free to do so.
- Your participation in this study will not influence the care of your family member who is receiving care at Bait-ul-Sukoon hospital. Your interview will be audio recorded. If you want

to participate in the research but you do not want your interview to be audio recorded then the researcher will take your interview notes.

- Transcribed transcripts of the interviews will be shared with you and you may wish to elaborate on your experiences.
- These interview notes will be assigned a transcript number and your name will be concealed.
- The researcher and her supervisors will see your transcribed data or interview notes.
- This research will be shared through a student's dissertation which will be submitted to the nursing graduate office, University of Alberta. This research will be presented at different forums and through publication in scientific journals.
- The presentation and publications will include the verbatim from your interview but your individual identity will not be reorganized as your name will be concealed and your interview transcripts will be assigned a code number.

Benefits

- Your participation in this research may provide you an opportunity to ventilate your feelings and concerns related to your relative's health who is receiving care at Bait-ul-Sukoon hospital. It is also possible that your participation in this study may not benefit you or your relative (patient) as an individual but the findings from this study may benefit society in general. Knowledge gained from this research may contribute to improving health care education, practice, and research. Also, it may benefit at the policy level to improve the systems.

Risk

- It is possible that talking about your experience will bring up negative feelings. You do not need to talk about anything that makes you feel uncomfortable.

Voluntary Participation

- You are under no obligation to participate in this study.
- Your participation in this study is completely voluntary and you are not obliged to answer any specific question even if you are participating in the study.
- You can opt-out from the study without any penalty and you can ask to have any collected data to be withdrawn from the database and it will not be included in the study.

Confidentiality & Anonymity

- Your personal identifier like the name will not be used. The researcher will encrypt the data and your anonymity will be maintained throughout the research process and disseminating the findings through research presentation and publication.
- Your interview recording will be saved on the primary researcher's computer which will be password protected. This computer will be in the custody of the researcher. Your interview will be translated into English and the interview transcript will be saved on the primary researcher's computer and in a folder in the primary researcher's computer and in the

University of Alberta secured computer. This folder will be accessible to the student and the research supervisors.

- The entire data set will be secured for a minimum of five years following completion of the research project. After that this data will be destroyed by deleting these files from the computer. Your confidentiality will be maintained throughout the research process.
- It is quite possible that the data collected for this study may be used for another research but this research will have to be approved by a research ethics board.

Freedom to withdraw

- You will have the right to withdraw from the study at any time within six weeks of your participation in the study. However, data withdrawal will not be possible after six weeks as thereafter, the data will be included in the analysis process.

Further Information

- If you have any further questions regarding this study, please do not hesitate to contact the researcher Salma Amin Rattani. Her contact details are provided in this form.
- The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.”

اپنڈکس G 2b

مریض کے اہل خانہ کے لئے معلوماتی مراسلہ

تحقیق کا عنوان: پاکستان میں، درد سے سکون پہنچانے کی نگہداشت تک رسائی کی

وضاحت کے لئے کیس اسٹڈی

محققہ: سلمہ امین رتانی

ای میل: rattani@ualberta.ca

فون نمبر: +923452341738

پروفیسر نگران: ڈاکٹر برینڈا کیمرون اور ڈاکٹر شیرلی ڈھلکے

ای میل: bcameron@ualberta.ca اور dahlke@ualberta.ca

فون نمبر: 1-888-492-8089 اور 780-492-8232

پتہ: فیکلٹی آف نرسنگ، ایڈمنٹن کلینک ہیلتھ اکیڈمی،

11405-87 ایوینیو، یونیورسٹی آف البرٹا،

ایڈمنٹن، البرٹا، کینیڈا T6G 1C9

پس منظر:

- آپ کو ایک تحقیقی پروجیکٹ میں شرکت کرنے کی دعوت دی جا رہی ہے کیونکہ آپ بیت السکون کینسر ہسپتال میں درد سے سکون پہنچانے کی نگہداشت حاصل کرنے والے مریض کے خاندان کے ایک رکن ہیں۔
- یہ تحقیق، فیکلٹی آف نرسنگ یونیورسٹی آف البرٹا، میں فلسفے کی ڈاکٹر کی سند کی جزوی ضروریات کے سلسلے میں ایک طالبہ (سلمہ امین رتانی) کا پروجیکٹ ہے۔ سلمہ یہ تحقیق یونیورسٹی آف البرٹا کی پروفیسر ڈاکٹر برینڈا کیمرون اور پروفیسر ڈاکٹر شیرلی ڈھلکے کی زیر نگرانی کر رہی ہیں۔

مقصد:

اس تحقیق کا مقصد بیت السکون کینسر ہسپتال میں مریض، اس کے اہل خانہ اور صحت مہیا کرنے والے افراد کے تجربات سے سمجھنا ہے۔

تحقیق کا طریقہ کار:

- اگر آپ اس تحقیق میں شرکت کے لئے رضامند ہوتے ہیں تو نگہداشت اور علاج تک رسائی سے متعلق آپ کے تجربات کے سلسلے میں اس تحقیق کی محققہ ایک انٹرویو کریں گی۔
- انٹرویو کا دورانیہ تقریباً تیس سے پینتالیس منٹ ہوگا اور اسکو آپ کی رازداری برقرار رکھنے کے لئے کسی نجی جگہ پر کیا جائے گا۔ انٹرویو کے دوران اگر آپ تھکاوٹ محسوس کریں تو آپ وقفے کے لئے کہہ سکتے ہیں یا انٹرویو کو کسی اور وقت کے لئے طے کر سکتے ہیں۔

- یہ بھی ممکن ہے کہ آپ کے انٹرویو کے نوٹس پر نظر ثانی کے وقت، مزید وضاحت کی ضرورت محسوس ہو۔ ایسی صورت میں آپ سے دوبارہ رابطہ کیا جائے گا اور آپ سے اس وضاحت کے اضافے کی درخواست کی جائیگی۔ چنانچہ یہ ممکن ہے کہ آپ کا انٹرویو ایک سے زائد مرتبہ کرنے کی ضرورت پیش آئے۔
- اگر کسی بھی موقع پر آپ اس تحقیق میں شرکت کو روکنا چاہیں تو آپ کو اس کی آزادی حاصل ہے۔
- اس تحقیق میں آپ کی شرکت، آپ کے مریض کو ہسپتال کے عملے سے ملنے والی نگہداشت پر اثر انداز نہیں ہوگی۔
- آپ کے انٹرویو کو آڈیو ریکارڈ کیا جائے گا۔ اگر آپ تحقیق میں شرکت کرتے ہیں لیکن اپنا انٹرویو آڈیو ریکارڈ کرانا نہیں چاہتے تو محققہ آپ کے انٹرویو کے صرف نوٹس درج کرے گی۔
- انٹرویو ز کی نقول آپ کو فراہم کی جائیں گی اور آپ اپنے تجربات کی وضاحت کرسکتے ہیں۔
- انٹرویو نوٹس کو ایک نقل نمبر دیا جائے گا اور آپ کے نام کو خفیہ رکھا جائے گا۔
- صرف محققہ اور انکے سپروائزرز آپ سے حاصل معلومات یا انٹرویو نوٹس دیکھ سکیں گے۔
- تحقیق سے حاصل نتایج کو طالبہ کے مقالے کے ذریعے ایک دوسرے تک پہنچایا جائے گا جو نرسنگ گریجویٹ آفس، یونیورسٹی آف البرٹا میں پیش کیا جائے گا۔ یہ تحقیق مختلف مباحثوں اور سائنسی جریدوں میں اشاعت کے ذریعے پیش کی جائیگی۔
- اس تحقیق کی نمائش اور اشاعتوں میں آپ کے انٹرویوز لفظ بہ لفظ شامل ہونگے مگر کہیں بھی آپ کی شناخت ظاہر نہیں ہوگی کیونکہ آپ کا نام خفیہ رکھا جائے گا اور آپ کے انٹرویو کی نقول کو ایک خفیہ نمبر دیا جائے گا۔

فوائد:

- اس تحقیق میں آپ کی شرکت آپ کے مریض کے اپنی صحت کے درجے سے متعلق آپ کے احساسات اور پریشانیوں کو سامنے لانے کا موقع فراہم کرسکتی ہے۔ یہ بھی ممکن ہے کہ اس تحقیق میں آپ کی شرکت آپ کو یا آپ کے مریض کو انفرادی طور پر تو کوئی فائدہ نہ پہنچائے
- لیکن اس کے نتائج عمومی طور پر معاشرے کو فائدہ پہنچاسکیں۔ اس تحقیق سے حاصل کردہ تعلیم صحت کی نگہداشت کی تعلیم، عمل اور تحقیق کو بہتر بنانے میں مددگار ثابت ہوسکتی ہے۔ اس کے علاوہ، یہ پالیسی کی سطح پر نظاموں کو بہتر بنانے میں بھی فائدہ مند ثابت ہوسکتی ہے۔

اندیشہ:

- یہ ممکن ہے کہ آپ کے تجربات کے بارے میں بات کرتے وقت آپ کو منفی احساسات کا سامنا ہو۔ آپ کو اس چیز کے بارے میں بات کرنے کی ضرورت نہیں ہے جس سے آپ بے چینی یا بے اطمینانی محسوس کریں۔

رضاکارانہ شرکت:

- آپ اس تحقیق میں شرکت کرنے کے پابند نہیں ہیں۔
- اس تحقیق میں آپ کی شرکت مکمل طور پر رضاکارانہ ہے اور اگر آپ تحقیق میں شرکت کرتے ہیں اور کسی خاص سوال کا جواب نہ دینا چاہیں تو آپ اس کا جواب دینے کے پابند نہیں ہیں۔
- آپ کسی وقت بھی خود کو بغیر کسی جرمانے کے تحقیق سے علیحدہ کرسکتے ہیں اور آپ سے حاصل کردہ تمام معلوماتی مواد کو ڈیٹا بیس سے نکالنے کے لئے کہہ سکتے ہیں اور وہ تحقیق میں شامل نہیں کیا جائے گا۔ البتہ ایک بار جب معلوماتی مواد تجزیاتی عمل میں شامل ہوجائے تو اسکو نکالنا ممکن نہیں ہوگا۔

رازداری اور گمنامی:

- آپ کی ذاتی شناخت جیسے کہ نام اور میڈیکل ریکارڈ نمبر استعمال نہیں کیا جائے گا۔ تحقیق کے تمام تر عمل کے دوران اور تحقیقی نمائش اور اشاعت کے ذریعے اس کے نتائج پھیلانے کے دوران آپ کی گمنامی کو برقرار رکھا جائے گا۔ آپ کی انٹرویو ریکارڈنگ کو مرکزی محققہ کے کمپیوٹر پر پاس ورڈ کے ذریعے محفوظ کیا جائے گا۔ کمپیوٹر محققہ کی دسترس میں رہے گا۔ آپ کے انٹرویو کانگریزی میں ترجمہ کیا جائے گا (جس میں آپ کی شناخت ہٹادی جائے گی) اور اسکی ایک نقل کو مرکزی محققہ کے کمپیوٹر پر ایک فولڈر میں اور دوسری نقل یونیورسٹی آف البرٹا کے کمپیوٹر پر محفوظ کردی جائے گی۔ اس فولڈر تک صرف محققہ اور تحقیق سپروائزرز کو رسائی حاصل ہوگی۔

- تمام تر مواد تحقیق پروجیکٹ کے مکمل ہونے کے بعد پانچ سال کے لئے محفوظ رکھا جائے گا۔ اس کے بعد تمام مواد کو کمپیوٹر سے نکال کر ضائع کر دیا جائے گا۔ تحقیق کے تمام تر عمل کے دوران آپ کی شناخت کا خفیہ رکھا جائے گا۔
- اس بات کا بھی کچھ امکان ہے کہ اس تحقیق کے لئے حاصل کردہ مواد کسی اور تحقیق کے لئے بھی استعمال ہو لیکن اس کے لئے اسکاکسی ریسرچ ایٹھکس بورڈ سے منظور ہونا ضروری ہے۔

تحقیق سے دستبردار ہونے کی آزادی:

- آپ کو تحقیق کے دوران کسی بھی وقت اس سے دستبردار ہونے کا حق حاصل ہے۔ البتہ ایک بار جب معلوماتی مواد تجزیاتی عمل میں شامل ہو جائے تو اسکو نکالنا ممکن نہیں ہوگا۔

مزید معلومات:

اگر اس تحقیق کے بارے میں آپ کے ذہن میں کوئی سوال ہو تو اس تحقیق کی محققہ سلمہ امین رتانی سے رابطہ کرنے میں کوئی تردد نہیں کیجئے گا۔ ان سے رابطے کی تفصیلات فارم میں درج ہیں۔ اس تحقیق کے اخلاقی اصولوں کی پاسداری کے لئے، منصوبے پر یونیورسٹی آف البرٹا کے ریسرچ ایٹھکس بورڈ نے نظر ثانی کی ہے۔ شرکت کنندہ کے حقوق اور ضابطہ اخلاق کے متعلق کسی بھی سوال کے لئے ریسرچ ایٹھکس کے دفتر، فون 2615 492 (780) پر رابطہ کیجئے۔

Appendix G 3a: Information Letter for Healthcare Providers

Study Title: Case study describing access to palliative care in Pakistan

Research Investigator: **Supervisors:**

Salma Amin Rattani Professor Supervisor: Dr. Brenda Cameron and Dr. Sherry Dahlke,

Email rattani@ualberta.ca bcameron@ualberta.ca cadahlke@ualberta.ca

Phone number +923452341738 1-888-492-8089 780-492-8232

Address Faculty of Nursing, Edmonton Clinic Health Academy

11405-87 Avenue University of Alberta

Edmonton Alberta, Canada T6G 1C9

Background

- You are invited to participate in a research project because you are a member healthcare team at Bait- ul-Sukoon Cancer Hospital.
- We are interested in your perspectives and experiences of patients and family members accessing and receiving treatment at the hospital.
- This research is a student's (Salma Amin Rattani) project in partial fulfillment of the requirements of the degree of Doctor of Philosophy, Faculty of Nursing, University of Alberta. Salma is conducting this research under the supervision of professors Dr. Brenda Cameron and Dr. Sherry Dahlke from the University of Alberta.

Purpose

- The purpose of the research is to learn from the experiences of the individual patient, family member, and health care providers at Bait- ul-Sukoon Cancer Hospital.

Study Procedures

- If you agree to participate you will be interviewed by the researcher.
- The interview will take approximately 30 – 45 minutes and will occur in a private space to maintain your confidentiality. During the interview, if you feel tired, you can ask for a break or the interview could be rescheduled.
- It is also possible that while reviewing your interview notes, the need for more description is identified. In such a situation, you will be approached and requested to add to the description. Thus, it is possible that you may be interviewed more than once.
- If at any time you wish to discontinue your participation in this study you are free to do so.
- Your participation in this study will not influence your employment status.

- Your interview will be audio recorded. If you want to participate in the research but you do not want your interview to be audio recorded then the researcher will take your interview notes.
- These interview notes will be assigned a transcript number and your name will be concealed.
- Transcribed transcripts of the interviews will be shared with you and you may wish to elaborate on your experiences.
- Only, the researcher and her supervisors will see your transcribed data or interview notes.
- The findings from this research will be shared through a student's dissertation which will be submitted to the nursing graduate office, University of Alberta. This research will be presented at different forums and through publication in scientific journals.
- These presentations and publications will include the verbatim from your interviews but your individual identity will not be recognized as your name will be concealed and your interview transcripts will be assigned a code number.

Benefits

- Your participation in this research may provide you an opportunity to share your idea, thoughts, and perspectives, feelings, and concerns related to palliative care. It is also possible that your participation in this study may not benefit you as an individual but the findings from this study may benefit society in general. Knowledge gained from this research may contribute to improving health care education, practice, and research. Also, it may benefit at the policy level for improving the systems.

Risk

- It is possible that talking about your experiences will bring up negative feelings. You do not need to talk about anything that makes you feel uncomfortable.

Voluntary Participation

- You are under no obligation to participate in this study.
- Your participation in this study is completely voluntary and you are not obliged to answer any specific question even if you are participating in the study.
- You can opt-out from the study without any penalty and you can ask to have any collected data to be withdrawn from the database and it will not be included in the study.

Confidentiality & Anonymity

- Your personal identifier like name and employee number will not be used. The researcher will encrypt the data and your anonymity will be maintained throughout the research process and disseminating the findings through research presentation and publication.
- Your interview recording will be saved on the primary researcher's computer which will be password protected. This computer will be in the custody of the researcher. Your interview will be translated into English (with identifiers removed) and the interview transcript will be

saved on the primary researcher's computer and in a folder at the University of Alberta secured computer. This folder will be accessible to the student and research supervisors.

- The entire data set will be secured for a minimum of five years following completion of the research project. After that this data will be destroyed by deleting these files from the computer. Your confidentiality will be maintained throughout the research process.
- It is quite possible that the data collected for this study may be used for another research but this research will have to be approved by a research ethics board.

Freedom to withdraw

- You will have the right to withdraw from the study at any time within six weeks of your participation in the study. However, data withdrawal will not be possible after six weeks as thereafter, the data will be included in the analysis process.

Further Information

- If you have any further questions regarding this study, please do not hesitate to contact the researcher Salma Amin Rattani. Her contact details are provided in this form.
- The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.”

اپنڈکس G 3b

صحت کی نگہداشت مہیا کرنے والوں کے لئے معلوماتی مراسلہ

تحقیق کا عنوان: پاکستان میں ، درد سے سکون پہنچانے کی نگہداشت تک رسائی کی وضاحت کے لئے کیس

اسٹڈی

محققہ: سلمہ امین رتانی

ای میل: rattani@ualberta.ca

فون نمبر: +923452341738

پروفیسر نگران: ڈاکٹر برینڈا کیمرون اور ڈاکٹر شیرا ڈھلکے

ای میل: bcameron@ualberta.ca اور dahlke@ualberta.ca

فون نمبر: 1-888-492-8089 اور 780-492-8232

پتہ: فیکلٹی آف نرسنگ، ایڈمنٹن کلینک ہیلتھ اکیڈمی،

11405-87 ایوینیو، یونیورسٹی آف البرٹا،

ایڈمنٹن، البرٹا، کینیڈا T6G 1C9

پس منظر:

- آپ کو ایک تحقیقی پروجیکٹ میں شرکت کرنے کی دعوت دی جارہی ہے کیونکہ آپ بیت السکون کینسر ہسپتال کی صحت سے متعلق نگہداشت مہیا کرنے والی ٹیم کے ایک رکن ہیں۔
- ہم اس ہسپتال میں مریض اور ان کے اہل خانہ کی علاج کے حصول اور اس تک رسائی کے سلسلے میں کے آپ کے احساسات اور تجربات جاننے میں دلچسپی رکھتے ہیں۔
- یہ تحقیق ، فیکلٹی آف نرسنگ یونیورسٹی آف البرٹا، میں فلسفے کی ڈاکٹر کی سند کی جزوی ضروریات کے سلسلے میں ایک طالبہ (سلمہ امین رتانی) کا پروجیکٹ ہے۔ سلمہ یہ تحقیق یونیورسٹی آف البرٹا کی پروفیسر ڈاکٹر برینڈا کیمرون اور پروفیسر ڈاکٹر شیرا ڈھلکے کی زیر نگرانی کر رہی ہیں۔

مقصد:

اس تحقیق کا مقصد بیت السکون کینسر ہسپتال میں مریض، اس کے اہل خانہ اور صحت مہیا کرنے والے افراد کے تجربات سے سمجھنا ہے۔

تحقیق کا طریقہ کار:

- اگر آپ اس تحقیق میں شرکت کے لئے رضامند ہوتے ہیں تو اس تحقیق کی محققہ آپ سے ایک انٹرویو کریں گی۔

- انٹرویو کا دورانیہ تقریباً تیس سے پینتالیس منٹ ہوگا اور اسکو آپ کی رازداری برقرار رکھنے کے لئے کسی نجی جگہ پر کیا جائے گا۔ انٹرویو کے دوران اگر آپ تھکاوٹ محسوس کریں تو آپ وقفے کے لئے کہہ سکتے ہیں یا انٹرویو کو کسی اور وقت کے لئے طے کر سکتے ہیں۔
- یہ بھی ممکن ہے کہ آپ کے انٹرویو کے نوٹس پر نظر ثانی کے وقت، مزید وضاحت کی ضرورت محسوس ہو۔ ایسی صورت میں آپ سے دوبارہ رابطہ کیا جائے گا اور آپ سے اس وضاحت کے اضافے کی درخواست کی جائیگی۔ چنانچہ یہ ممکن ہے کہ آپ کا انٹرویو ایک سے زائد مرتبہ کرنے کی ضرورت پیش آئے۔
- اگر کسی بھی موقع پر آپ اس تحقیق میں شرکت کو روکنا چاہیں تو آپ کو اس کی آزادی حاصل ہے۔ اس تحقیق میں آپ کی شرکت، آپ کی ملازمت پر اثر انداز نہیں ہوگی۔
- آپ کے انٹرویو کو آڈیو ریکارڈ کیا جائے گا۔ اگر آپ تحقیق میں شرکت کرتے ہیں لیکن اپنا انٹرویو آڈیو ریکارڈ کرانا نہیں چاہتے تو محققہ آپ کے انٹرویو کے صرف نوٹس درج کرے گی۔
- انٹرویو ز کی نقول آپ کو فراہم کی جائیں گی اور آپ اپنے تجربات کی وضاحت کر سکتے ہیں۔
- انٹرویو نوٹس کو ایک نقل نمبر دیا جائے گا اور آپ کے نام کو خفیہ رکھا جائے گا۔
- صرف محققہ اور انکے سپروائزرز آپ سے حاصل معلومات یا انٹرویو نوٹس دیکھ سکیں گے۔
- تحقیق سے حاصل نتائج کو طالبہ کے مقالے کے ذریعے ایک دوسرے تک پہنچایا جائے گا جو نرسنگ گریجویٹ آفس، یونیورسٹی آف البرٹا میں پیش کیا جائے گا۔ یہ تحقیق مختلف مباحثوں اور سائنسی جریدوں میں اشاعت کے ذریعے پیش کی جائیگی۔
- اس تحقیق کی نمائش اور اشاعتوں میں آپ کے انٹرویوز لفظ بہ لفظ شامل ہونگے مگر کہیں بھی آپ کی شناخت ظاہر نہیں ہوگی کیونکہ آپ کا نام خفیہ رکھا جائے گا اور آپ کے انٹرویو کی نقول کو ایک خفیہ نمبر دیا جائے گا۔

فوائد:

- اس تحقیق میں آپ کی شرکت آپ کو اپنی سوچ، خیالات اور نکتہ نظر، آپ کے احساسات اور پریشانیوں کو سامنے لانے کا موقع فراہم کر سکتی ہے۔ یہ بھی ممکن ہے کہ اس تحقیق میں آپ کی شرکت آپ کو یا آپ کے مریض کو انفرادی طور پر تو کوئی فائدہ نہ پہنچائے لیکن اس کے نتائج عمومی طور پر معاشرے کو فائدہ پہنچاسکیں۔ اس تحقیق سے حاصل کردہ تعلیم صحت کی نگہداشت کی تعلیم، عمل اور تحقیق کو بہتر بنانے میں مددگار ثابت ہو سکتی ہے۔ اس کے علاوہ، یہ پالیسی کی سطح پر نظاموں کو بہتر بنانے میں بھی فائدہ مند ثابت ہو سکتی ہے۔

اندیشہ:

- یہ ممکن ہے کہ آپ کے تجربات کے بارے میں بات کرتے وقت آپ کو منفی احساسات کا سامنا ہو۔ آپ کو اس چیز کے بارے میں بات کرنے کی ضرورت نہیں ہے جس سے آپ بے چینی یا بے اطمینانی محسوس کریں۔

رضاکارانہ شرکت:

- آپ اس تحقیق میں شرکت کرنے کے پابند نہیں ہیں۔
- اس تحقیق میں آپ کی شرکت مکمل طور پر رضاکارانہ ہے اور اگر آپ تحقیق میں شرکت کرتے ہیں اور کسی خاص سوال کا جواب نہ دینا چاہیں تو آپ اس کا جواب دینے کے پابند نہیں ہیں۔
- آپ کسی وقت بھی خود کو بغیر کسی جرمانے کے تحقیق سے علیحدہ کر سکتے ہیں اور آپ سے حاصل کردہ تمام معلوماتی مواد کو ڈیٹا بیس سے نکالنے کے لئے کہہ سکتے ہیں اور وہ تحقیق میں شامل نہیں کیا جائے گا۔ البتہ ایک بار جب معلوماتی مواد تجزیاتی عمل میں شامل ہو جائے تو اسکو نکالنا ممکن نہیں ہوگا۔

رازداری اور گمنامی:

- آپ کی ذاتی شناخت جیسے کہ نام اور میڈیکل ریکارڈ نمبر استعمال نہیں کیا جائے گا۔ تحقیق کے تمام تر عمل کے دوران اور تحقیقی نمائش اور اشاعت کے ذریعے اس کے نتائج پھیلانے کے دوران آپ کی گمنامی کو برقرار رکھا جائے گا۔ آپ کی انٹرویو ریکارڈنگ کو مرکزی محققہ کے کمپیوٹر پر پاس ورڈ کے ذریعے محفوظ کیا جائے گا۔ کمپیوٹر محققہ کی دسترس میں رہے گا۔ آپ کے انٹرویو کانگریزی میں ترجمہ کیا جائے

گا (جس میں آپ کی شناخت بٹادی جائے گی) اور اسکی ایک نقل کو مرکزی محققہ کے کمپیوٹر پر ایک فولڈر میں اور دوسری نقل یونیورسٹی آف البرٹا کے کمپیوٹر پر محفوظ کردی جائے گی۔ اس فولڈر تک صرف محققہ اور تحقیق سپروائزرز کو رسائی حاصل ہوگی۔

- تمام تر مواد تحقیق پروجیکٹ کے مکمل ہونے کے بعد پانچ سال کے لئے محفوظ رکھا جائے گا۔ اس کے بعد تمام مواد کو کمپیوٹر سے نکال کر ضائع کر دیا جائے گا۔ تحقیق کے تمام تر عمل کے دوران آپ کی شناخت کا خفیہ رکھا جائے گا۔
- اس بات کا بھی کچھ امکان ہے کہ اس تحقیق کے لئے حاصل کردہ مواد کسی اور تحقیق کے لئے بھی استعمال ہو لیکن اس کے لئے اسکا کسی ریسرچ ایتھکس بورڈ سے منظور ہونا ضروری ہے۔

تحقیق سے دستبردار ہونے کی آزادی:

- آپ کو تحقیق کے دوران کسی بھی وقت اس سے دستبردار ہونے کا حق حاصل ہے۔ البتہ ایک بار جب معلوماتی مواد تجزیاتی عمل میں شامل ہو جائے تو اسکو نکالنا ممکن نہیں ہوگا۔

مزید معلومات:

اگر اس تحقیق کے بارے میں آپ کے ذہن میں کوئی سوال ہو تو اس تحقیق کی محققہ سلمہ امین رتانی سے رابطہ کرنے میں کوئی تردد نہیں کیجئے گا۔ ان سے رابطے کی تفصیلات فارم میں درج ہیں۔ اس تحقیق کے اخلاقی اصولوں کی پاسداری کے لئے، منصوبے پر یونیورسٹی آف البرٹا کے ریسرچ ایتھکس بورڈ نے نظر ثانی کی ہے۔ شرکت کنندہ کے حقوق اور ضابطہ اخلاق کے متعلق کسی بھی سوال کے لئے ریسرچ ایتھکس کے دفتر، فون (780) 492 2615 پر رابطہ کیجئے۔

Appendix H a: Consent Form

Part 1

Title of Study: A Case study describing access to palliative care in Pakistan

Principle Investigator: Salma Amin Rattani

Phone Number(s): +923452341738

Study Supervisors: Dr. Brenda Cameron and Dr. Sherry Dahlke

Phone Number(s): 1-888-492-8089 780-492-8232

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (7800 492-2615. This office is independent of the researchers.

Part 2 (to be completed by the research Participants):

	<u>Yes</u>	<u>No</u>
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you are free to withdraw from the study within six-weeks of your participation in the study without having to give a reason and without affecting your (future medical care/employment or without penalty?	<input type="checkbox"/>	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand who will have access to the research information (your personal identifiers will be known to the PI and she will encrypt the data?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to have the interview audio-taped?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree for your information to be securely stored at (password protected computer of the researcher) and the University of Alberta secure server?	<input type="checkbox"/>	<input type="checkbox"/>

Use of my research information beyond this research

Do you agree for your information to be securely stored at (password protected computer of the researcher) and the University of Alberta secure server to facilitate future use?

Future contact

Do you agree to be contacted for future research?

Who explained this study to you? _____

I agree to take part in this study.

Signature of Research Participant _____

(Printed Name) _____ Telephone Number _____

Date _____

Signature of witness _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator _____ Date _____

A Witness line is only required if you anticipate that your participants will be unable to read the consent for themselves. If so, an impartial witness (i.e. not associated with the study team) must be present during the entire informed consent discussion and is witnessing that the participant understood what was discussed (i.e. not just witnessing the signature process).

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

This should be signed by the person who is conducting the informed consent discussion (if that is not the Investigator – the person that obtained the consent needs to sign here)

Signature of Investigator or Designee _____ Date _____

THE INFORMATION SHEET WILL BE ATTACHED TO THIS CONSENT FORM AND A COPY WILL GIVEN TO THE RESEARCH PARTICIPANT

اینڈکس H b
رضامندی فارم

حصہ اول

تحقیق کا عنوان: پاکستان میں ، درد سے سکون پہنچانے کی نگہداشت تک رسائی کی وضاحت
کے لئے کیس اسٹڈی
محققہ: سلمہ امین رتانی
پروفیسر نگران: ڈاکٹر برینڈا کیمرن اور ڈاکٹر شیری ڈھلکے
فون نمبر: 1-888-492-8089
فون نمبر: 780-492-8232
+923452341738

(تحقیق کے شرکت کنندگان نے مکمل کرنا ہے):

حصہ دوم:

- 1 کیا آپ کو علم ہے کہ آپ سے ایک تحقیق میں شرکت کے لئے کہا گیا ہے؟
- 2 کیا آپ نے منسلکہ معلوماتی مراسلے کی نقل حاصل کر لی ہے اور پڑھ لی ہے؟
- 3 کیا آپ کو اس تحقیق میں حصہ لینے سے حاصل فوائد اور ممکنہ خطرات کے بارے میں علم ہے؟
- 4 کیا آپ کو تحقیق پر گفتگو کرنے اور سوالات پوچھنے کا موقع فراہم کیا گیا؟
- 5 کیا آپ کو علم ہے کہ آپ اس تحقیق سے کسی بھی وقت، کوئی وجہ بتائے بغیر، اور آپ کی مستقبل کی طبی نگہداشت پر یا ملازمت پر اثر انداز ہوئے بغیر، یا کسی جرمانے کے بغیر، دستبردار ہوسکتے ہیں؟
- 6 کیا آپ کو رازداری کے معاملے کے متعلق وضاحت کردی گئی ہے؟
- 7 کیا آپ کو علم ہے کہ تحقیق کی معلومات تک آپ کو رسائی حاصل ہوگی؟ (بشمول آپ کی صحت سے متعلق دی گئی معلومات)
- 8 کیا آپ اپنا انٹرویو ٹیپ ریکارڈ کئے جانے پر متفق ہیں؟
- 9 کیا آپ اپنی معلومات کا (محققہ کے کمپیوٹر پر پاس ورڈ کے ذریعے) اور یونیورسٹی آف البرٹا کے محفوظ سرور پر ذخیرہ کئے جانے پر متفق ہیں؟
- اس تحقیق سے ہٹ کر میری معلومات کا استعمال:
- کیا آپ اپنی معلومات کا (محققہ کے کمپیوٹر پر پاس ورڈ کے ذریعے) اور یونیورسٹی آف البرٹا کے محفوظ سرور پر، مستقبل میں استعمال میں کسی اور تحقیق میں سہولت کے لئے ذخیرہ کئے جانے پر متفق ہیں؟
- مستقبل میں رابطہ:
- کیا آپ مستقبل کی تحقیق کے لئے رابطہ کرنے پر رضامند ہیں؟
- آپ کو اس تحقیق کی کس نے تفصیل پیش کی؟

میں اس تحقیق میں حصہ لینے پر رضامند ہوں:

شرکت کنندہ کے دستخط:

نام:

فون نمبر:

تاریخ:

گواہ کے خانے کی صرف اسی وقت ضرورت ہوگی جب آپ یہ سمجھیں کہ آپ کے شرکت کنندگان رضامندی خود نہ پڑھ سکتے ہوں۔ اگر ایسا ہو، تو ایک غیر جانب دار گواہ (یعنی جس کا تعلق تحقیقاتی ٹیم سے نہ ہو)، اسکو تحریری رضامندی کے تمام تر گفتگو کے عمل میں موجود ہونا چاہیے اور اسکو یہ گواہی دینا چاہیے کہ جو کچھ بھی گفتگو کی گئی وہ شرکت کنندہ نے سمجھ لی ہے (یعنی صرف دستخط کے عمل کی گواہی نہیں)۔

میں یقین کرتا ہوں کہ جو شخص اس فارم پر دستخط کر رہا ہے وہ سمجھتا ہے کہ اس تحقیق میں کیس شامل ہے اور اس میں شرکت کے لئے رضاکارانہ طور پر راضی ہے۔
یہاں وہ فرد دستخط کرے گا جو تحریر رضامندی کی گفتگو میں حصہ لے رہا ہے (اگر وہ محققہ نہیں ہے ، تو وہ فرد جس نے رضامندی حاصل کی ہے ، اس کے دستخط کی ضرورت ہوگی)

محققہ/نامزد کردہ کے دستخط: _____

تاریخ: _____

معلوماتی شیٹ اس رضامندی فارم کے ساتھ لگائی جائے گی اور اس کو ایک نقل تحقیق کے شرکت کنندہ کو دی جائے گی۔

Appendix I 1a: Interview Guide to Interview Patients

Study Title: A Case study describing access to palliative care in Pakistan

Research Investigator: Supervisor

Salma Amin Rattani Professor Supervisor: Dr. Brenda Cameron and Dr. Sherry Dahlke,
Email rattani@ualberta.ca bcameron@ualberta.ca dahlke@ualberta.ca
Phone number +923452341738 1-888-492-8089 780-492-8232
Address Faculty of Nursing, Edmonton Clinic Health Academy
11405-87 Avenue University of Alberta
Edmonton Alberta, Canada T6G 1C9

Greetings!

Thank you for agreeing to participate in this study.

1. Please tell me about how your condition started?
2. What signs and symptoms did you notice?
3. When did you first notice these signs and symptoms?
4. How did you seek help for these signs and symptoms?
5. What supported you in getting help with these signs and symptoms?
6. What made it hard for you to get help with these signs and symptoms?
7. What facilitated your journey since you first noted the signs or symptoms of your disease?
8. What challenges did you find from the time of appearance of a sign or a symptom of your disease till now?
9. How would you describe your overall experience since the time your diagnosis till the present state of your health?
10. In your opinion how does an individual's socioeconomic standing influence his/her access to palliative care?
11. How does the context of Pakistan influence an individual's access to palliative care?
12. Any other point that you would like to add.

Thank you for your participation

اینڈکس I 1b
مریضوں سے انٹرویو کے لئے انٹرویو گائیڈ

تحقیق کا عنوان: پاکستان میں ، درد سے سکون پہنچانے کی نگہداشت تک رسائی کی وضاحت کے لئے کیس اسٹڈی

محققہ: سلمہ امین رتانی
ای میل: rattani@ualberta.ca
فون نمبر: +923452341738

پروفیسر نگران: ڈاکٹر برینڈا کیمرون
ای میل: bcameron@ualberta.ca
فون نمبر: 1-888-492-8089
پتہ: فیکلٹی آف نرسنگ، ایڈمنٹن کلینک ہیلتھ اکیڈمی،
11405-87 ایوینیو، یونیورسٹی آف البرٹا،
ایڈمنٹن، البرٹا، کینیڈا T6G 1C9

اور ڈاکٹر شیری ڈھلکے
ای میل: dahlke@ualberta.ca
780-492-8232

السلام و علیکم،

- اس تحقیق میں شرکت کئے لئے رضامندی پر آپ کا شکریہ،
- 1) براہ مہربانی ہمیں یہ بتائیے کہ آپ کو یہ حالت کب شروع ہوئی؟
 - 2) آپ نے کیا علامات اور آثار محسوس کئے؟
 - 3) آپ نے ان علامات اور آثار کو پہلی مرتبہ کب محسوس کیا؟
 - 4) آپ نے ان آثار اور علامات کے لئے کیسے مدد حاصل کی؟
 - 5) ان آثار اور علامات کے لئے کس چیز نے آپ کا ساتھ دیا؟
 - 6) ان آثار اور علامات کے سلسلے میں مدد کے لئے کس چیز نے آپ کے لئے مشکل پیدا کی؟
 - 7) جب آپ نے اپنی بیماری کے آثار اور علامات کو پہلی مرتبہ محسوس کیا تو اس کے بعد کے سفر میں کس چیز نے آسانی پیدا کی؟
 - 8) اپنی بیماری کے آچار اور علامت ظاہر ہونے کے بعد سے اب تک آپ کو کن چیلنجوں کا سامنا ہوا؟
 - 9) مرض کی تشخیص سے لے کر آپ کی صحت کے موجودہ درجے تک آپ اپنے تمام تر تجربے کو کیسے بیان کریں گے؟
 - 10) آپ کی رائے میں کسی فرد کی سماجی مالیاتی صورت حال اسکے درد سے سکون پہنچانے کے لئے دی جانے والی نگہداشت پر کس طرح اثر انداز ہوتی ہے؟
 - 11) پاکستان میں علاج کے حوالے سے بات کریں تو وہ درد سے سکون دی جانے والی نگہداشت تک کسی فرد کی رسائی پر کیسے اثر انداز ہوتا ہے؟
 - 12) کوئی اور نکتہ جو آپ شامل کرنا چاہیں:

آپ کر شرکت کا بہت بہت شکریہ!

Appendix I 2a: Interview Guide to Interview Family Members

Study Title: A Case study describing access to palliative care in Pakistan

Research Investigator:	Supervisors	
Salma Amin Rattani	Professor Supervisor: Dr. Brenda Cameron and Dr. Sherry Dahlke,	
Email rattani@ualberta.ca	bcameron@ualberta.ca	dahlke@ualberta.ca
Phone number +923452341738	1-888-492-8089	780-492-8232
Address	Faculty of Nursing, Edmonton Clinic Health Academy 11405-87 Avenue University of Alberta Edmonton Alberta, Canada T6G 1C9	

Greetings!

Thank you for agreeing to participate in this study.

1. Please tell me about your experience as a family member of a patient receiving care at Bait- ul-Sukoon Cancer Hospital.
2. When did the family know about the health issue for which a person (patient) is under treatment?
3. What did the family do when the problem was identified? (Probe will be to note was the treatment at home, approached health care facility or any other setting)
4. What signs and symptoms were noted?
5. What helped the family to get the person (patient) to get treatment for these signs and symptoms?
6. What made it hard for your family to get the family member treatment for these symptoms?
7. How would you describe the experience the family had and or is having since diagnosis to date?
8. In your opinion how does an individual's socioeconomic standing influence his/her access to palliative care?
9. How does the context of Pakistan influence an individual's access to palliative care?
10. Any other point that you would like to add.

Thank you for your participation

اینڈکس I 2b
مریض کے اہل خانہ سے انٹرویو کے لئے انٹرویو گائیڈ

تحقیق کا عنوان: پاکستان میں ، درد سے سکون پہنچانے کی نگہداشت تک رسائی کی وضاحت کے لئے کیس اسٹڈی

محققہ: سلمہ امین رتانی
ای میل: rattani@ualberta.ca
فون نمبر: +923452341738

پروفیسر نگران: ڈاکٹر برینڈا کیمرن
ای میل: bcameron@ualberta.ca
فون نمبر: 1-888-492-8089
اور ڈاکٹر شیریں ڈھلکے
ای میل: dahlke@ualberta.ca
780-492-8232

پتہ: فیکلٹی آف نرسنگ، ایڈمنٹن کلینک ہیلتھ اکیڈمی،
11405-87 ایوینیو، یونیورسٹی آف البرٹا،
ایڈمنٹن، البرٹا، کینیڈا T6G 1C9

السلام و علیکم،

اس تحقیق میں شرکت کئے لئے رضامندی پر آپ کا شکریہ،

- 1) براہ مہربانی بیت السکون کینسر ہسپتال میں نگہداشت حاصل کرنے والے مریض کے خاندان کے ایک رکن کی حیثیت سے مجھے اپنے تجربات کے بارے میں بتائیے۔
- 2) مریض کی حالت کے بارے میں جس کے لئے وہ ابھی زیر علاج ہے اہل خانہ کو کب علم ہوا؟
- 3) جب مسئلے کی نشاندہی ہوئی تو اہل خانہ نے کیا کیا؟ (چھان بین میں نوٹ کرنا ہوگا کہ آیا علاج گھر پر ہوا، کسی صحت مہیا کرنے والے ادارے پر یا کسی اور جگہ)
- 4) کیا آثار اور علامات محسوس کی گئیں؟
- 5) ان آثار اور علامات کے لئے مریض کے علاج کے لئے اہل خانہ کا کس چیز نے ساتھ دیا؟
- 6) ان آثار اور علامات کے مریض کے علاج کے سلسلے میں کس چیز نے آپ کے لئے مشکل پیدا کی؟
- 7) مرض کی تشخیص سے لے کر اب تک اہل خانہ کو جن تجربات کا سامنا ہوا وہ کیسے بیان کریں گے؟
- 8) آپ کی رائے میں کسی فرد کی سماجی مالیاتی صورت حال اسکے درد سے سکون پہنچانے کے لئے دی جانے والی نگہداشت پر کس طرح اثر انداز ہوتی ہے؟
- 9) پاکستان میں علاج کے حوالے سے بات کریں تو وہ درد سے سکون دی جانے والی نگہداشت تک کسی فرد کی رسائی پر کیسے اثر انداز ہوتا ہے؟
- 10) کوئی اور نکتہ جو آپ شامل کرنا چاہیں:

آپ کر شرکت کا بہت بہت شکریہ!

Appendix I 3a: Interview Guide to Interview Healthcare Providers

Study Title: A Case study describing access to palliative care in Pakistan

Research Investigator: Supervisor:

Salma Amin Rattani Professor Supervisor: Dr. Brenda Cameron and Dr. Sherry Dahlke,
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Greetings!

Thank you for agreeing to participate in this study.

1. Please tell me about your experience as a healthcare team-member providing care to the patients at Bait- ul-Sukoon Cancer Hospital.
2. In your experience as a health care provider, what are the common types of cancers?
3. What are the factors that contribute to cancer?
4. What are the facilitators in accessing palliative care?
5. What are the barriers to accessing palliative care?
6. What is the stage of cancer when a patient comes for treatment?
7. What are the challenges faced by patients?
8. What are the challenges faced by family members?
9. What are the challenges faced by healthcare providers?
10. What supports or motivates you in providing palliative care?
11. Generally is palliative care covered in the curriculum in medicine, nursing, pharmacy or other professional education in the health sector? In your program was palliative care included in the curriculum?
12. What education is required for working in palliative care settings?
13. What are the mechanisms for ongoing or continuing education for working in a palliative care setting?
14. How does an individual's socioeconomic standing influence on his/her access to palliative care?
15. How does the context of Pakistan influence an individual's access to palliative care?
16. Any other point that you would like to add.

Thank you for your participation.

اینڈکس I 3b

صحت کی نگہداشت مہیا کرنے والوں سے انٹرویو کے لئے انٹرویو گائیڈ

تحقیق کا عنوان: پاکستان میں ، درد سے سکون پہنچانے کی نگہداشت تک رسائی کی وضاحت کے لئے کیس اسٹڈی
محققہ: سلمہ امین رتانی

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ڈاکٹر شیری ڈھلکے اور

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فیکلٹی آف نرسنگ، ایڈمنٹن کلینک ہیلتھ اکیڈمی،

پتہ:

11405-87 ایوینیو، یونیورسٹی آف البرٹا،

ایڈمنٹن، البرٹا، کینیڈا T6G 1C9

السلام و علیکم،

اس تحقیق میں شرکت کئے لئے رضامندی پر آپ کا شکریہ،

- 1) براہ مہربانی بیت السکون کینسر ہسپتال میں نگہداشت حاصل کرنے والے مریضوں کو نگہداشت مہیا کرنے والے کی حیثیت سے مجھے اپنے تجربات کے بارے میں بتائیے۔
- 2) اپنے پیشے کے تجربے کی روشنی میں بتائیے کہ سرطانوں کی عام اقسام کیا ہیں؟
- 3) وہ کیا عوامل ہیں جو سرطان کا باعث بنتے ہیں؟
- 4) درد سے سکون پہنچانے والی نگہداشت تک رسائی میں کیا سہولتیں میسر ہیں؟
- 5) درد سے سکون پہنچانے والی نگہداشت تک رسائی میں کیا رکاوٹیں ہیں؟
- 6) جب کوئی مریض علاج کے لئے آتا ہے تو وہ سرطان کا کون سا درجہ ہوتا ہے؟
- 7) مریضوں کو کن چیلنجوں کا سامنا کرنا پڑتا ہے؟
- 8) مریضوں کے اہل خانہ کو کن چیلنجوں کا سامنا کرنا پڑتا ہے؟
- 9) صحت کی نگہداشت مہیا کرنے والوں کو کن چیلنجوں کا سامنا کرنا پڑتا ہے؟
- 10) درد سے سکون پہنچانے کے نگہداشت میں آپ کی کون مدد کرتا ہے اور حوصلہ افزائی کرتا ہے؟
- 11) کیا عام طور پر، صحت کے سیکٹر میں ، طبی، نرسنگ، فارمیسی یا دیگر پیشہ ورانہ تعلیم کے نصاب میں، درد سے سکون پہنچانے والی نگہداشت شامل ہے؟ کیا آپ کے پروگرام میں ، درد سے سکون پہنچانے والی نگہداشت کی تعلیم نصاب میں شامل تھی؟
- 12) درد سے سکون پہنچانے والی نگہداشت مہیا کرنے والی جگہ پر کام کرنے کے لئے کس تعلیم کی ضرورت ہے؟
- 13) درد سے سکون پہنچانے والی نگہداشت مہیا کرنے والی جگہ پر کام کرنے کے لئے مسلسل اور جاری تعلیم کے لئے کیا میکانیز درکار ہیں؟
- 14) آپ کی رائے میں کسی فرد کی سماجی مالیاتی صورت حال اسکے درد سے سکون پہنچانے کے لئے دی جانے والی نگہداشت پر کس طرح اثر انداز ہوتی ہے؟
- 15) پاکستان میں علاج کے حوالے سے بات کریں تو وہ درد سے سکون دی جانے والی نگہداشت تک کسی فرد کی رسائی پر کیسے اثر انداز ہوتا ہے؟
- 16) کوئی اور نکتہ جو آپ شامل کرنا چاہیں:
- 17) آپ کر شرکت کا بہت بہت شکریہ!

Appendix J: Guide for Observation

Study Title: A Case study describing access to palliative care in Pakistan

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- 1) What is the physical appearance of the environment?
 - a) Capacity for in-patients and outpatients
- 2) Observations of how patients and families navigate care processes. Also how the people enter, who they talk to first.
- 3) The appearance of the health care providers
 - a) How are they dressed?
 - b) How are they interacting with patients and their family members
- 4) Actions of the patients
 - a) Are the patients bedridden
 - b) Are patients moving around
- 5) Actions of the family members
 - a) Is a family member required to stay with the patient throughout the stay in the hospital
 - b) Are family members visiting the patients
- 6) Actions of the health care providers
 - a) What types of activities do health care providers engage with patients and their family member
- 7) Type of services available in the facility
 - a) In-patient admission.
 - b) Daycare services
 - c) Consultation services
 - d) Treatment modalities available: chemotherapy, radiation therapy, surgery, supportive care
 - e) Support services available: counseling services from a psychologist
- 8) Coordination among these facilities
 - a) Available within the Bait- ul-Sukoon Cancer Hospital or are on other campuses

Appendix K: Checklist for Organizational Record

Study Title: A Case study describing access to palliative care in Pakistan

Research Investigator: Supervisors:

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- 1) How many patients come to the clinic in a day or in a month?
- 2) How many patients come for treatment under different services?
 - a) Radiotherapy
 - b) Chemotherapy
 - c) Surgery
 - d) Other services if any and what are those
- 3) What is the demography of patients coming for treatment
 - a) Age, sex, type of cancer (e.g. breast, cervix, lung, oral,). Locality they are coming from (e.g. which squatter of the city, from a city other than Karachi (the hospital is located in Karachi)
- 4) How does Bait-ul-Sukoon cancer hospital define its policies and procedures for providing palliative care?
- 5) How these policies are related to country-level policies (e.g. narcotics control)

Appendix L: Checklist for Artifacts

Study Title: A Case study describing access to palliative care in Pakistan

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What pamphlets, posters or other material is used for education and dissemination of the information for health and improving access to palliative care.

*How are these artifacts being used?

* e.g. through circulation as hard copy, soft copy at institution's website, any other mechanism.

