Rise Above: Experiences of Spirituality among Family Caregivers of Palliative Care Patients in a Hospice Setting in Pakistan

by

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Abstract

Background: Family caregivers play a vital role during the time of illness of a family member. Family caregivers experience various physical, emotional, psychosocial, and spiritual concerns while caring for a family member with a life-threatening illness, especially in a hospice setting. Current literature mainly adds to understanding the physical, psychological, and emotional aspects of family caregiving. Spiritual aspects of family caregiving such as personal values and the meanings that family caregivers ascribe to their caregiving roles often remain unaddressed. While caring for a seriously ill family member receiving palliative care, family caregivers go through multiple transitions, make new resolutions, adjust to changing roles and expectations, and experience grief and other complex caregiving situations where their search for meaning becomes evident. There is an increasing need to explore such experiences of spirituality among family caregivers to support their caregiving actions and practices.

Purpose: The study aimed to describe the experiences of spirituality among family caregivers and how these experiences shape their family caregiving practices while caring for a terminally ill family member in a hospice setting in Karachi, Pakistan.

Research Design: Interpretive descriptive design guided the study. Individual in-depth interviews were used as a method of data collection. Study setting was Baitul-Sukoon Cancer Hospital and Hospice in Karachi, Pakistan. A sample of family caregivers (n=18) and healthcare professionals (n=5) was selected from a cancer hospice facility in Karachi. A total of 28 interviews were taken from the family caregiver participants. For collateral data collection, 5 interviews were taken from the healthcare providers. The qualitative data analysis software, Quirkos, was used to manage the data. Permission for the study was obtained from the Bait-ul-Sukoon Hospice. Ethical approval was obtained from Human Research Ethics Board of the University of Alberta.

Results/Findings: Demographic characteristics of family caregivers showed that mean age of family caregivers was 34.06years. 83% were Muslims, 78% were female, 72% were married, 28% did not have any formal education, and 72% were living in extended families. 61% reported their income between Canadian $160-200/month. The average caregiving period was 1.72years. Analysis of the rich descriptions revealed four themes under study which were: family love, attachment, and belongingness; honoring family values and dignity; acts of compassion and selfless service; and seeking God's kindness and grace. All these themes led to a central theme 'rise above or self-transcendence'. The four themes reflect the unique experiences of spirituality among family caregivers. Family caregivers identified their uncertainties, losses, and sufferings as part of life and perceived them as invitations to open themselves to the depths of their spirits and to the support, service, and love of others as they experienced 'rise above' or self-transcendence. Family caregivers' uncovered meaningful engagement, a sense of belonging, and a sense of attachment while serving family and others. They highly valued the love, respect, and honor of the family, showed compassion, believed in God's blessings and grace and experienced constant spiritual growth and self-transcendence.

Conclusion: My findings present a novel perspective of spirituality and family caregiving from a eastern context. Findings signify that spirituality is a major resource of coping among family caregivers. Healthcare professionals need to acknowledge and develop spiritual care interventions to support family caregivers' spirituality and spiritual wellbeing at the end of life in the hospice setting.

Keywords: Spirituality, experiences, family caregivers, sense of belongingness, compassion, spiritual growth, self-transcendence, hospice, Pakistan

Preface

This thesis is an original work by Nasreen Lalani. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “EXPERIENCES OF SPIRITUALITY AMONG FAMILY CAREGIVERS OF PATIENTS RECEIVING PALLIATIVE CARE IN A HOPISCE SETTING, KARACHI, PAKISTAN”, No. Pro00068683, 13/12/2016.

Dedication

I would like to dedicate my dissertation to all the family caregivers who participated in my study. Without them this dissertation and my overall understanding of spirituality would have remained incomplete. Working on this study was a meaningful experience for me. On one hand, I believe that letting the family caregivers speak about their experiences supported them and provided them an opportunity to vent their feelings with me. On the other hand, their experiences gave me an enriching insight that life may not treat everyone fairly, but ***the art of living is human-it's spiritual***. Being a nurse and a researcher, I can reinforce such humanistic and spiritual values to generate the true meaning of caring and nursing. I am grateful for having had this life-long learning experience during my nursing education.

Acknowledgments

I would like to acknowledge my supervisors, Dr. Wendy Duggleby and Dr. Joanne Olson and my committee member, Dr. Anna Santos Salas for their continuous support and guidance throughout the research study. At each step of my research, they assisted me to inquire further into details of different aspects of the research, which resulted in a deeper understanding of the overall research process. Without them, I would not have been able to develop such broad and meaningful constructs around the concepts of spirituality and family caregiving. I am also thankful for all the funding support received during the research.

I would also like to extend my sincere thanks to my examiner, Dr. Shane Sinclair for his support and valuable comments provided on my dissertation. My sincere thanks to Dr. Pauline Paul and Dr. Diane Kunyk for being on my dissertation examining committee.

I would also like to acknowledge my family, especially my husband and my two sons. Without their continuous support and encouragement, this research would not have been a reality. I came to Canada and started my PhD in 2013, when my two boys were six and 11 years old. Now they are 11 and 16 years old. It was a big transition for me and my young children, settling in Canada, pursuing studies, and managing all other responsibilities. In the midst of all these experiences, conducting my PhD research felt like a kind of spiritual call, leading to my personal and professional growth. After all these experiences, now I see myself a stronger and better individual.

My friends and community were major sources of support throughout my entire PhD journey. They kept me motivated, inspired, and goal-driven. They guided me well in all the steps of this wonderful journey.

I would like to acknowledge my pen pal and mentor, Kathleen Beyerman, for her continuous support and mentorship during my dissertation.

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Table of Contents

Chapter One: Introduction ... 1
Purpose of the Research ... 5
Research Questions ... 5
Significance of the Research ... 5
The Pakistan Context ... 6
Burden of Cancer and Palliative Care in Pakistan ... 6
Family Caregiving in Pakistan ... 8
Researcher's Background and Position within the Research Context ... 9
Conceptual Definitions of Research Terms ... 10
Spirituality ... 10
Spiritual Wellbeing ... 10
Spiritual Distress ... 11
Spiritual Needs ... 11
Spiritual Care ... 11
Family Caregivers ... 11
Healthcare Professionals ... 11
Palliative Care ... 11
End-of-Life (EOL) Care ... 12
Hospice ... 12
Culture ... 12
Chapter Two: Literature Review ... 13
The Meanings of Spirituality ... 13
Spirituality and Healing ... 16
Spirituality from an Islamic Perspective of Health and Healing ... 17
Culture and Spirituality ... 19
Expressions of Spirituality ... 20
Research Studies on Spirituality and Family Caregiving in Palliative Care ... 21
Spiritual Needs and Resources of Family Caregivers during Palliative Care ... 25
Role of Spirituality in Family Caregivers' Healthcare Decision Making ... 27
Summary and Conclusion ... 28
Chapter Three: Methodology ... 30
Interpretive Description as an Approach to Inquiry ... 30
Basic Philosophical, Epistemological, and Ontological Tenets of Interpretive Description ... 31
Study Setting ... 34
Sampling ... 35
Family Caregivers ... 35
Healthcare Professionals ... 35
Sample Size ... 35
Inclusion Criteria for Family Caregivers ... 36
Inclusion Criteria for Healthcare Professionals ... 36
Recruitment of the Participants ... 37
Data Collection ... 38
Interview Guide ... 38
Procedure for the Interview ... 39
Translation of Data ... 42
Data Analysis ... 43
Steps to Ensure Rigor ... 47
Epistemological Integrity ... 47

Trustworthiness and Credibility ... 47
Preventing Analytic Errors ... 48
Moral Defensibility ... 48
Ethical Considerations of the Study ... 48
Information Letter and Consent ... 48
Privacy and Confidentiality ... 49
Emotional Distress ... 50
Power Relations and Power Differential ... 51
Conclusion ... 52

Chapter Four: Study Findings ... 54
Section 1: Demographic Variables of Study Participants ... 54
Demographic Characteristics of Family Caregivers ... 55

Table 1: Demographic Characteristics of Family Caregiver Participants (N=18) ... 55
Demographic Characteristics of Healthcare Professionals ... 56
Section 2: Context of Caregiving ... 57
Poverty ... 57
Non-Traditional Practices ... 58
Living Far from the Hospice ... 58
Extended Family Structure ... 59
Juggling with Multiple Responsibilities ... 59
Hospice: A Place of Peace and Comfort for Family Caregivers ... 61
Section 3: Experiences of Spirituality among Family Caregivers ... 61
Family Love, Attachment, and Belongingness (*Apnaiyat*): "My family gives me purpose in my life" ... 62
Honoring Family Values and Dignity: "I don't want to bring any shame or dishonor for my family." ... 65
Acts of Compassion and Selfless Service: "I find peace and eternal satisfaction in serving family and others" ... 68
Seeking God's Kindness and Grace: "Everything lies in God's hands" ... 70
Rise Above or Self Transcendence: "I see myself a better person" ... 76
Section 4: Family Caregiver Expectations from Healthcare Providers ... 81
Healthcare Professionals Care and Support: "We need your presence and a listening ear" 81
Summary of the Findings ... 83
Figure 1: Themes under Study ... 84

Chapter Five: Discussion and Implications ... 85
Spirituality is experienced in Sense of Belongingness and Love for the Family ... 86
Spirituality is experienced in Family Relationships ... 88
Spirituality is experienced in Honoring and Respecting Family Values ... 90
Spirituality is experienced in Gratitude and Faith in God ... 94
Spiritual Practices as Major Sources of Coping among Family Caregivers ... 96
Rise Above or Self-Transcendence ... 97
Role of Healthcare Professionals in Spirituality of Family Caregivers ... 99
Summary of the Discussion ... 102
Strengths and Limitations of the Study ... 103

Study Implications ... 105
Implications for Practice ... 105
Implications for Health/Nursing Education ... 107
Implications for Research ... 108
Conclusion of the Study ... 109

References ... 111

Appendix A: Information Script and Verbal Consent for Family Caregivers 132
Appendix B: Demographic Data Sheet for Family Caregivers 135
Appendix C: Interview Guide for Family Caregivers 136
Appendix D: Information Letter and Informed Consent for the Healthcare Professionals ... 137
Appendix E: Demographic Data Sheet for Healthcare Professionals................................... 140
Appendix F: Interview Guide for Healthcare Professionals 141

List of Tables

Table 1. Demographic Characteristics of the Family Caregiver Participants…………..56

List of figures

Figure 1. Themes under study……………………………………………………….84

Chapter One: Introduction

Family caregivers play a vital role during the illness of a family member. Family caregivers can be spouses, parents, friends, or close relatives who are responsible to provide physical, social, psychological, emotional, and spiritual support for the ill person in the family (Khan, 2012). While caring for a seriously ill family member in a palliative care setting, family members often experience multiple transitions such as making new resolutions, adjusting to changing roles and expectations, and acknowledging loss (Duggleby et al; 2010). With increasing caregiving demands, family caregivers find themselves in a state of disharmony of mind, body, and spirit and their search for meaning becomes evident (Narayanasamy, 2007). Spirituality shape the caregiving attitudes and practices of family caregivers and assists them to find meaning in their experiences (Deal, 2011; Hodge & Sun, 2012; Newberry et al., 2013; Viswanath, 2015).

Spirituality has received special attention in the end-of-life and palliative care literature. Palliative care supports that improving the quality of life and wellbeing of family caregivers will ensure the best quality of life for the people that they are caring for (World Hospice Palliative Care Alliance, (WHPCA), 2014). The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the World Health Organization (WHO) encourage healthcare professionals to determine spiritual and existential concerns of both patients and their families in palliative care (Buck & McMillan, 2008). Knowing family caregivers' experiences of spirituality will assist healthcare professionals to identify how the illness experience is affecting and challenging family caregivers' sense of meaning and purpose, and their connectedness. Additionally, it will guide healthcare professionals to recognize whether those experiences are facilitating or limiting family caregivers' engagement in caregiving practices (Puchalski, Lunsford, Harris, & Miller, 2006) and enable them to develop supportive care interventions for families in palliative care settings.

Despite the increasing importance of spirituality among family caregivers, limited knowledge is available pertaining to spirituality and spiritual experiences of family caregivers, especially in different contexts of palliative care (Edwards, Pang, Shiu, & Chan, 2010; Puchalski, 2007; Puchalski et al., 2009). Spirituality has been identified as a key priority for research in end-of-life and palliative care (Riffin et al., 2015). Family caregiving and spirituality are both highly personal and contextual concepts (Berry, Bass, Forawi, Neuman, & Abdallah, 2011). Most studies around caregiving focused mainly on family caregivers' physical, psychological, emotional, and socio-economic experiences rather than their spiritual experiences (Funk et al., 2010; Steinhauser et al., 2015). Very few studies were found on spirituality among family caregivers, and they were mainly among Judeo-Christian faith communities in North America or the United Kingdom. Only three studies were found on spirituality among Muslims from Middle Eastern countries such as Saudi Arabia and Iran (Cheraghi, Payne, & Salsali, 2005; Rahimi, Anoosheh, Ahmadi, & Foroughan, 2013; Tayeb, Al-Zamel, Fareed, & Abouellail, 2010) and none of those had a Southeast Asian context. Consequently, there is an increasing need to generate knowledge and create awareness regarding the significance of spirituality and its experiences among family caregivers in palliative care settings from varied contexts, religions, and cultures.

Pakistan is a developing country with a predominantly Muslim population. The concepts of hospice palliative care and spirituality are new to Pakistan's healthcare system. Few hospices in the country provide palliative care services and then only to advanced-stage cancer patients. The family is an essential resource in the care of a sick person in a Pakistani community. Various cultural values and beliefs influence healthcare attitudes and practices within the community. For example care of a sick person is given priority over every other responsibility within the family. Caring for a family member suffering from a life-threatening illness brings additional socio-cultural and financial responsibilities which may

put families into multiple stressful situations (Khan, 2012). Studies conducted in various other contexts have revealed that increasing caregiving burdens and demands affect the physical, mental, and spiritual wellbeing of family caregivers, who experience disharmony, pain, loss, and spiritual distress (Delgado-Guay et al., 2013; Kristjanson & Aoun, 2004; Young, Nadarajah, Skeath, & Berger, 2015). No such research evidence was found in the literature within a Pakistani context. Hence, a need was felt to conduct a study that could explore experiences of spirituality among family caregivers of advanced-stage cancer patients in a palliative hospice care setting in Pakistan. This study will make a unique contribution to the areas of palliative care and family caregiving research in a Pakistani Muslim context. This particular study generated new knowledge regarding experiences of spirituality among family caregivers and how these experiences influenced family caregivers' actions and practices in a cancer hospice setting in Pakistan. The descriptions generated from the study will help us understand the significance of spirituality among family caregivers, determine how spirituality shapes their caregiving practices, identify various spiritual practices and their influence on the caregiving experiences of the family caregivers. Recommendations from the study will guide healthcare professionals when integrating spirituality into supportive caregiving interventions for families during palliative care in Pakistan.

Family members play a crucial role during palliative care. Each year, nearly 20 million people globally need palliative care. Of those 20 million, it is estimated that 18 million do not receive it. Seventy-eight percent of these people who require hospice and palliative care reside in developing countries (WHPCA, 2014). These statistics show a huge need to address and support families in palliative care, especially in developing countries. In Pakistan, where socio-economic determinants of health are poor with an increased burden of chronic and progressive illnesses and limited palliative care resources and services, families experience multiple transitions and go through various physical, economic, and socio-cultural

constraints and pressures while caring for a seriously ill family member in a palliative care setting (Khan, 2017). A spiritual perspective can help patients and families transcend the difficulties faced while dealing with life-threatening illnesses (Reed & Rousseau, 2007). Previous studies have also indicated that spirituality has been a source of comfort, peace, strength, and coping for both patients and families during palliative care (Bernard, Maddalena, Njiwaji, & Darrell, 2014; Edwards et al., 2010; Herrera, Lee, Nanyonjo, Laufman, & Torres-Vigil, 2009; Paiva, Carvalho, Lucchetti, Barroso, & Paiva 2015; Spichiger, 2008; Tang, 2009). In many ethnic and cultural communities, family caregiving is considered sacred and has been believed to bring many eternal rewards and much spiritual satisfaction to the family caregivers' lives (Chang et al., 2012; Kim, Hayward, & Reed, 2014; Penman, Oliver, & Harrington, 2013).

However, none of the studies about family caregiving and spirituality at the end of life were conducted in a Pakistani context. This study was a preliminary step in exploring and interpreting the experiences of spirituality among family caregivers caring for a seriously ill family member in palliative care in Pakistan. The study drew attention to the hidden voices of family caregivers and brought awareness to ways to address the spirituality of family caregivers. Consequently, it can guide healthcare professionals to develop supportive programs for families in palliative care settings in Pakistan.

The remainder of this chapter presents the research purpose, research questions, and the significance of the study. It also presents a brief overview of Pakistan, existing palliative care services in Pakistan, and the significance of family caregiving and spirituality in Pakistan. The conceptual definitions of the terms used in the research are described at the end of the chapter.

Purpose of the Research

The purpose of this research was to explore the experiences of spirituality among family caregivers of terminally ill patients in a hospice setting in Pakistan. The study aimed to describe the experiences of spirituality among family caregivers and how these experiences shaped their caregiving practices while caring for a family member in a hospice setting. Findings led to recommendations for healthcare providers that recognize the significance of spirituality among family caregivers, integrate family caregivers' experiences of spirituality into plans of care, and promote the development of supportive family care interventions in palliative care settings in Pakistan.

Research Questions

The following research questions guided my study:

- How do family caregivers in Pakistan describe their experiences of spirituality while looking after their family member receiving palliative care in a hospice care setting?
- How do experiences of spirituality shape family caregiving practices in Pakistan?
- How do spiritual practices impact family caregivers' caregiving experiences?

Significance of the Research

This research was the first of its kind about family caregiving and spirituality in a palliative care setting in Pakistan. By listening to families talk about their experiences and the concerns they had while caring for their terminally ill family member, I was able to gather new knowledge about family caregivers' spirituality in the hospice setting. This new knowledge will potentially guide healthcare professionals when addressing spiritual concerns of family caregivers and developing culturally relevant spiritual care intervention during end-of-life care in Pakistan.

The Pakistan Context

Pakistan occupies an area of approximately 796,095 km.^{2} It is located on the Arabian Sea, and shares borders with India to the east, Iran to the southwest, Afghanistan to the northwest, and China to the north. Pakistan is comprised of four provinces (Punjab, Sindh, Khyber Pakhtunkhwa (KPK), and Baluchistan), and four federal territories. Pakistan is a developing country where the majority of people are Muslims. According to the United Nations (UN) Statistics Division (2016), Pakistan has a population of 192 million people. Sixty-two percent of the Pakistani population live in rural areas and the remaining 38 percent live in urban areas. Life expectancy is between 65-67 years. The literacy rate in 2012 was reported to be 57 percent (The World Bank, 2015). As per an economic survey by the Government of Pakistan, Ministry of Finance (2014), 60 percent of the population live under the internationally defined poverty line of less than US $2per day (United States [US] currency). In 2014, Pakistan spent only 2.6% of its total budget on the healthcare of its population (WHO, 2016) compared to the 8.9% spent by Organization for Economic Cooperation and Development (OECD) countries and 16.9% by the US, excluding investments (OECD Health Statistics, 2015). Public, private sector, and non-governmental organizations (NGOs) share the burden of healthcare in Pakistan. The percentage of non-communicable diseases such as diabetes, hypertension, coronary artery disease, chronic lung disease, cancer, and malignancies has increased from 47% to 73% during the last decade (Nishtar et al., 2013). These diseases are now among the top 10 causes of morbidity and mortality and account for one in four deaths in the country (Jafar et al., 2013).

Burden of Cancer and Palliative Care in Pakistan

There is a huge burden of cancer diseases in Pakistan and it is one of the most common causes of mortality among both males and females. According to a WHO (2014) report, nearly 1,332,000 deaths occured in the lower middle class during 2014. The death

rate for cancer among males is 10% whereas among females it is 25%. Yusuf (2013) stated that every year there is an increase of 150,000 new cases of cancer and between 60-80% of these patients die each year. Nearly 80% of these patients present in late or advanced stages of cancer due to a lack of education and awareness, poor socio-economic determinants, and lack of resources (Yusuf, 2013). These patients and families suffer a lot of physical, psychological, emotional, and spiritual distress. Provision of palliative care and support services can be a source of relief and coping for the patients and their families (Meghani & Aziz, 2008).

According to the WHPCA report (2014), about one-third of people who need palliative care suffer from cancer. Each year more than 20 million people globally require palliative care during end of life. Eighty percent of the global need for palliative care is in low- and middle-income countries; however, it is mainly provided in high-income countries (WHPCA, 2014). Palliative care is at an infancy stage in Pakistan (Khan, 2017; Punjwani, et al., 2015). No specialized palliative care services are available within most of the government-run hospitals. Patients with advanced stages of cancer or other life-limiting diseases are kept with other acutely or chronically ill patients within the tertiary care hospital facility. These hospitals only provide curative services or some form of pain management to the patients needing palliative care. They do not have any specially trained palliative care staff or resources to support the palliative care needs of the patients and their families. Currently, only two private hospitals in two different cities in Pakistan provide palliative care services. One is the Aga Khan University Hospital situated in Karachi, which provides home-based palliative services. The other is the Shaukat Khanum Memorial Cancer Hospital and Research Center situated in Lahore, which has a separate palliative care unit in the hospital. There are only two hospices in the whole country. Both are located in Karachi. These hospices are non-profit and run as charitable organizations with dedicated medical and

nursing staff who work on a voluntary basis without formal training in palliative care (Yusuf, 2013). These hospices provide only pain and symptom management to patients who are at advanced stages of their cancer. Minimal or no psychological, emotional, or spiritual support is available to patients or their families at these centers (Lalani, Lakhani, & Shah, 2011).

Family Caregiving in Pakistan

Family and friends are the major sources of care during the illness of any family member. Family caregivers constitute mainly parents, spouses, children, friends, and closest relatives who are responsible for providing physical, social, psychological, emotional, and spiritual support for the ill person (Khan, 2012). Care of a sick family member is a cultural and religious responsibility. The caregiving practices are highly influenced by religious and cultural values and beliefs. As part of cultural expectations, it is often the elderly male member or elder son in the family who makes the final decisions regarding the treatment and care of the dying family member (Ahmad, 2012). According to religious beliefs, the act of caregiving is viewed as sacred and a source of spiritual enlightenment (Hasnain & Rana, 2010). Muslims believe that God expects them to care for the weak, suffering, and outcasts of society, and that those who fulfill those expectations will receive special blessings and rewards in their after-life (Hasnain & Rana, 2010; Khan, 2017). Families often turn to prayers, religious rituals, and practices while caring for their family member with life-threatening illnesses. Families in Pakistan experience significant caregiving demands and pressures due to the lack of palliative care, poor socio-economic determinants of health, and socio-cultural expectations of caregiving. However, because of various cultural and religious values and beliefs, they often do not complain about their caregiving demands or any suffering (Khan, 2012; Khan, 2017).

In light of the above context, there is a possibility that drawing on spirituality could play a significant and intentional role in supporting these families. Faith and spirituality can

be major sources of coping and strength for families. There is a dearth of literature about the role of spirituality among family caregivers in palliative care. A literature search did not turn up any research study from Pakistan that describes experiences of spirituality among family caregivers in a hospice setting. All these reasons strongly encouraged me to pursue this research in Pakistan.

Researcher's Background and Position within the Research Context

Choosing spirituality as a topic of my research was not an easy decision. Spirituality is an abstract concept and a highly subjective phenomena. It is intertwined in our daily living experiences, and all our actions and behaviors reflect spirituality. My research journey was led by my own experiences, extensive literature reviews, and guidance from my supervisors.

From the very beginning of my PhD studies, I was passionate about focusing on something very important in palliative care and generating knowledge that can be useful in the practice setting. As a Muslim nurse from Pakistan with more than 20 years of professional working experience in healthcare generally and palliative care specifically, I have personally observed family caregivers facing numerous challenges while giving care to their seriously ill family member in a hospice setting. Due to lack of palliative care and spiritual support, family caregivers often experience emotional, psychological, and spiritual distress. One would rarely find any kind of spiritual assessment or discussions of spirituality with the family during their hospital stay. Healthcare professionals do not receive any kind of training to initiate such conversations with the family. The concepts of palliative care and spirituality are rarely studied or given importance in the nursing or medical curricula in Pakistan (Punjwani et al, 2015; Khan, 2017).

Coming from a place where families are culturally and religiously held responsible to care for their sick family members (and must do so with limited facilities and resources), I was passionate to explore what provides meaning in daily family caregiving practices. I had

a desire to examine spirituality in the caregiving experiences and practices of families looking after a terminally ill family member. I strongly felt that addressing these issues would generate knowledge to inform healthcare professionals in a way that would allow them to provide holistic care and support families providing end of life care. Literature as well as my own clinical observations support that spirituality has a significant impact on the wellbeing of patients and families. Spirituality can help transcend fears and anxieties, provide strength, and allow families to grow in difficult and painful situations during life-threatening illnesses. Spirituality provides meaning to their practices and helps families cope with day-to-day challenges of caregiving for a dying family member. I personally believe that this unique study will be highly beneficial for nursing and healthcare in Pakistan as it intends to create awareness and knowledge around spirituality in a palliative care setting from a Pakistani Muslim context. The knowledge will guide healthcare professionals to design culturally relevant spiritual care interventions for family caregivers in a palliative care setting.

Conceptual Definitions of Research Terms

Spirituality

"An aspect of humanity that refers to the way individuals seek or express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred" (Puchalski et al., 2009, p.887).

Spiritual Wellbeing

The ability to experience and integrate meaning and purpose in life through a person's connectedness with self, others, or a power greater than oneself. Signs of spiritual wellbeing include having inner peace and harmony, hope, goals and ambitions, social connections, feelings of uniqueness, value and dignity, and the ability to cope and share emotions with others (Murray, Kendall, Boyd, Worth & Benton, 2004).

Spiritual Distress

"A state of suffering related to the impaired ability to experience meaning in life through connectedness with self, others, world, or a superior being." (Caldeira, Carvalho, & Vieira, 2013, p.82).

Spiritual Needs

What an individual wants or requires finding meaning, purpose, and value in life. Spiritual needs may vary as per the individual's value and belief systems and life events or situations (Murray et al., 2004). Hermann (2007) has identified six spiritual needs at EOL care such as the need for religion, need for companionship, need for involvement and control, need to finish business, need to experience nature, and the need for a positive outlook.

Spiritual Care

Care that serves the whole person—the physical, emotional, social, and spiritual. Such service is inherently a spiritual activity (Puchalski, 2001).

Family Caregivers

Parents, spouses, children, friends, and closest relatives who are responsible to provide physical, social, psychological, emotional, and spiritual care for an ill person (Khan, 2012).

Healthcare Professionals

Physicians, nurses, paramedical staff, and other healthcare providers involved in palliative care.

Palliative Care

"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, whether physical, psychosocial, and/or spiritual" (WHO, 2002).

End-of-Life (EOL) Care

"Provision of supportive and palliative care in response to the assessed needs of patient and family during the last phase of life and into bereavement" (p. 3). It includes management of pain and other symptoms and provision of psychological, social, spiritual, and practical support (The National Council for Palliative Care, 2006).

Hospice

A place where compassionate care, comfort, and support are provided to persons with life-limiting conditions. Hospice aims to provide pain management to patients and other physical, emotional, and spiritual support to patients and family caregivers (National Hospice and Palliative Care Organization, 2016).

Culture

A dynamic relational process of shared meanings or symbols that originate through social interactions among individuals. These shared meanings and symbols orient people in their ways of thinking, feeling, and being in the world (Carpenter-Song, Nordquest Schwallie & Longhofer, 2007).

Chapter Two: Literature Review

This chapter provides a literature review on spirituality and its significance in family caregiving. The literature review begins with describing various meanings of spirituality, and the relationship between spirituality and health and healing. This is followed by discussions on spirituality from an Islamic perspective of health and healing, the role of culture and spirituality, and various expressions of spirituality. The latter part of the review offers an integrative review and critical appraisal of various research studies conducted specifically on spirituality and experiences of family caregivers' spirituality, spiritual needs, and resources, and the role of spirituality in family caregivers' decision-making in the palliative care setting. Lastly, it summarizes and signifies the need for this research in Pakistan.

The Meanings of Spirituality

Spirituality is derived from the word "spirit," or the Latin root "spiritus," which means breath, inspiration, character, or soul. In Hebrew, Greek, and Roman cultures, the spirit was defined as the "breath of life" (Delgado, 2005). Western belief systems consider spirit to be something that gives life and self-awareness and is other than one's physical body (Eliason, Samide, Williams, & Lepore, 2010). The terms spirituality and religion are often used inter-changeably in literature. Until the late twentieth century, people often talked about spirituality in a religious context (Cohen, Holley, Wengel, & Katzman, 2012). Most authors now believe that concepts of religion and spirituality are distinct from each other and that spirituality is a broader concept than religion (Buck, 2006; Cohen et al., 2012; Delgado, 2005; Doka, 2003; McSherry, Cash, & Ross, 2004; Sessanna, Finnell, & Jezewski, 2007). Religion is commonly defined as an organized system of beliefs, practices, rituals, and symbols that enables a person's closeness or submission to a higher power or God, whereas spirituality is defined as a personal search for meaning or purpose in life (Koenig, McCullough, & Larson, 2001). Every human experiences spirituality, yet each experience is

individual (Miner-Williams, 2006). For some, spirituality is defined by a particular set of beliefs or a religion while for others spirituality is a unique individual journey (Pesut, 2008). An individual can express his/her spirituality without having an affiliation with any religion or religious values and beliefs.

Current literature provides various evolving perspectives and diverse definitions of the term “spirituality.” Spirituality is an inherent aspect of our being-ness (Burkhardt & Nagai-Jacobson, 2002). Most authors define spirituality as a search for meaning and purpose in life, and connectedness with self and others, nature, or some higher being (Asgeirsdottir et al., 2013; Buck, 2006; Buck & McMillan, 2008; Delgado, 2005; Tanyi, 2002). An individual personally chooses a spiritual connection which may or may not be limited to some higher power, supernatural or omnipotent (Tanyi, 2002). It could be one’s connectedness to oneself, to the metaphysical, to the transcendent, and a unifying principle in the universe (Burkhardt, 1989; Burkhardt & Nagai-Jacobson, 2002), connection to the divine or sacred (Alcorn et al., 2010) or to the world and others (Tanyi, 2002). According to Sinclair, Pereira, and Raffin (2006), spirituality is a chord that binds humanity together. These connections can be reflected in our relationships—with family, friends, relatives, or the overall community—that inspire us to achieve our optimal being (Sherman et al., 2005) and promote our self-awareness (O'Brien, 2014).

Several authors have also defined spirituality as a journey towards integration or wholeness (Meraviglia, 1999; O'Brien, 2014). Spirituality integrates and brings harmony to all human dimensions such as body, mind, and soul (Malinski, 2002; Meraviglia, 1999). Spirituality is the “glue” that keeps together all other dimensions of humans—physical, psychological, social, and cultural (Malinski, 2002).

Spirituality has also been defined as an experience of the transcendent i.e. beyond self, everyday living, and suffering (Buck, 2006; Khorami, Markani, Yaghmaei, & Khodayari

Fard, 2013; Nolan et al., 2006; Vachon, 2008; Weathers, McCarthy, & Coffey, 2015; Yuen, 2007). The transcendent experience can be intrapersonal (within oneself), interpersonal (with others or the environment), or transpersonal (with the unseen or the sacred). For some individuals, it is a metaphysical or mystical experience which is often difficult to describe in words (Sessanna et al., 2007).

Spirituality is a continually evolving concept in health and nursing literature. Some authors believe that spirituality should be defined within contextual and cultural boundaries (Cohen et al., 2012; Sessanna et al., 2007), whereas others believe that spirituality goes beyond cultural and religious boundaries (Delgado, 2005). Thus, there is no consensus on a single definition or view around spirituality. This makes it difficult for a novice researcher to clearly understand and articulate the phenomena of spirituality (Berry et al., 2011; Cohen et al., 2012; Moberg, 2010). Most literature around spirituality comes from a western context and carries a Judeo-Christian perspective (Sessanna, Finnell, Underhill, Chang, & Peng, 2011). Very few studies about spirituality were found in the eastern context and among other religions in the world. Therefore, for the purpose of this research, I will use a definition that reflects a comprehensive understanding of the term spirituality. Elaborating on that definition, Puchalski et al. (2009) write that “spirituality is an aspect of humanity that refers to the way individuals seek and express meaning and purpose, the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred.” This definition was developed at a consensus conference in California as part of the National Consensus Project for Quality Palliative Care. Palliative care leaders from nursing, medicine, and other health professions participated in the conference. They all mutually agreed to use this particular definition of spirituality for palliative care purposes.

Spirituality and Healing

As discussed earlier, spirituality is a universal phenomenon. Every human experiences spirituality and demands spiritual wellbeing. Thus, it is imperative to understand the history of the meaning of spirituality and its relationship to healing. Health and healing were viewed within the spiritual domain well before the Western modern medicine era (Delgado, 2005). Health was defined as a harmony among body, mind, and spirit (O'Brien, 2014). In societies with animistic theologies, both in the eastern and western parts of the world, people would go to a priest or a shaman to restore harmony and balance essential for health and healing (Delgado, 2005). Meehan (2012) reports that 7000-year-old images of nurses from the Indo-European era symbolize the spirit of care and protection of human life. Also, similar images from Greek mythology, which are 5000 years old, show nurses giving compassionate care to sick and injured people (Meehan, 2012). Across seven millennia, spirituality was the principle focus of nursing and healthcare in different cultures (Tyler & Raynor, 2006).

Technological advancements in the modern medicine era brought rapid changes to healthcare delivery and shifted the focus of care from a service-oriented model to a technological cure-oriented model (Puchalski, 2001). In other words, the approach to healthcare became more mechanized than humanistic. Healthcare personnel started to give more emphasis to the physiological aspects of care instead of the emotional and spiritual aspects. However, these old concepts of health and healing are now re-emerging rapidly and gaining popularity within healthcare disciplines (Cohen et al., 2012). Scholars and practitioners in various health disciplines are now advocating for a humanistic and holistic approach to health and healing within which spirituality is a vital aspect of care in health (Egan et al., 2011; Pattison, 2013). Spirituality and spiritual care have now been recognized in academia, practice, research, and policy (Chiu, Emblen, Van Hofwegen, Sawatzky, &

Meyerhoff, 2004). Healthcare disciplines such as medicine, nursing, psychology, social work, and occupational therapy have introduced spirituality as part of their care frameworks (Puchalski et al., 2009; Unruh, Versnel, & Kerr, 2002).

Research studies have shown that spirituality has a significant impact on an individual's wellbeing. It allows individuals to connect with the world and build relationships (Tanyi, 2002) and brings transcendent values of love, faithfulness, generosity, and selflessness (Eliason et al., 2010). These attributes of spirituality engender a sense of inner peace, wellbeing, contentment, and serenity (Cohen, et al., 2012; Delgado, 2005; Isgandarova & O'Connor, 2012; Narayanasamy, 2007). Swinton and Pattison (2010) assert that spirituality is the guiding force for every human and is a source of power and energy. This power and strength usually develop after an experience of illness or suffering and often result in a new appreciation of life and death and bring personal and spiritual growth (Ando et al., 2010; Bash, 2004; Deal, 2011; Malinski, 2002). Spirituality changes an individual's perception of reality and transforms certain values and goals. This transformation provides positive experiences, peace, tranquility, and comfort during times of hardships, physical difficulties, or health deterioration of old age or suffering from a life-threatening illness (Delgado, 2005; Delgado-Guay et al., 2013; Reed & Rousseau, 2007). It has been commonly observed that people with a strong spiritual outlook are better able to cope with their difficulties and are often more resilient (Egan et al., 2011). Spirituality is an important domain of health and therefore, should be considered as a powerful resource while providing holistic care to patients and their families, especially in the palliative care setting (Puchalski, 2013).

Spirituality from an Islamic Perspective of Health and Healing

The study was conducted in Pakistan, where the majority of people are Muslims; that is, they follow Islam as a religion. Islam teaches that there is only one God, and that the

Prophet Muhammad (peace be upon him) is God's last messenger. Muslims refer to the holy book, the Quran, for their guidance. There is a need to understand spirituality and its relationship to health and healing as per Islamic principles, values, and beliefs. Spirituality has existed within the Islamic principles of health and healing for centuries. One of the attributes of God in Islamic literature is Shafi (the one who heals or cures). Quran Verse 26:80 says: "And when I am ill, it is He who cures me." Also, one of the names of Prophet Muhammad (peace be upon him) is Shaf or Shafeen, which means Healer. Health is seen as a harmony between mind, body, and spirit (Ramezani, Ahmadi, Mohammadi, & Kazemnejad, 2014). Jafari, Loghmani, and Puchalski (2014) report that many Muslim scientists and philosophers have shown positive relationships between spirituality, health, and healing. During the 10th century, Muhammad ibn Zakariya Razi, a Persian Muslim philosopher, believed that there was a strong relationship between physical and spiritual wellbeing. Another famous Muslim physician and philosopher, Ibn-Sina, also introduced the concept of holistic care in his famous book, Al-Canon fi al Tibb (the Canon of Medicine). The work of both these authors reflect the significant role of spirituality in Islamic medicine and concepts of care. Jafari et al. (2014) reported that in the late 19th and 20th century, these concepts were neglected and not given due importance in medicine.

Little consensus exists among Muslim scholars as to how the concepts of spirituality and religion relate to each other. Rassool (2000) believes that spirituality is meaningless without religious thoughts and performances. However, in some of the recent reports by Muslim authors and in research studies in Muslim countries, spirituality is understood as a broader concept than religion (Jafari, Loghmani & Montazeri, 2012; Rahimi, Anoosheh, Ahmadi, & Foroughan, 2013). According to Islamic principles, all humans are spiritual beings and it's only the spirit that is immortal. There is a strong belief in life after death. Thus, care of the spirit and spiritual values are of the utmost importance to all Muslims

(Cheraghi, et al., 2005; Harford & Aljawi, 2013). Of all the dimensions in Islam—physical, social, emotional, psychological—spirituality is one of the most important human dimensions (Ramezani, Ahmadi, Mohammadi, & Kazemnejad, 2014). According to Islamic principles, spirituality gives meaning and purpose in life, and is reflected in one's connectedness and relationship to self, others, and God (Rassool, 2000). It is also a way to achieve transcendence (Isgandarova, 2012). Religion provides a road map to achieving one's spiritual goals. As per Islamic principles, adherence to religious beliefs and practices, altruistic values, selflessness, and service to others are common expressions of an individual's spirituality. The ultimate goal of every Muslim's life is transcendence of the soul and being with God (Hatamipour, Rassouli, Yaghmaie, Zendedel, & Majd, 2015). Thus, spiritual values and beliefs carry a high value in every Muslim's life. To achieve God's blessings, service to humanity (Huooqul Ibaad) is the second most important principle after having complete faith in God ((Haqooqu Allah). Family and community needs often take precedence over individual needs. Family caregiving is a blessed task, a spiritual and enlightening experience (Ahmad, 2012, Khan, 2017). A few studies conducted among Muslim population have reported spirituality as a source of strength and coping during illness or any suffering experience (Cheraghi et al., 2005; Isgandarova, 2012; Rahimi et al., 2013). However, no studies can be found that focus specifically on the experiences of spirituality among Muslim family caregivers.

Culture and Spirituality

Spirituality is deeply rooted in culture (Jafari et al., 2014) and integrated in our everyday lives as an important facet of our existence (Pike, 2011). Palliative care brings multiple spiritual and existential concerns which are influenced and guided by our cultural values, thoughts, and actions (Abudari, Hazeim, & Ginete, 2016; Mayer & Viviers, 2014; Selman, et al., 2014). Rather than taking an essentialist view of culture, this study viewed

culture from a constructivist perspective that appreciates the diversity within cultural groups rather than limiting it to race and ethnicity. Culture was defined as a dynamic relational process of shared meanings or symbols that originate through social interactions among individuals (Carpenter-Song, Nordquest Schwallie, & Longhofer, 2007). Human life and health was understood as a whole rather than the product of specific behaviors and beliefs (Garneau & Pepin, 2015). It is well documented in the literature that the shared meanings and interpretations that family caregivers assign to their experiences of spirituality are influenced by their own personal values and belief systems, societal structures, socio-historical circumstances, and inner and outer constructions of self and others (Fang, Sixsmith, Sinclair, & Horst, 2016; Mayer & Viviers, 2014). Hence, it was assumed that the experiences of spirituality would be embedded within cultural and societal values and would provide important context for the findings.

Expressions of Spirituality

Spirituality can be expressed in several ways. The expressions of spirituality are often influenced by personality traits, developmental processes, values, belief systems, environment, and culture (Johnstone et al., 2012; Pesut, 2008). A person can express spirituality through religious and non-religious practices (Koenig et al., 2001; Tanyi, 2002). The various ways to express one's spirituality may include practices such as prayers, meditation, nature walks, community participation, and yoga (Anandarajah, 2008), showing love, being present, listening, and communication (Egan et al., 2011). In addition, art, music, literature, dance, drama are also forms of spiritual expression (Delgado, 2005). These spiritual expressions allow family caregivers to meet and understand their own and others' spiritual needs and also guide their caregiving decisions and actions (Egan et al., 2011). Studies have indicated religious rituals, recitations, and prayers as commonly used spiritual

expressions among different faith communities (Ahmad, 2012; Dedeli, Yildiz, & Yuksel, 2015; Rahimi,et al., 2013).

Research Studies on Spirituality and Family Caregiving in Palliative Care

An integrative literature review was conducted to examine spirituality and family caregiving in palliative care using various databases such as MEDLINE, CINAHL, EMBASE, PSYC Info, and ATLA Religion. Inclusion criteria defined for the search strategy were studies on spirituality conducted with family caregivers (parents, spouses, relatives, or friends) caring for an adult (age>18years) with a life-threatening illness or advanced stage disease, in a hospice or palliative care setting. To gain a wide understanding of spiritual needs and experiences of family caregivers, the search was not limited to any geographical region, culture, religion, or ethnic group. Both theoretical and empirical articles using quantitative, qualitative, Delphi, and mixed methods research designs were included in the search. For feasibility purposes, only the studies reported in English were used. Studies referring to pediatric populations and those focusing exclusively on spiritual care/needs of formal caregivers such as doctors, nurses, and other allied health care professionals were excluded. Various filters were used to minimize the number of articles, such as removing duplicates, foreign language other than English, and publication dates. With the assistance of a librarian, the following key search terms were used to locate the articles: palliative, terminal, end of life, advanced/late stage illness or life limiting illness, palliative care, hospice care, long term care, terminally ill patients, death and dying, spiritual or religious/religion, caregiver/caregiving, family, spouse or husband or partner or wife, mother, father, parents, relative, friend, pastoral or faith or soul or Muslim or Islam or Judaism or Jewish or Christian or Buddhism or Hindus or Sikh. The search terms were recorded for review purposes and for maintaining transparency of the selection process. The databases revealed a total of 450 articles from various sources such as academic journals, books,

magazines, dissertations, and non-print sources. In addition to searching the databases, I conducted hand searches using various relevant articles to look for other articles specific to the spiritual experiences of family caregivers in palliative care or at the terminal/advanced stages of illness. Articles written in English and published from 2000-2016 were used. Forty-nine peer-reviewed studies were selected which were relevant and pertinent to my research. Some articles included in the search discussed the positive aspects of family caregiving and thus, contained several attributes of spirituality.

The literature review revealed that although some of the studies showed family caregiving pressures, stressors, and burdens, few focused on the rewarding and/or meaningful experiences that family caregivers had while caring for their terminally ill family members. Family caregivers experienced caregiving as an opportunity to relive their relationships (Wong, Ussher, & Perz, 2009), enhance their sense of connectedness, and provide new directions towards their own life goals and aspirations (Jo, Brazil, Lohfeld, & Willison, 2007; Park, Edmondson, Hale-Smith, & Blank, 2009; Weitzner, Haley, & Chen, 2000). Additionally, family caregivers found personal growth (Caserta, Lund, Utz, & de Vries, 2009; Thombre, Sherman, & Simonton, 2010; Wong et al., 2009), a time of closeness, reflection, and enhanced family interactions (Kristjanson & Aoun, 2004), and better self-acceptance (Salmon, Kwak, Acquaviva, Brandt, & Egan, 2005). Family caregivers also reported increased satisfaction and a sense of accomplishment (Koop & Strang, 2003), positive views of their roles (Hudson, 2004; Hudson, 2006), strengthened relationships, and changes to their worldview (Mok, Chan, Chan, & Yeung, 2003). These positive family caregiving experiences demonstrate several attributes of spirituality. Most of these studies were quantitative in nature; several aspects of caregiving were measured on predefined scales rather than examined or interpreted in depth. Most of these studies presented general characteristics of positive caregiving and very briefly explained spirituality aspects of family

caregiving and how these aspects shape the family caregivers' daily caregiving experiences, actions, or practices or how spirituality contributes to their overall lives.

Few studies were found that specifically talked about spirituality among family caregivers in the palliative care setting. Studies reported that engaging in spirituality was a rewarding experience and a powerful coping resource during end-of-life care. Penman et al. (2013) examined the lived experiences of patients (n=4) and family caregivers (n=10) at terminal stages of illness and found that engaging in spiritual practices was rewarding for both patients and caregivers. Engaging in spirituality brought a sense of meaning and compassion to the family caregivers' caregiving practices, enhanced their bonding with the patients, allowed them to cope, and framed their caregiving experiences as rewarding. Bernard et al. (2014) reported similar findings while examining the role of spirituality of family caregivers (n=14) at EOL among Black community in Nova Scotia, Canada. Spirituality and spiritual actions such as prayer, expressing one's faith, reading the Bible, singing hymns, and being in the presence of friends and others all helped these community members to cope with the stressful situations they faced while giving care to a dying family member. Family caregivers found that spirituality was a powerful resource for coping while in the midst of providing palliative care and helped them to deal with difficult situations, loss, and grief. Nonetheless, the findings were limited, because the study only looked at family caregivers who belong to a church or had publicly expressed their faith.

Several studies looked at people who were actively practicing their faith. For these people, as with those in the Nova Scotia study, attending religious rituals and prayers were a major resource for coping and strength to deal with the challenges of caregiving at end of life. Religious practices enhanced family caregivers' relationships with the sacred and others, improved a sense of satisfaction with life and helped them to endure challenges and miseries (Delgado, 2005; Ferrell & Baird, 2012; Hodge & Sun, 2012; Pargament et al., 2003). Prayers

served as a means of socialization and provided a sense of connectedness with others and the community (Hodge & Sun, 2012; Paiva et al., 2015; Ross & Austin, 2015).

Cultural and societal values have also been reported to influence families' caregiving actions, meanings that the families assigned to these actions, and the families' experiences of spirituality. Multiple studies have showed that culture plays a significant role in mediating the stressful effects of caregiving and helps family caregivers to find their role rewarding (Delgado-Guay et al., 2013; Sloss, Lawson, & Burge, 2012; Spitzer, Neufeld, Harrison, Hughes, & Stewart, 2003). Delgado-Guay et al. (2013), in a survey of 43 family caregivers from the Judeo-Christian community, found that engaging in spirituality through family relationships and participating in various community and other religious activities served as a source of strength and coping for family caregivers. Similarly, in a study that looked at HIV/AIDS patients, Aga, Nikkonen, and Kylmä (2014) found significant socio-cultural influences on families' caregiving actions and the practices of family caregivers. However, their study mainly focused on exploring the socio-cultural constraints of caregiving rather than examining the overall influence of culture on spirituality.

A small number of studies reported that spirituality helps family caregivers to transcend both their known and unknown fears while caring for their dying family members (Penman & Ellis, 2015). Family caregivers reported that talking about spirituality provided comfort, peace, strength, and support. It enabled them to rethink life issues and their quest to connect with their religion (Paiva et al., 2015). Sterba et al. (2014), in their study of African American breast cancer patients and their family caregivers, found that having a positive spiritual outlook towards illness guided illness management efforts and facilitated recovery.

Research studies showed that spirituality plays a significant role in family caregiving. It helps family caregivers to cope with caregiving demands, transcend known and unknown fears of caregiving, and find the strength to manage with day-to-day challenges of caregiving

at end of life. However, most of these studies lacked a clear definition of spirituality and explanation of its several dimensions. The religious dimension was given priority over several other dimensions of spirituality such as personal or existential. The majority of the studies looked at people who practiced their religion or faith regularly. Prayers and other religious rituals were considered primary expressions of spirituality whereas other expressions of spirituality were not explored or interpreted in detail. Individuals in all cultures experience spirituality whether or not they belong to any religious group (Bernard et al., 2014). The meanings or interpretations of spirituality vary in different cultures and are not bound by or limited to specific religions. To generate a clear, well-defined description and an in-depth interpretation of experiences of spirituality and of spirituality's potential influence on family caregivers' practices during palliative care within a cultural context, more studies are needed.

Spiritual Needs and Resources of Family Caregivers during Palliative Care

Family caregivers exhibit several spiritual needs and concerns while caring for their family members at EOL (Chang et al., 2012; Edwards, et al., 2010; Ross & Austin, 2015; Skalla, Smith, Li & Gates, 2013). Spiritual needs are not limited to religious needs such as religious rituals and practices. Hermann (2007) argues that spiritual needs include all those things that an individual wants or requires to find meaning, purpose, and value in life. She identified six spiritual needs at end of life. These include the need for religion, companionship, and involvement and control; the need to finish business and experience nature; and the need for a positive outlook.

Research has shown that identifying and addressing spiritual needs and resources of family caregivers in palliative care can support these caregivers in their search for meaning, and nurture their inter, intra, and transpersonal connectedness and enhance their spirituality (Taylor & Mamier, 2005). Family caregivers found their caregiving experience rewarding if

their spiritual needs were met (Ross & Austin; 2015). On the other hand, if their needs and concerns were not addressed adequately, they were likely to experience spiritual pain and spiritual distress (Delgado-Guay et al., 2013). Identifying and meeting spirutal needs can promote family caregivers' spiritual wellbeing, quality of life, comfort, and peace. Morever, it can reduce feelings of loneliness and isolation in palliative care settings (Ross & Austin, 2015). Spiritual needs are significant, but they often remain unidenitfied or ignored or are given low priority in a palliative care setting (Jafari, Loghmani, & Puchalski, 2014). Family caregivers are often seen struggling with their spiritual and existenital needs. They need someone to talk to and listen to them, and they expressed the need for support and sensitivity from staff (Ross & Austin, 2015; Skalla, et al., 2013).

Family, friends, and relatives are essential spiritual resources for family caregivers (Sherman et al., 2005). Family, relatives, and friends serve as powerful social supports as they assist with activities of daily living, run errands, manage illnesses, and maintain household responsibilities. These people can instill positive energy and encouragement with their love, care, and compassion (Burton et al., 2012). Studies report that family caregivers described their spirituality not as the ability to perform religious practices and rituals, but as being with friends and family, laughing, and seeing the smiles of friends (Buck & McMillan, 2008; Chang et al., 2012; Tan, Wilson, Olver, and Barton, 2011). Tan et al. (2011) defined spirituality as a web of relationships. Family caregivers' spirituality was reflected in relationships with families and loved ones. The acts of caregiving and fulfilling the desires and wishes of the ill family member were experienced as spiritual (Tan et. al., 2011). In a meta-study of qualitative research on spirituality and its potential role at the end of life, Edwards et al. (2010) found that spirituality is principally expressed in terms of relationships rather than just meaning-making. Relationships are an integral part of spirituality and if these relationships are broken, it may cause spiritual distress. Being present, journeying together,

listening, connecting, creating openings, and engaging in reciprocal sharing are some of the ways to express and achieve one's spirituality.

Most studies discussed above clearly indicate that family caregivers have multiple spiritual needs and concerns that are integral to the family caregivers' experiences of spirituality. Spiritual support was not limited to religious rituals but can be expressed as showing love, hope, and maintaining relationships with family and friends. Family caregivers whose spiritual needs were fulfilled were better able to cope, possessed a sense of acceptance towards death, and tended to have more positive outcomes (Bernard et al., 2014; Paiva et al., 2015). Conversely, family caregivers whose spiritual needs were not met experienced spiritual pain and distress which affected their wellbeing and quality of life (Delgado-Guay et al., 2013). Most studies in the literature measured spiritual needs and resources using quantitative scales. A richer and deeper understanding of spiritual needs and their contribution in day-to-day family caregiving experiences is needed to help us to develop supportive family caregiving interventions in a palliative care setting.

Role of Spirituality in Family Caregivers' Healthcare Decision Making

The literature also suggests that spirituality influences an individual's or family's healthcare decision-making. Several authors encourage acknowledging an individual's or family caregiver's spirituality while making decisions or planning care, especially at end of life and in palliative care settings (Jaul, Zabari, & Brodsky, 2014; Mollica, Underwood, Homish, Homish, & Orom, 2016; Riffin et al., 2015). Family caregivers often turn to their faith and spirituality while making treatment decisions or choices for advanced directives and advanced care planning at end of life (Balboni, Balboni & Fitchett, 2015). Johnson et al. (2016) examined the spiritual and cultural perspectives on end-of-life care decision-making using focus group discussions. They found that faith and beliefs have a significant impact on decision-making in palliative and hospice care settings and that there is a strong need to

improve communication between family caregivers and healthcare professionals around these topics in such settings. The study suggested that knowing about the faith and beliefs of patients and their family caregivers help healthcare professionals to facilitate sensitivity to care and promote discussing preferences when making health-related decisions. Similar findings were reported by Sessanna (2008) using a grounded-theory approach to look at spirituality and decision-making among older adults at end of life. Sessanna also found that spirituality was involved in everyday life decision-making and played a significant role in the lives of family caregivers when they were making treatment choices and establishing preferences about end-of-life care. Similarly, Koenig (2005) in her study also found that family caregivers family caregivers relied on spirituality to resolve ethical dilemmas during their daily caregiving actions. In her study, family caregivers described spirituality as an overall philosophy of life that included both religious and non-religious values and beliefs. These studies clearly suggest that healthcare professionals should generate value-based discussions that can enable family caregivers to use their spirituality while facing ethical dilemmas or making ethical decisions during caregiving. Patients and families often have a need to discuss their concerns and feelings (Balboni et al., 2015). Nonetheless, it has been reported that healthcare professionals often do not feel comfortable talking about spirituality with patients and families. Major reasons involve time constraints, individual attitudes, organizational and cultural barriers, increased workload, lack of understanding and training of spirituality in different contexts (Balboni et al., 2015; Khan, 2017; Meehan, 2012; Punjwani et al., 2015; Ruder, 2013; Tiew & Creedy, 2010). Thus, discussions around spirituality often remain a low priority which further limits the provision of holistic care and support to both patients and families in palliative care settings.

Summary and Conclusion

The literature review shows that spirituality can be a significant resource for families

to endure loss, grief and suffering as well as enhance their decision-making and coping abilities during palliative care. However, little is known about how family caregivers experience spirituality in their day-to-day caregiving situations, especially among Muslim and Asian populations. Most studies found in the literature focus mainly on the overall satisfaction of family caregivers, and their psychosocial, informational, and emotional needs during care. Little attention seems to have been given to experiences of spirituality and spiritual needs of family caregivers in the palliative care setting. A lack of definitional clarity about the term "spirituality" and other related terminologies was found in the majority of studies. The definitions and meanings of terminologies such as religion, religiousness, spirituality, spiritual needs, and spiritual care were unclear, confusing, and overlapped with each other. Most studies focused on a religious dimension rather than exploring the personal and existential dimensions of spirituality.

The literature review calls for an in-depth contextual understanding of the experiences of spirituality among family caregivers and how spirituality contributes to their day-to-day caregiving practices in palliative care. The experiences of spirituality are influenced by multiple cultural and societal aspects such as familial roles, relationships, gender, one's individual values, and socio-economic factors. An in-depth exploration of spirituality in relation to these aspects is therefore needed to assist families in their caregiving practices in palliative care setting. This study will extend further clarity regarding the spirituality of family caregivers, identify how spirituality shaped their caregiving practices, and determine the influence of culture and religion on their experiences of spirituality in a hospice palliaitve care setting in Pakistan.

Chapter Three: Methodology

Spirituality and family caregiving are highly complex clinical phenomena, and little has been learned about either, especially as concerns the family caregiver population during palliative care. No studies were found on spirituality and family caregiving in palliative care from a Pakistani context. The experiences and expressions of spirituality and family caregiving are contextually driven and entail multiple meanings that shape caregiving actions and practices of family caregivers in palliative care. To examine and interpret those meanings of spirituality and family caregiving in the hospice palliative care setting in Pakistan, I decided to use a qualitative approach, Interpretive Description (ID).

This chapter provides a methodological framework of the study and includes a brief overview of the ID approach with its philosophical, epistemological, and ontological underpinnings. It also shares methodological and ethical considerations undertaken during the study.

Interpretive Description as an Approach to Inquiry

The ID approach was developed by Sally Thorne, Sheryl Reimer Kirkham, and Jane MacDonald-Emes in 1997. It is a relatively new and evolving qualitative research approach within the discipline of nursing. ID is neither a formal method nor is it a prescriptive, circumscribed sequence of steps that will reliably lead to new discoveries (Thorne, 2016). Instead, the goal of the ID approach is to provide clarity about complex experiential questions from our daily practice setting, questions that cannot be readily answered by traditional qualitative methodologies (Hunt, 2011). Its focus is on actual clinical practice goals and building upon what is known and needs to be known based on our own clinical wisdom and available empirical evidence (Thorne, 2016).

ID was chosen to study the complex phenomena of spirituality and family caregiving in depth, to go beyond the evident and search for what else might be there (Thorne, 2016).

Moreover, to generate new knowledge and insight based on subjective, experiential, tacit, and patterned aspects of human health experience and behaviors to shape new inquiries applicable to practice (Thorne, 2016). The ID approach allows the researcher to understand and address complex phenomena, helps to develop a contextual understanding of these concepts, and provides a guide to critically analyze and interpret the existing empirical knowledge around these concepts (Thorne, 2016). The purpose of using the ID approach in this study was to generate experiential and contextual knowledge regarding spirituality among family caregivers caring for their family member in a hospice setting. The experiential and contextual knowledge generated from the study promoted an in-depth understanding of spirituality among family caregivers and will help healthcare professionals to acknowledge and support the spirituality of family caregivers and integrate spiritual care aspects into palliative care settings in Pakistan.

Basic Philosophical, Epistemological, and Ontological Tenets of Interpretive Description

The philosophical tenets of ID are influenced by naturalistic inquiry which implies that both researcher and research participants are engaged in a natural setting of inquiry and generate, in this case, a shared understanding and knowledge about the phenomena of spirituality and family caregiving. A contextual subjective and experiential knowledge regarding the experiences of spirituality were generated and shared among the researcher and research participants. There were commonalities as well as individual expressions of variance within a common shared experience of spirituality (Thorne, 2016). According to ID approach, a priori theory cannot encompass multiple realties, but recognizes instead that the theory that will help clarify the phenomenon of spirituality must emerge from or be grounded in that phenomenon (Thorne, 2016). The generated knowledge in this case will serve as a

fundamental source of clinical insight regarding spirituality in the palliative care setting in Pakistan.

From an epistemological point of view, the ID approach affirms that the reality doesn't exist "out there" as an objective entity. It should only be understood through an individual's subjective experiences, which are often socially constructed (Thorne, 2008). Interpretive description does not believe in generating "Truth" but a "tentative truth claim" is constituted based on what is common about the phenomena being studied (Thorne, Kirkham, & O'Flynn-Magee, 2004). Based on this principle, the subjective experiences of participants in the study constituted a "tentative truth claim" to inform our clinical reasoning and broaden our insights about spirituality and family caregiving practices, enabling us to make realistic decisions in the palliative care setting in Pakistan. Furthermore, ID helps us understand the complexities involved in our day-to-day practice settings and guides us in developing sensible and applicable interventions in our real practice settings (Thorne, 2016).

The ontological stance of the ID approach is grounded in interpretivism, suggesting that there are multiple shared and constructed realities (Guba & Lincoln, 1994) that are often influenced by contextual and cultural considerations. Literature supports that family caregivers' experiences of spirituality, and their caregiving actions and practices, are influenced by their cultural and socio-political environment (Jafari et al., 2014; Mayer & Viviers, 2014). The spiritual meanings or realities assigned by the people are commonly associated within their social context and are influenced by various factors such as race, class, gender, language, and culture (Dahnke & Dreher, 2011). As a researcher, my major focus was on understanding (interpreting) the meanings, purposes, and intentions (interpretations) people assigned to their own experiences, actions, behaviors, and interactions with others within their contexts rather than focusing on the descriptions of the reality coming from the human consciousness (Thorne, 2008). The ID approach informed an

in-depth contextual understanding about spirituality and family caregiving which would presumably be acceptable by the healthcare community in Pakistan and would be readily applied in palliative care settings in Pakistan.

ID offered an inductive approach toward understanding the phenomena being studied. The data analysis process involved inductive reasoning, constant engagement, testing, challenging preliminary interpretations and, finally, conceptualizing to understand the phenomenon (Thorne, 2008). Using the ID approach, I kept myself continually engaged with the data to discover associations, relationships, and patterns within the phenomenon. I constantly endeavored to unfold the elements of experience and articulate claims for those interpretations to create in-depth knowledge and understanding (Thorne, 2008). I exercised a constant process of inherent reflective reasoning and continually searched for underlying meanings within the descriptions (Thorne et al., 2004). To establish an "interpretive turn," I constantly sought beyond what was "self-evident" to see what else might exist to create new insights for the inquiry and its application to the practice (Thorne, 2008). Eventually, a thematic or integrative description was made explicit within the interpretations (Thorne, 2008).

The ID approach explicitly recognizes and capitalizes on the researcher's role in shaping the nature and outcome of the inquiry. ID acknowledges the experiential knowledge of the researcher and calls for an intersubjective construction of knowledge between the researcher and participants (Thorne, 2016). Thorne (2016) suggests that the inter-subjectivity of the researcher and participants in the research facilitates the smooth application of research outcomes in the practice setting. The ID approach enabled me to generate insightful meanings and interpretations including multiple patterned aspects of experiences of spirituality among family caregivers. It is hoped that the findings generated will extend the understanding and significance of spirituality in family caregiving practices in a Pakistani

context. The findings will also potentially assist healthcare professionals to develop culturally sensitive and spiritually based family interventions in palliative care settings in Pakistan.

Study Setting

The study was conducted in Karachi, one of the major cities in Pakistan, with a population of 23.5 million. There are only two facilities in Karachi that provide hospice and palliative care services, mainly to advanced-stage cancer patients. Those are the Bait-ul-Sukoon Cancer Hospital and Hospice, and The Medical Aid Foundation and Rahat Kada Hospice. Both hospice facilities are non-profit and run as charitable institutions. At the time of the study, only one facility, Bait-ul-Sukoon Cancer Hospital, was functional and the other facility was temporarily closed for construction. Therefore, this hospice was chosen as a study setting. In addition, I had worked in this setting when I was a clinical faculty member in Pakistan and used the facility as a clinical placement for nursing students from the Aga Khan University in Karachi. I was familiar with the hospice setting, work spaces, medical and nursing staff, and their care routines and was therefore comfortable being in the hospice as a researcher.

Established in 1999, Bait-ul-Sukoon (House of Peace and Contentment) is a 45-bed cancer hospital with a hospice care facility for advanced-stage cancer patients. The facility is funded through public and private charities and donations. Healthcare professionals working in the facility include doctors, nurses, psychologists, social workers, and pharmacists. The average occupancy ratio is 95-98% per year. Nearly 38% are advanced stage cancer patients and require hospice support. The average length of stay for patients requiring hospice support is two weeks to a month. These patients usually die in the facility. The nurse-to-patient ratio is 1:20 (Bait-ul-Sukoon Cancer Hospital, 2015). Physical and hygiene care is provided to the patients by their family members in the hospice. Nursing staff administer

medications and infusions, monitor vital signs, carry out physician orders and complete documentation. Most of the patients admitted belong to the low socio-economic class. The facility provides comfort care, meals, and symptom and pain management. However, the facility has a limited supply of morphine and other potent pain medications. Minimal emotional and spiritual support is provided to patients and their families. Low income families living outside the city are also referred here. The care facility provides them with financial support including boarding, lodging, and treatment costs (Bait-ul-Sukoon Cancer Hospital, 2015).

Sampling

The study participants included family caregivers and healthcare professionals. Sampling for family caregivers and healthcare professionals is discussed below.

Family Caregivers

Both purposive and theoretical sampling were used to select the study participants. I included participants who were caring for their terminally ill family members in the hospice and were willing to share their experiences. Theoretical sampling was applied as patterns and themes emerged from the initial data collection and analysis. Based on the emerging data, I added more participants to determine the similarities and distinctions within the data.

Healthcare Professionals

A purposive sampling strategy was used to select healthcare professionals in the study. Healthcare professionals were not the primary participants. Rather, they were included to supplement the data gathered from the primary study participants, the family caregivers.

Sample Size

At the initial stage, I anticipated recruiting 10 family caregivers (n=10) but I ended up including 18 (n=18) in the study. Healthcare provider (n=5) were included in the sample. As the findings and interpretation unfolded, I continued to add family caregiver participants in

the study until I had enough detailed and in-depth information on the topic under my study. To ensure this, I continually referred to the patterns and themes in my data, used my own inherent reasoning and judgement, and consulted my supervisors for their expert opinions (Thorne, 2016). I communicated with my supervisors through regular emails and biweekly Skype calls for additional support and guidance. I shared my reflections and data on the encrypted shared drive of a University of Alberta online server. The drive could only be accessed by me and my supervisors.

Inclusion Criteria for Family Caregivers

Family caregivers included parents, siblings, spouses, children, friends, in-laws, and close relatives who were responsible for providing physical, social, psychological, emotional, and spiritual care for an ill person (Khan, 2012). Included as study participants were those males and females who were 18 years or older, and caring for their terminally ill family member, friend, or relative receiving hospice care. All the study participants could speak Urdu and were willing to share their experiences with the researcher.

To ensure maximal variation in the data, study participants included both male and female family caregivers of different ages, who had different roles and relationships such as spouse, sibling, parents, in-laws, relatives, or friends. As well, caregivers were both working and non-working, had varying lengths of relationship with the ill person, and belonged to different religious and ethnic groups. Maximal variation in the sample added richness to the data and allowed me to look beyond the commonalties or common patterns and find the distinctions or variations within the sample of the data generated (Thorne, 2016).

Inclusion Criteria for Healthcare Professionals

As mentioned earlier, healthcare professionals were not the primary participants in the study but were selected to supplement the data gathered in the study. Healthcare professionals included physicians and nurses who had worked in the hospice setting for at

least one year, could read, write and speak English or Urdu, and were willing to share their experiences with the researcher.

Recruitment of the Participants

I sent a permission letter along with all other information about the study (brief proposal, questionnaire, information letter, consent letters, and flyers for recruitment) to the institutional head in Karachi, Pakistan. I also phoned the head and spoke with him in detail, responding to his concerns and queries regarding the study, study setting, and recruitment of study participants. I then submitted the permission letter, ethical application, and study protocol to the ethical review board of the University of Alberta to obtain ethics approval to conduct the study. Upon reaching Pakistan, I visited the hospice with the permission letter and ethical approval from the University of Alberta Human Research Ethics Board. I conducted an initial meeting with the hospice supervisor to discuss my research plans. I took a tour of the setting and met with the staff in the unit. I also conducted a separate meeting with the staff and shared the intent and purpose of the study. I utilized multiple recruitment strategies to recruit study participants. I shared the eligibility criteria for inclusion of study participants with the staff and sought their assistance to recruit the participants in the study. I made several flyers and posters (in both Urdu and English) that included the information about the study, eligibility criteria, my name, and contact information. I posted the flyers and posters on notice boards both in the male and female units of the hospice. I asked the staff to provide study information to the eligible participants. Those who were willing to participate were then referred to me for data collection. Some family members approached me directly after reading about the study on the flyers and posters. A snowball sampling strategy was part of the initial plan to recruit the study participants but was not needed in the actual setting. Most eligible participants contacted me directly after hearing about the study from the staff, through flyers, or after watching me conduct the interviews in the hospice setting.

As discussed earlier, healthcare professionals were not the primary participants in the study and were contacted to provide additional information in the study. I met and interviewed the staff who were willing to provide data at their convenient time in the hospice setting. Health providers were asked about their own perceptions and views regarding the significance of spirituality, spiritual care, and spiritual support among family caregivers in the palliative care setting. All the participants were informed that their participation was on a voluntary basis.

Data Collection

I conducted face-to-face semi-structured individual audiotaped in-depth interviews to gain rich subjective experiences from the study participants on the phenomena of study (Thorne, 2016). Face- to-face semi-structured interviews allowed me to discuss issues that arose spontaneously during the interview and assisted me in elaborating or clarifying the information that might be important to the participants and might not have been considered initially in the study (Doody & Noonan, 2013). Family caregivers' interviews mainly focused on their experiences of spirituality, meanings in caregiving, spiritual concerns, practices, values and beliefs, and practices during family caregiving. Healthcare professional's interviews focused on obtaining additional information about their own perceptions and views regarding the significance of spirituality, spiritual care, and support among family caregivers in the palliative care setting.

Interview Guide

With the help of my supervisors, I developed two separate semi-structured interview guides, one for family caregivers and one for healthcare professionals (Appendix C & F). I also added probes to the interview guides. I wrote the interview guides in English and then I hired a translator to translate the guides into Urdu. I also formulated two separate demographic sheets: one for family caregivers and another for healthcare providers

(Appendix B & E). The demographic sheets provided information about the characteristics of the participants and assisted me in developing a sampling strategy. Before the interviews, I pilot-tested the interview guides with two family caregivers to ensure that the language and questions were clear and comprehensible. I shared findings from the translated pilot-tested interviews with my supervisors.

Pilot-testing the interview guides helped me to determine how best to approach the subject of spirituality with caregivers. An important finding resulted. I found that if I started the interview with a direct question about spirituality, the participants had a hard time responding. It was also difficult for them to define spirituality. However, when I asked them a general question about family caregiving, they were able to make a connection between those experiences and spirituality. Pilot-testing also enabled me to reflect on my own interviewing process, thus shedding light on my own strengths and weaknesses while conducting interviews with the participants. Additionally, it helped me to develop more insight on how to generate in-depth information from the participants on the topics of spirituality and family caregiving. Based on the findings of these interviews, I made further modifications in the interview guides with the help of my supervisors.

Procedure for the Interview

I read the information script and verbal consent in Urdu language to my participants and recorded simultaneously before starting the actual interview (Appendix A). I encouraged the participants to ask any questions or concerns regarding the study before the interview. I conducted all the interviews in Urdu. I told all the study participants that their participation was voluntary and if they decided to withdraw, they should inform me within three months of data collection. Two family caregivers expressed a need to obtain permission from the family before giving consent for the interview. This need was respected. I provided time for these potential participants to consult with their families before consenting to the interviews.

A total of 28 interviews were conducted with the participants. The total number of interviews included both in-depth interviews and follow up interviews. Some participants were not included in the follow up interviews because their family member had died in the hospice or discharged. They lived far from the city and I was unable to contact them by phone. It appeared that the participants were more comfortable and open in the follow-up interviews, particularly when sharing their spiritual experiences of family caregiving. Some of the follow-up interviews were more detailed and therefore allowed me to obtain additional clarity and explanations about the initial information that the participants had provided.

I conducted all the interviews with the participants in a separate small room on the same floor where their ill family members were admitted. There were two floors in the hospice. One was assigned to male patients and one to female patients. The interview room was originally a changing room where staff could rest, eat, or offer prayers during their on-call hours. Each day, after asking and being granted permission from the staff, I used the room for family caregiver interviews. The room, which was small, contained a desk, chair, bed, tube-light, and fan. There was an attached bathroom. The room could be closed from inside during the interviews. Most interviews were conducted during the two-hour visiting time in the hospice. During this time, most participants felt comfortable to sit with me and share their experiences while another person was looking after their family member in the hospice. There were some participants who chose to talk with me when family was not around. Before each interview, I showed the room to the participant and asked if they were willing and comfortable having me conduct the interview in this separate, closed room. As their family members were terminally ill, I allowed participants to keep their mobile phones switched on during the interview. I also told them that they were allowed to leave the room if there was any emergency with their family member or for any other reason they deemed important.

I started each interview with an open-ended question about their experiences as a family caregiver. Building on their experiences, I further asked how they perceived spirituality in their caregiving experience. Sometimes, rather than asking directly about spirituality, I used words/questions like "what gives you meaning or purpose in your life or particularly in your caregiving practices; what provides you with a sense of connectedness; how you would describe yourself as a human-being/person? and what are some of the important values, beliefs, and practices in your lives that provide you comfort, peace, and strength? I also added probes and questions to the interview guide as per the flow and direction of the interview. I informed the participants that they could refuse to answer any question during the interview or ask to end the interview at any time, if they felt uncomfortable or distressed. Few participants felt distressed and cried during the interview. I offered a little break to these participants and asked them if they wished to discontinue. Most participants continued the conversation as they felt it was an opportunity to share their experiences and painful feelings and verbalized that they felt relieved after sharing their sorrow and grief with me. After the interview, I gave each participant light refreshments including biscuits and juice.

I did most follow-up interviews within one or two weeks after the initial interview. At the first meeting, I negotiated the preferred day, time, and place for the second or third interviews to further extend the data and clarify codes and emerging themes. The average duration of each initial interview was 30- 60 minutes whereas the average duration of the follow-up interview was 40- 80 minutes. The participants seemed to be more open and comfortable during the follow-up interviews. All interviews were conducted face to face in the hospice setting except two follow-up interviews which were conducted on phone. These participants had left the hospice upon the death of their family member and informed me that they were unable to revisit the hospice as they resided far away from the hospice. An

ongoing verbal consent was taken before each interview, including telephonic interviews. All interviews were tape-recorded for analysis.

As discussed earlier, to obtain additional information and supporting data, I also conducted brief interviews with the healthcare professionals in the hospice. Before each interview, I provided an information letter and obtained a written consent from each healthcare provider (Appendix D). I conducted staff interviews in the staff offices. The average duration of the interview with the healthcare professional was 20-30 minutes. I started each staff interview with a broad open-ended question about their professionals' working experience with the families, followed by specific questions regarding their own values, perceptions, and opinions in relation to the importance of spirituality among family caregivers. I conducted staff interviews in Urdu language. I told the staff that their participation in the study was voluntary and they were allowed to refuse or end the interview at any time, if they felt uncomfortable. At the end of each interview, I provided light refreshments to the staff.

Following each interview, I made separate field notes about the participant's non-verbal actions, emotions, and behaviors as well as about the setting where the data was collected. In my field notes, I recorded the context of all data-gathering episodes and linked those contexts to the phenomena being studied (Speziale, Streubert, & Carpenter, 2011). After every two or three interviews, I wrote self-reflections about my personal ideas, opinions, and feelings regarding the interview process and other observations in the field. Both the field notes and reflexive notes added richness to the data and helped me to gain greater insight into the data and understand it better (Thorne, 2008; Thorne, 2016).

Translation of Data

I used a bilingual approach in the study. I collected the data in the local language, Urdu (source language), and translated into English (target language) for presentation and

written purposes as well as for communicating with a larger community. The transcription and translation began soon after the first interview. Santos, Black, and Sandelowski (2015) state that if the translation process is started soon after data collection, the data analysis between the researcher and translator will be more interactive and the risk of misinterpreting actual meanings during the thematic analysis phase will be minimized. Literature suggests three common approaches to translation for qualitative studies: single, back, and parallel translation. I used the parallel translation approach for my study as suggested by Sutrisno, Nguyen, and Tangen (2014). Parallel translation maintains the accuracy and trustworthiness of the study findings and ensures conceptual and dynamic equivalence in bilingual research (Sutrisno et al., 2014).

I interviewed and hired a bilingual (Urdu and English) research assistant in Pakistan to translate and transcribe the data. We each transcribed and translated the data gathered during the interviews. My research assistant and I then compared and checked both versions of each translated transcript to check for similarities, consistency, and equivalency of words. I then shared all the translated data with the supervisors using a shared drive at the University of Alberta. I received ongoing feedbacks from my supervisors through regular emails and biweekly Skype meetings as discussed earlier.

To mitigate the challenges of translation, we maintained the original source language (Urdu) for original words and quotes that could have lost their actual meaning or cultural interpretation had they been translated into the target language (English). In this way I was able to keep the participants' original meanings and quotes and not risk changing, concealing or losing their real voices (Van Nes, Abma, Jonsson & Deeg, 2010).

Data Analysis

The ID approach continually demands engagement, imagination, and conceptual creativity and does not provide any structured guide for the analysis. Rather it encourages

the researcher to use her/his innate analytic and conceptual capacities to achieve rigorous, credible, and meaningful findings (Thorne et al., 2004). I used an iterative and inductive analysis approach as encouraged by ID design (Thorne, 2016). The literature search that I conducted while formulating the study proposal served as a preliminary framework for data analysis. I began my data analysis at the initial stages of data collection, after the first two interviews with family caregivers as study participants.

After each interview, I downloaded the recorded data and saved the voice files with the date and time of the recording on a separate password-protected folder on the University of Alberta shared drive. I listened to each recording multiple times to obtain a sufficient understanding of the data. As stated on the previous page, my research assistant and I transcribed and translated the data. I then compared both the transcripts and checked for equivalency in the data that we had recorded. In the initial two interviews, there were some inconsistencies in the parallel translation of our transcripts, mostly in terms of the use of word selection for the translation and discrepancies in the way we used English. To rectify this issue, my research assistant and I saw together and thoroughly discussed the discrepancies in the translation before moving to the third transcript. I reminded my research assistant to keep the original words in the source language. I read each transcript multiple times, sometimes while listening to the recording, to understand, reflect, and get the feel of the tone, words, and emotions that the participants used in the interviews while describing their experiences of spirituality. While listening, transcribing, and analyzing the data, I also compared my field notes and reflexive notes. All these strategies helped me to deeply and repeatedly immerse myself in the data. Repeated data immersion prior to beginning coding, classifying, or creating linkages helped me to make sense of what lay beyond the immediate impression of the data and assisted me to locate underlying meanings within the data. At this stage, I started searching for the emerging categories, links, and patterns in the data. I

flagged important pieces of data early in the analysis process and created a "quotable quotes" file as suggested by Thorne (2016), using Quirkos qualitative analysis software.

Rather than seeing individual cases, I looked at the whole data set to search for similarities as well as differences emerging in the data and to search beyond what is self-evident. I continued looking for the emerging relationships and linkages within the data, which provided me further clarity in understanding the data in depth. I continuously explored the following questions: "What am I seeing, why am I seeing that, what is happening here, why this is here, why not something else, what does it mean?" This technique enabled me to look at the alternative angles and perspectives embedded in the data (Thorne, 2016). I continued this mental exercise and tried to find the heuristic "aha!" at multiple times in the analytic process of the study (Thorne et al., 2004). I made analytic as well as reflective notes that included dated collections of thematic lists, questions among cases, and emerging patterns. I used the analytic notes to track my emerging patterns and linkages, identify similarities and differences, and enabled me to find key elements embedded in my data. As new insights, ideas, and observations started to develop, I searched for new literature that might not have seemed important during my initial literature search (Thorne, 2016). Throughout the data analysis process, I regularly shared my data analysis with my supervisors. Once a month, I made presentations to share my preliminary data analysis with my supervisors and sought their guidance and assistance on my emerging categories, themes, patterns, and linkages within the data. They assisted me in refining my data analysis process and guided me in each step of my data analysis.

As the findings generated new angles or discoveries, I looked for additional literature from other disciplines to see what other new, similar or opposing ideas or perspectives existed within the themes arising in my own study. This strategy helped me to further advance my interpretations, capitalize on my existing data, and add new insights to the

existing knowledge from a variety of diverse perspectives and disciplines. I continued to search for what was already known, to see what else might be there to achieve an enriched understanding of the data gathered. The process of ongoing reasoning and constant engagement with the data, searching for new and opposing ideas from the literature or clinical experts, continually challenged my emergent theorizing and assisted me in refining the theoretical linkages within my data. It also helped me to bring conceptual creativity and the heuristic "aha" to the final product of analysis (Thorne, 2016).

As discussed earlier, throughout the data analysis process I made separate field notes to record and link the context of all data-gathering episodes to the phenomena being studied. Field notes assisted me in retracing themes or abstractions developed in the findings and ensured that the analytic directions were defensible (Speziale et al., 2011). Likewise, these notes also helped me to gain new insights and an in-depth understanding of the experiences of the participants in a contextual manner that could be applied in similar practice settings. Simultaneously, I made notes to help me reflect on my opinions, feelings, intuitions, and biases during the process of data collection and data analysis. These notes gave further richness to the data and enhanced the credibility of my study (Tracy, 2010).

Using appropriate analytical processes such as constant engagement, ongoing critical questioning, continuous reflection, and coherent reasoning while interpreting the findings prevented me from making analytic errors like premature closure, over-determination of patterns, misinterpretation of frequency, and over-inscription of myself in the data analysis process (Thorne, 2016). Additionally, ongoing consultation, input, and feedback from my supervisory committee helped to reduce errors in my findings and contributed to generating an enriched and in-depth interpretation of the phenomena being studied. The final interpretative account, which I generated while using appropriate and rigorous analytic

techniques, is a rich experiential document of spirituality and family caregiving that will potentially guide and inform the palliative practice discipline in Pakistan.

Steps to Ensure Rigor

Ensuring rigor is an essential consideration in any qualitative inquiry. The steps to maintaining rigor vary somewhat in the ID design as compared to other qualitative approaches. I used the following steps to ensure rigor in my study as recommended by Thorne (2016). These steps included epistemological integrity, trustworthiness and credibility, preventing analytic errors, and moral defensibility.

Epistemological Integrity

There is a paucity of palliative care and understanding of spirituality in the Pakistani healthcare system. Family caregivers need compassionate care and spiritual support while providing care to their terminally ill family members in a hospice setting. My research questions are relevant to the needs of palliative care in Pakistan and well-grounded in the literature. The research questions address spirituality of family caregivers and deliver the voices of family caregivers to enhance palliative care in the hospice setting. My research questions guided my data sources, analytic framework, and interpretive strategies. I ensured that there was a logical flow in the research questions, assumptions, and decisions that I made while conducting data collection and data analysis and in the final interpretive account of the family caregivers' experiences of spirituality (Thorne, 2008).

Trustworthiness and Credibility

Prolonged and in-depth engagement with the data and literature ensured representative credibility and substantive completeness (Thorne, 2008). To ensure analytic credibility, I kept an audit trail of all the methodological and analytic decisions made during the study. I maintained a log of all my research activities, developed memos and process notes, maintained a reflective journal, and documented all data collection and analysis

procedures throughout the study (Morse, 2015). I consulted regularly with my supervisors and shared all of these documents with them.

Preventing Analytic Errors

I avoided analytic errors such as premature closure, over-determining patterns, misinterpreting frequency, and over-inscribing of the self as discussed by Thorne et al., (2004). I did this by constantly engaging and repeatedly immersing myself in the data, and by using an appropriate analytical process, inherent reasoning, and regular consultation with and guidance from my supervisors.

Moral Defensibility

Moral defensibility requires the researcher to justify the needs of the study, rationalize the need to select specific study participants, and protect the ethical rights of the participants (Thorne, 2016). My research rationalizes the significance of spirituality and need for studying the spiritual experiences of family caregivers in the practice setting of the given context. Throughout the study, ethical considerations were strictly followed as discussed in the last section of this chapter.

Ethical Considerations of the Study

I received permission from the study setting in Pakistan and obtained ethical approval from The University of Alberta Health Research Ethics Board, Edmonton, Canada, to conduct the study. Ethical considerations such as study information and consent, privacy and confidentiality, emotional distress, and power relations and the power differential were considered and addressed throughout the study. Each area is described in detail below.

Information Letter and Consent

The verbal consent script, written consent, and information letters were in both English and Urdu. The consent forms and information letters included information about the purposes and outcomes of the study; potential risks and benefits of participating in the study;

and statements about confidentiality and privacy of the data, freedom to withdraw, and future use of data.

I obtained ongoing verbal consent from each family caregiver before the initial and follow-up interviews. The procedure for obtaining consent from family caregivers and healthcare providers is discussed in detail in the "Procedure for the interview" section of the document (p.58).

Privacy and Confidentiality

The thick descriptions of the data, field notes, and other findings produced in the research pose unique concerns regarding participants' privacy and confidentiality. Peter (2015) suggest that the researcher must ensure that the field notes and other findings must not become public and must not cause harm to the participants in their social and familial roles. To ensure participants' privacy and confidentiality, I informed study participants that their data would be kept anonymous and findings would be shared with the research assistant and supervisors after their names and any other identification were removed. During the interview process, I recorded the verbal consent and interview of each participant on the recorder and then transferred it to the encrypted computer voice files on the same day, after the interview was completed. I assigned pseudonyms to each voice file and were only shared with research assistant for transcription and translation purposes on an encrypted USB drive. I then shared the data transcripts with the supervisors on an online password-protected shared drive on the Health Research Data Repository (HRDR) at the University of Alberta. I recorded participants' demographic information on a separate sheet. I kept all the demographic information sheets and forms separately in a locked cabinet.

As per the University of Alberta policy, all the data will be stored for at least five years. I will keep the data until all scholarly activity related to this study ends. I will shred all the hard copies of the data in a confidential shredder. While disseminating the results of

the study at any forum, I will use group demographic data rather than individual data to protect the identity of the individual participants in a small sample size qualitative study. I had communicated this information to each participant at the time of consent.

Emotional Distress

Considering the nature of the study in a hospice setting, emotional distress was a major ethical concern. Some of the study participants felt vulnerable and experienced emotional distress and started to cry or weep while sharing their experiences with me (Boston & Mount, 2006; Lee & Kristjanson, 2003). Whereas some of them saw the interview as an opportunity for sharing and reflecting their emotions and feelings and perceived it as a source of support (Tan, Wilson, Olver, & Barton, 2010). During these situations, I paused the interview and offered the participant water and emotional support. I asked if the participant wished to take a break or continue the interview. Among all the study participants, only one felt uncomfortable enough to postpone the interview to a later date. The rest expressed their desire to continue with the interview even if they cried or felt like crying. Most of the participants said that they felt relief and comfort after sharing their feelings and experiences. For example, in one of the interviews, the participant said, "this is the first time I got an opportunity to express all of my feelings and emotions regarding caregiving." That interview was the longest in duration of all of the interviews.

Even as a researcher, I experienced emotional distress several times during the data-collection process. I often ended up in tears while listening to or transcribing my interviews and sharing my feelings or experiences with others. Many times, it became difficult for me to take a neutral position and exclude my emotions from the findings (Peter, 2015; Sivell et al., 2015). After five interviews, I informed the hospice staff, and did not conduct any interviews in the following week. I shared my feelings with my supervisors. For my self-care, I chose to socialize and reenergize myself with my friends and family. I reflected on

my own views, feelings, and emotions writing reflexive journals and diaries. After giving a week's break, I went back to the hospice and continued my interviews with my study participants. Using these several strategies of self-care, I could enhance my rapport, observations, and interviewing skills during the research process.

Power Relations and Power Differential

Literature suggest that a power asymmetry may arise between the researcher and participant at any time in the qualitative research process. There is a possibility that participants may feel obliged and agree to participate because their own family member has been admitted to the hospital and may fear that their family member could suffer in some way if they refuse to participate (Shanmugasundaram, O'Connor, & Sellick, 2009). To avoid such coercion, I did not personally contact the family caregivers to participate in the study. As discussed earlier, the eligibility criteria for the selection of participants was shared with the staff. In addition, posters and flyers about the study with my contact information were put on the notice boards in the hospice. All the participants were informed that their participation was voluntary and their refusal in the study would not affect the care of their patients in any way. I also kept reflective journals and field notes to write about relational issues, participants' attitudes, and reactions during the interviews as suggested by Haahr, Norlyk, & Hall (2014). Effective rapport and a trusting relationship with the participants were maintained by providing comfort, adequate information, and privacy during each interaction (Sivell, et al., 2015).

I am originally from Pakistan, but I had been living and studying in Canada for four years before I travelled to Karachi to collect data. During my data collection, I felt like both an insider and outsider researcher in the field. I continuously kept reflecting on several questions such as: How would my research participants respond to me during the interactions? Would they consider me as an insider or an outsider? Would they be willing to

share their personal and sensitive experiences of spirituality and family caregiving with me or not? What approaches should I adopt to reduce power differentials and enhance their comfort and readiness for an open and in-depth communication? I shared those feelings with my supervisors as well as in my reflexive journals on an ongoing basis.

I used several strategies to overcome the above-mentioned challenges. During my visits to the hospice, I was mindful of my physical attire as well as my spoken language, attitudes, and gestures during each interaction with my participants. Before starting data collection, I oriented myself to the hospice environment and staff. The first two days, I just sat in the hospice to familiarize myself with the staff, families, and patients without doing any interviews. All these strategies helped me to overcome my anxiety and enabled me to develop an effective rapport with staff and other people in the hospice. After few days, I felt more like an insider than an outsider. I also observed that family caregivers became more comfortable approaching me by themselves to participate in the study. We conveniently negotiated the time and place for the interview. All these strategies facilitated an enriched understanding of the context and facilitated my interactions with the study participants. Overall, these approaches not only guarded against power differentials but promoted a smooth path for an in-depth and enriched inquiry.

Conclusion

I found ID to be a valuable approach for studying the experiences of spirituality among family caregivers during end-of-life care in Pakistan. The in-depth interpretive approach using ongoing coherent reasoning, reflective thinking, and questioning techniques at every step of the research process enabled me to imagine, clarify, interpret, and develop an enriched understanding of the complex phenomena of spirituality and its significance among family caregivers in the palliative care setting in Pakistan. Ethical considerations and ongoing reflexivity were followed throughout the study process. Using the methodological

rigor of the design, I aimed to generate intersubjective, experiential, contextual, credible, and defensible knowledge around spirituality and family caregiving during palliative care. It is my hope that the information I generated through my study will prove to be relevant, meaningful, and applicable in practice settings in Pakistan. The study findings will inform healthcare professionals about the spiritual experiences of family caregivers and enable them to facilitate families' spiritual wellbeing in palliative care settings in Pakistan.

Chapter Four: Study Findings

The following chapter presents my study findings. Asking about and navigating stories of the spiritual experiences of family caregivers was a challenging yet joyful experience for me. Spirituality was embedded in the detailed life stories of family caregivers and was reflected in their daily caregiving tasks and responsibilities. Each story painted a unique experience of the family caregiver with ebbs and flows evident in their voices, feelings, and enriching spiritual experiences. The following research questions guided my study:

- How do family caregivers in Pakistan describe their experiences of spirituality while looking after their family member receiving palliative care in a hospice care setting?
- How do experiences of spirituality shape family caregiving practices in Pakistan?
- How do spiritual practices impact family caregivers' caregiving experiences?

The study findings are divided into four sections in this chapter. Section One includes the demographic information about the study participants, including family caregivers and healthcare professionals. Section Two describes the caregiving context of the family caregivers. Section Three describes the experiences of spirituality among family caregivers. Section Four reflects recommendations for healthcare providers as suggested by the family caregivers. It was not the major aim of the study, but I included in the findings the family caregivers' collective responses to the last item in the interview questionnaire. That question had to do with how the family caregivers saw the healthcare professionals' role in facilitating their experiences of spirituality. These four sections of findings are described under separate headings as below:

Section 1: Demographic Variables of Study Participants

Study participants included family caregivers and healthcare professionals. Family caregivers served as a primary source of data collection in the study whereas healthcare professionals served as additional sources of data that supplemented the family caregivers'

responses. Demographic variables of the family caregivers and healthcare professionals are provided under separate headings below:

Demographic Characteristics of Family Caregivers

A total of 18 family caregivers were included in the study. The demographic information of all the family caregivers was collected before the actual interviews were conducted. The mean age of family caregivers was 34.06 years. Thirteen (72%) were married whereas five (28%) were single. Fourteen (78%) were female and four (22%) were male. Five (28%) of the caregivers did not have any formal education. In terms of occupation, 10 (56%) were home-makers, four (22%) were skilled workers, three (17%) were self-employed and one (6%) was a student. Thirteen (72%) family caregivers were living in extended families with an average size of eight to nine members living together under one roof. Eleven (61%) of the family caregivers reported their income to be between Canadian Dollar (CAD)$160-200/month. The average caregiving period was 1.72 years, with a standard deviation (SD) of 1.1years. Most of the family caregivers (15) were Muslims (83%), two (11%) were Hindu and one (6%) was Christian. Three (17%) of the family caregivers themselves were suffering from chronic illnesses such as hypertension, diabetes, and hepatitis. The demographic variables of the study participants are shown below in Table 1.

Table 1: Demographic Characteristics of Family Caregiver Participants (N=18)

Characteristics		**Number (N=18)**	**Percentages (%)**
Age of Interview (years) Mean: 34.06 Range: 34-44years Standard Deviation (SD): 10.95	20-30 31-40 41-50 51-60 >60	8 4 5 1	44% 22% 28% 6%
Gender	Male Female	4 14	22% 78%
Marital Status	Single Married	5 13	28% 72%
Education	None Primary	5 3	28% 17%

	Secondary Post-Secondary Undergraduate	6 1 3	33% 6% 17%
Occupation	Homemaker Skilled Worker Self Employed Student	10 4 3 1	56% 22% 17% 6%
Religion	Islam Hindu Christianity	15 2 1	83% 11% 6%
Relationship to Patient	Daughter Daughter-in- law Son-in-law Brother-in-law Wife Sister Nephew	4 4 2 1 3 2 1 1	22% 22% 11% 6% 17% 11% 6% 6%
Length of Caregiving (years) Mean: 1.72 years SD: 1.10	<1year 1-2years 2-3years >3years	3 9 5 1	17% 50% 28% 6%
Caregiver Illness	Yes No	3 15	17% 83%
Number of Family Members Living Under One Roof Mean: 8.56 SD: 4.69	1-5 6-10 11-15 16-20	6 6 4 2	33% 33% 22% 11%
Monthly Income	100-150 160-200 200+	6 11 1	33% 61% 6%
Type of Family	Extended Nuclear	13 5	72% 28%

Demographic Characteristics of Healthcare Professionals

Healthcare professionals (n=5) were interviewed for the study. All were working in the hospice setting at the time. The healthcare professionals included medical residents (2), and registered nurses (3), males (3), females (2), married (4), single (1). Healthcare professionals were between the ages of 30-40 years. All were Muslims. Their overall working experience ranged from two to 20 years, whereas their experience in a palliative care setting ranged from seven months to 18 years. None of the healthcare professionals had taken any specific training or courses in palliative care or hospice care.

Section 2: Context of Caregiving

Study findings included the data that specifically represent the caregiving context of family caregivers in the study and is exclusively presented in this section. Findings about the context of family caregivers helped me in understanding and reflecting on the experiences of spirituality among study participants caring for their terminally ill family member in the hospice setting. The context is described under several themes that include: poverty, non-traditional practices, living far from hospice, extended family structure, juggling with multiple priorities, and hospice as a place of peace and comfort for family caregivers.

Poverty

Most family caregivers in the hospice were living in poverty; 11 (60%) had a family income ranging between CAD$160-200. Family caregivers reported living under extreme financial constraints. Some had to take financial loans or take on debt to cover the healthcare and other expenses incurred while their family member was being treated. Family caregivers said that due to poverty, they were unable to afford and provide proper and adequate medical treatment for their ill family members. Consequently, treatment for their ill family member was delayed and the disease progressed to terminal stages. One of the participants commented:

> We went to Jinnah Hospital [government hospital] where we found out that he had oral cancer. We didn't have money. We took a loan and went for surgery, but his disease continued to get worse. We didn't have money - that's why we lagged. If we had money we could progress. The disease progressed but we couldn't.

Another participant said that doctors advised her to go to India for a liver transplant for her husband, but her family had no money and therefore did not go. Charity was not an option, she added: "I would never spread my hands [beg] before anyone except for Allah [God]."

In the face of poverty and other adverse situations, family caregivers wanted maximum affordable care. Interviews with healthcare professionals confirmed what was said by the family caregivers. The healthcare professionals said that most people admitted to hospice are poor and have minimal support and view the hospice as their last resort of care. In Pakistan, the family is mainly responsible for the care of their ill family members and experiences lot of stress and challenges due to socio-economic constraints and limited healthcare resources.

Non-Traditional Practices

In addition to relying on modern medicine, family caregivers used non-traditional medicine and spiritual healing practices such as going to shrines or religious scholars to receive some kind of cure or symptom relief for the family member suffering from advanced illness. As one of the participants said:

> We went to shrines. We got holy threads from there which we tied around his/her arms and neck for a cure. We met religious scholars. We needed money to go there, now we are left with no money. Nothing seemed to be working.

Some of the family caregivers reported receiving special prayers by telephone from a spiritual healer. They said that these special prayers provided some comfort and relief for their patients for a limited time period. One of the family caregivers reported travelling to another city to get a special kind of wheat flour to feed his father, who was suffering from cancer. She reported that the flour provided symptom relief for some time but soon after discontinuing this practice, the symptoms got worse. Some family caregivers also reported using home remedies and herbs for symptom relief for their patients.

Living Far from the Hospice

Most participants had to travel more than a couple of hours using public transportation to visit their family member in the hospice. A few participants reported living in other cities and therefore had to stay at their relative’s home while their sick family

member was in the hospice. A participant who said, “We live too far from the hospice,” added that “every day going and coming back to the hospice is not easy, but we are managing with it. Hope sustains the world.”

As per the hospice policy, females were not allowed to stay with male patients during the night hours. As a result, females who were caring for their spouses in the hospice faced a lot of difficulties around travel and accommodations. One of the female participants caring for her spouse reported sleeping on the streets near the hospice during the night. She wept as she explained how she didn’t want to leave her dying husband and go back home:

> My sister-in-law comes in the night and sleeps with me on the streets outside the hospice. My elder son stays at night with my husband. I don’t go home. I don’t feel like going home. I call my kids and talk to them on the phone. I tell my kids to take food and go to sleep as I am with your father. I don’t like anything.

Extended Family Structure

Most participants reported living in extended families. The average family size was eight to nine people living together under one roof. One of the participants has four married brothers-in-law, all of whom live together in a six-room house. “The total number of people living in the house is 20,” she said.

Living in extended families is highly valued. One of the participants said. “We can share our responsibilities among each other and get our chores/errands done together.”

Juggling with Multiple Responsibilities

Family caregivers had multiple responsibilities including home care, childcare, work, and caregiving for their ill relative. They seemed to juggle with multiple priorities with limited support and resources. One of the participant said, “If one gets sick in the family, the entire family gets affected. The entire household dismantles.” Another participant added:

> I sleep for two hours only. I look after my mother-in-law during the night. In the morning, when I go back home, I prepare breakfast for my husband, send my older kids to school, and look after my two-year-old son at home.

A female participant looking after her husband in the hospice had two sick daughters at home:

> When I am at the hospice, my older daughter takes care of the house. She also takes care of her two other sisters. One is 30 years old, diagnosed with thalassemia and other is 10 years old and has a mental illness… It's been years, I am managing with multiple illnesses in my family.

One of the male participants was caring for his father-in-law in the hospice for a month. He said that during this time, he missed his own family and children. Regardless, he did not want to quit his caregiving responsibilities:

> I have a five-year-old mentally challenged daughter at home who used to sleep on my lap every night. It's been a month now I am not being able to see my daughter. I miss her badly.

Some family caregivers themselves were suffering from multiple chronic illnesses such as hypertension, cardiac disease, and hepatitis. Instead of complaining to others about their weaknesses or limitations, they preferred to remain strong and resilient. Family caregivers were found to be responsible and committed to their caregiving roles and responsibilities. One of the participant said:

> The breath of a sick person is connected to the breath of the attendant (caregiver).... if the attendant loses stamina it is like losing the person one is caring for. The attendant can prolong the life of the sick person if he/she is keen and honest with his work.

Another participant added:

> One has to deal with all the responsibilities with strength and courage. If there are bad days in life, there will also be good days to come. One needs to deal with different situations in life. We have to do it; otherwise who else will do?

Healthcare professionals supported the finding that families suffer from role strain as constant caregivers. This strain is exacerbated by socio-economic constraints and multiple responsibilities. Healthcare providers added that often, it is only the family caregiver who knows about the patient's diagnosis. This creates an additional responsibility for the family caregivers. One of the healthcare professionals explained the situation this way: At times, the family caregiver is under more stress and anxiety than the patient itself. The caregiver

remains continuously worried about what will be and what will not be the situation [and whether] there any resources left or not.

Hospice: A Place of Peace and Comfort for Family Caregivers

Hospice was a place of peace and comfort for most family caregivers. Family caregivers said that hospice staff was supportive and responsive. The participants found the hospice to be different from other hospitals; they found it to be a small yet clean place where most of them felt comfortable caring for their sick family member. All the caregivers were provided with free meals in the hospice. Each caregiver had a folding chair near the patient's bedside to sit and relax. The hospice had a small kitchen where family caregivers were allowed to warm food or make tea. Family caregivers were often seen socializing with each other in the kitchen. Family caregivers reported that they felt like a family in the hospice and found comfort in sharing their stories and feelings with each other. One of the family caregivers said, "When they see or hear others in pain their own pain feels less."

There was a small prayer corner in the hospice. Families were allowed to bring a religious scholar to pray or perform religious rituals for their patients in the hospice. Family caregivers said that they wished they could be provided with a place in the hospice where they could have a warm shower and wash themselves for prayers. The hospice had no separate counseling or grieving room for families. There were no social workers or volunteers to provide additional support for family caregivers.

Section 3: Experiences of Spirituality among Family Caregivers

This section reports the findings describing the experiences of spirituality of family caregivers of persons with terminal illness in a Pakistani hospice. The study context discussed in Section 2 provided a richer and broader understanding of the experiences of spirituality among family caregivers. The rich descriptions of spirituality among family caregivers suggested that regardless of poverty, socio-economic constraints, multiple

responsibilities, and limited resources, participants valued caring for a family member. They were continually struggling and improvising their current circumstances to render peace and comfort to their ill family member. Amidst all the hardships and constraints, participants demonstrated a deep sense of love and belongingness; acts of compassion and kindness; and strong faith in God, religious values, and practices while caring for their family member in the hospice. These spiritual experiences collectively provided resiliency, hope, and inspiration among family caregivers.

Analysis showed that for the family caregivers, spirituality was a major resource of coping among the family caregivers. Spirituality was evident in the daily lives of the family caregivers as well as in their caregiving actions and practices. These experiences of spirituality were represented by four themes of the study which are:

1. Family love, attachment, and belongingness (*apnaiyat*): "My family gives me purpose in my life."
2. Honoring family values and dignity: "I don't want to bring any shame or dishonor for my family."
3. Act of compassion and selfless service: "I find peace and eternal satisfaction in serving family and others."
4. Seeking God's kindness and grace: "Everything lies in God's hands".

All these themes collectively led to a central theme: Rise Above or Self-Transcendence: "I see myself a better person."

Family Love, Attachment, and Belongingness (*Apnaiyat*): "My family gives me purpose in my life"

Each caregiving story was imbued with a sense of love, attachment, and belongingness, all of which were displayed by the family caregivers caring for their terminally ill family member in the hospice setting. While describing their experiences of

spirituality, most family caregivers used the Urdu word '*apnaiyat'*. When translated into English this word means "belonginginess" or "relatedness" or "attachment." The caregivers said that to them, spirituality is '*apnaiyat',* meaning "a feeling of relatedness," or "belongingness towards family and others." According to the participants, all humans belong to each other and it is their sense of belongingness that motivates them to care for and serve their family and others. "Spirituality to me is the feeling of being with others," one of the participants said "it is natural, not everyone has it …. This feeling grows as you live with others, care for others, you develop attachment or belongingness."

Similarly, healthcare providers also referred to spirituality as "an emotional attachment/sense of belongingness to patients and their families."

Spirituality was referred to as belonging to each other. Participants said that their spirituality and inner-selves call for them to love and show kindness towards each other. As one participant put it, "To be human is to be spiritual; our very existence purports to love and show kindness towards our fellow beings."

Family is highly regarded and valued. Family relationships formed an integral part of the caregiver participants' lives. There were strong relationship bonds among the family members, which enhanced their sense of belonging to one another. Love and care for the family was the utmost priority in their lives. The strong sense of belongingness and attachment towards their patients and other relatives provided spiritual strength and gave meaning and purpose to their existence.

Here is a sample of some of the quotations participants offered about their love, belongingness, and attachment:

> It is my own sense of belongingness that gives me spiritual serenity and spiritual certitude in serving her.
>
> It's my (family), love and belongingness that gives me meaning and spiritual strength in my life. While they are with me, I have strength in myself.

> Nothing else but loving and caring for my family gives me spiritual peace and comfort.

> Caring for my husband, my in-laws, and my family is my spirituality. All of this gives me meaning and purpose in my life.

> Giving her care on time, keeping her clean, giving her [a] bath, changing her clothes gives me happiness. It gives me eternal happiness.

Love and affection were demonstrated by a strong sense of perseverance and devotion to the family. Family care needs often preceded individual needs and preferences. Family caregivers were willing to sacrifice their own self-care needs to give comfort to their ill family member. Most family caregivers said that family caregiving is a difficult task but a rewarding experience. Participants believed that caregiving is a blessed activity and they were the ones who had been chosen to fulfil those responsibilities. One of the participants, a 23-year-old female family caregiver, was taking care of her father who had been suffering from a terminal illness for the last four years. She traveled between two cities for her father's treatment and finally was referred to this hospice. She was residing at her relative's house to look after her father in the hospice. She was the eldest in the family. Her parents separated when she was only 12 and after that she was responsible to take care of her two younger siblings and her sick father. She used to make bangles to earn money to raise her siblings and financially support the family. According to her, her love and affection for her father enabled her to face all the adversities in her life and made her strong and resilient. She didn't want to leave a single stone unturned in the care of her father. She expressed the love for her father with these words:

> If the sun does not rise a day, how would it be? If my father is not there, it would be like the sun not rising. It's his presence that gives me a lot of strength…. I have a kind of connection and closeness with him. So much so that if he moves his eyes (to ask for something), I get to know what he wants.

For the family caregivers, upholding family trust and fulfilling one's roles and responsibilities were forms of showing love, affection, and attachment towards their patients

and other family members. Participants said that their families provided them the courage and strength to manage personal hardships and multiple responsibilities in their lives. One of the male caregivers who was taking care of his father-in-law in the hospice said that although it had been a month since he had seen his wife and children, he never felt that caring for his father-in-law was a burden. Rather, this act of caregiving gave him a sense of self-worth. He felt humbled to have this responsibility and cherished the trust his family had placed in him:

> My family trusts me to care for him and now it is unto me to fulfil their expectations and not break their trust. . . To share love and affection means everything to me. It gives me courage and strength. I like doing more and more for my elders. I would like to meet and fulfill all their expectations. They should not have any stress because of me.

Another participant expressed her love for her family by pledging to care for her mother in law: “I deliberate that till my death, till the last breath of my life, whether it’s my life or hers, I want to care for her and my family.”

Some participants also felt that end-of-life care reinforced the value and importance of family relationships. They saw it as an opportunity to spend time with their loved ones and develop stronger ties with them. One of the male caregivers said that “After taking care of my father-in-law for a long time, I realized how strong one’s relationships are.”

Along with love and a deep sense of belongingness towards family, family caregivers highly valued honoring family values and dignity. This formed another theme of the study i.e. honoring family values and dignity.

Honoring Family Values and Dignity: "I don't want to bring any shame or dishonor for my family.”

Family caregivers also describe their experiences of spirituality as honoring and preserving family values and morale. These spiritual values were of significant importance among all the family caregivers. Participants believed that disrespecting or forsaking family values could bring disgrace or dishonor to their family within the community where they

lived. One of the participant said, “I want to do more and more for my family, to meet all their expectations. I don’t want to bring any shame or dishonor to my family.”

Family values were highly regarded and guided family caregivers’ actions and practices. Values such as caring for parents, the elderly, and in-laws were considered a cultural norm as well as an ethical and moral responsibility. Family caregivers respected and valued the teachings of the elderly and modeled their actions and behaviors accordingly. Serving parents or the elderly was considered a blessed task. Most of the participants believed the saying, “Unfortunate are those who forsake the responsibility of caring for their parents.”

Participants quoted:

> Yes, it is not a (ehsaan) favor to my parents. This gives me happiness. I am lucky that I am getting to serve him in this condition. I have seen many people who do not give any importance to their parents. It is a huge sin. I say that if parents are there in one’s life there is meaning in it, otherwise, there is no life without them.”

> My biggest belief and value is to serve and provide care to my parents. Respecting and caring for our elderly is our responsibility. The more we care for our parents, the more rewards we will get in this world as well as in the other world. Those who don’t have their parents - ask them how they feel. Those who have got their parents and are alive -, they should value and show respect towards their parents.

Participants believed that the elderly bring wisdom and enlighten the house and therefore they should be given respect, care, and attention. Participants said:

> Without an elder in the family, the house feels empty. (*Ghar katne ko dorta hai)*. She is the enlightenment of our house *(Ghar kee ronak hai*). She is our elder and I believe elderly people bring happiness and cheerfulness to the house. Nowadays, when she is not there I don’t feel like going downstairs in the hallways and sitting there.”

> My elders should not have any stress because of me. Their love and affection mean everything to me. It gives me courage and strength. I feel like doing more and more for my elders and meeting all their expectations.

> ....by serving elderly, you get their prayers and blessings. It’s the most important thing in my life. Some people say that money is the most important thing in life. We get money, money can be lost. In reality, after death, you only take your coffin with you and your relatives fight among each other behind you for your money.

It was interesting to note that among female married participants who were living with their in-laws, serving in-laws with love and affection was a familial and cultural expectation. These participants believed that fulfilling this expectation would bring honor and rectitude to their families as well as pleasing their husbands and making their own parents feel proud of them. Seeking parents' and husband's respect and happiness were found to be common cultural and personal expectations among daughters-in-laws who were filling caregiver roles. Participants quoted:

> She is my mother-in-law. I am responsible to care for her no matter what. She should never feel in her heart that I have not taken care of her well. My husband becomes happy when he sees me caring for her.
>
> Being a daughter-in-law, I don't want to do any such thing that makes people raise their finger at me and say that such and such thing happened because of her. I don't want other people to complain to my father. My father has been a very big support to me since my childhood and I would never want to embarrass him in front of my in-laws. He calls me his favorite daughter and I want to make sure that I should not do any such thing after marriage that can bring any shame or dishonor to him.
>
> I try to abide by the words and teachings of my parents. I must show respect and care for everyone in my family. Whatever happens, I must try to do my best for my family. Nobody should turn back and blame me [or say] that something bad has happened because of me.
>
> My mother has told me that if you will keep your mother-in-law happy then I will be happy and that is the same thing my husband also expects from me.
>
> Upon my marriage, my mother and father both told me that I should take care of my in-law's family; I am the eldest daughter-in-law and therefore, it is my responsibility to take care of my in-law's family. Now even if I get tired or don't feel like doing things, these words of my parents encourage me to continue with my responsibilities. I don't want to let down my family's honor.

Family caregivers viewed the act of serving others and humanity as an essential trait that must be followed from generation to generation. Family caregivers believed that their actions and values of showing love, respect, and care for others would be modeled by their own children in the future. As one participant said, "Whatever we will do with our parents or elders, our kids will do the same with us."

The analysis of the findings and excerpts of family caregivers show that maintaining family honor and dignity were vital to the family caregivers. Respect and care for parents and the elderly were highly honored by the participants and seen as a legacy for future generations. Such values and acts also demonstrate a deep sense of closeness and engagement among family members and are reflected in their roles and relationships. Besides love and belongingness for the family and respecting family values, family caregivers also showed a strong sense of compassion and kindness for serving family and others which constituted another theme of the study i.e. acts of compassion and selfless service.

Acts of Compassion and Selfless Service: "I find peace and eternal satisfaction in serving family and others"

Family caregivers also reflected their experiences of spirituality by demonstrating acts of compassion and selfless services during the caregiving process. They shared that they had an internal desire to selflessly serve both their families and others including their neighbors or community. Participants reported that the act of serving and caring for others provided a spiritual sense of wholeness and made them feel complete. As one of the participants said:

> Serving is life…without it life seems meaningless and incomplete. I feel addicted to serving others. If I am self-bound, I feel useless, agitated, and dull. But when I go to look after someone or serve in the community, I become fresh. I look around for the people and places that need me…. Serving others keep me composed, peaceful, and calm.

Some of the participants said that their families raised them with values of compassion, serving, and caring for others and now those values had become a part of their everyday lives. Some of the participants said that "serving is like a virus in me" or "I feel addicted to serving others." One of the participants said:

> I am not here only because he is my cousin. Even if it was someone else I would have done the same care for him, too. My heart aches and I feel sad whenever I see a sick person. This is how I have been since my childhood. I have exams in the university from the 15th of February, but I am here to look after him.

Family caregivers relished compassionate and altruistic values. They found joy and a sense of personal fulfillment in caring for and serving others. They expressed a strong sense of collectiveness vs self. They were willing to sacrifice their self-care needs for the needs of others. The acts of selflessness and self-sacrifice among family caregivers were highly evident in the caregiving stories. As one of the caregivers said, “I do it selflessly; it doesn’t matter whether the other person pays me any regards or not.” Another participant said:

> Don’t I have work, family, and friends? I have my own desires too. But I have learned, I have practiced, and I have lived with it. I like to serve, and I like it even more when I am of use to someone…. This is everything to me. This is my life. I feel happy and enjoy helping other people. I feel that I am born to do this work.

The inherent values of compassion and the family caregivers’ acts of kindness towards others were also influenced by religious values. One of the participants who was caring for her dying neighbor in the hospice said:

> We, as Muslims, know that it is essential to take care of someone’s life. There was no one to look after her so I decided to stay and care for her in the hospice. I have been here for 10 days. I thought of my young children who are going to school, but then I reminded myself that saving someone’s life is meaningful and rewarding.

Providing unconditional love and demonstrating an enlightened attitude toward the dying individual in the hospice were rewarding and self-fulfilling acts. Family caregivers got a strong sense of self-worth and positive spiritual outlook from such acts. Family caregivers said that they believed that God sent human beings to earth to serve and care for others. By serving others and humanity, one can obtain God’s blessings, and hence achieve Nirvana or the ultimate reality (the goal of every human being on this earth). Below is a sampling of participants’ quotes about the theme of serving others:

> Serving others is an opportunity given to us by God and, therefore, it must be fulfilled with respect and wholeheartedly.

> My religion teaches me that if you see someone in pain and suffering, you should help and care for them. Whatever you could possibly do, try to help and serve others, do for others. Never let down others. *(kisi ko hikarat se na dekho)*. Don’t think that if you are caring for a sick person you will get their illness.

> In my *Geeta* (holy book for Hindus), it is written that if someone is thirsty, offer him a drink, if someone is hungry, then feed him. By giving, Allah (God) would be happy. If someone is sleeping or is sick, then take care of that person; give him a shower and dress him. All the world religions say similar things. These things are useful and guide people.

In summary, family caregivers' spiritual acts of love and belongingness, respect for family values, selfless service, and compassion towards family and others provided meaningful engagement, a positive spiritual outlook, spiritual strength, eternal peace and satisfaction. In addition, family caregivers showed strong faith in God's blessings and grace, which was found to be another source of strength while caring for a terminally ill family member in the hospice setting. This framed another theme of the study i.e. seeking God's kindness and grace.

Seeking God's Kindness and Grace: "Everything lies in God's hands"

Most family caregivers expressed their spirituality as having firm belief in God or a higher power. Participants believed that "God is absolute" and whatever happens in life is by the "will of God" and, therefore, one should aim to "seek God's kindness and grace" at all times. For the family caregivers' spirituality meant having complete faith in God, the divine or a higher power. As one participant said, "My inner strength lies in my faith in God. Medicine and treatment are all secondary."

For most family caregivers, faith constituted obeying God's commands and seeking God's pleasure in all endeavors of life: in other words, aligning one's will with the will of God. "Everything lies in God's hands," one participant said. According to the participants, strong faith and acts of submission follow the path of spiritual attainment. Muslim participants used the term "Allah" for God. Below are comments that the participants made about those themes:

As humans, we should be humble and show our submissiveness to God.

> Since my childhood, I have been taught that I should do everything with complete faith in Allah…. If one does not have complete faith in Allah (God) it is of no use.

> When we seek sickness from Allah (God), he gives us sickness. When we seek the cure from him, he gives us the cure. When we seek tears from Allah, he gives us tears. When we seek work from Allah, he gives us work. Everything lies in Allah's hands. Life and death are in Allah's hands; so are our earning and money matters. Everything is in God's hands.... All is from Allah. A servant of Allah cannot do anything without his will.

Some of the family caregivers also asked several existential questions such as why God put disease, poverty, and other adversities into their lives. Participant said: "Sometimes I get angry and feel that there is no peace or comfort in my life." Another participant who was worried about her financial and other constraints during caregiving added, "Why does God give this disease to poor people? If he wants to test us, then he should provide us strength and resources to cope with our difficulties. I don't like to beg others or ask for money to help us."

Family caregivers expressed deep sorrow, distress, fear of separation, and fear of losing their loved one. Below are comments from the participants:

> I feel so much pain, so much anger. Oh God! Show us any path of cure, open any door of healing, and get us [a] cure from somewhere. Save my husband's life.

> …. it is very painful when you see someone dying who took you by the hand and taught you how to walk. Now he is dependent on you. The one who taught you how to talk - now he is unable to talk. It gives me a lot of pain.

> Wherever I found a temple, I went there to pray for him. We went to shrines. We got threads from shrines. We put those threads on him. We met religious scholars. God, open a door for me where I can find peace and [a] cure for my husband.

While pondering several existential questions and experiencing the loss of and grieving for their dying family member, participants constantly showed hope and courage. They had a firm belief that God is merciful and would ease their miseries, despair, and sufferings. Family caregivers stated, "Every time I have been in trouble, Allah has guided and supported me."

Family caregivers expressed their submission and gratitude towards God for whatever they had in their lives. They said that they don't like to whine or grumble at God and have complete faith in God who will show them the path of light and recovery. A strong sense of gratitude was highly evident among caregivers, as demonstrated in the following comments

> A person should not have complaints for Allah. It's a human ignorance to have complaints for Allah.
>
> I do not have any expectations from anyone else except Allah…. if God has given us hardships or suffering then he would also provide the courage and strength to cope with difficulties, troubles, and worries in life. Allah provides us the strength to bear the pain with courage.
>
> Sometimes I feel like complaining to God but then I remind myself…. there must be something good for me in these difficult times.

Family caregivers believed that life and death is determined by God. They said they felt that healthcare staff should not determine or decide about the fate or future of their patients. Rather, it is God who decides our destiny in life. The following are comments the participants made about that theme:

> Allah is above everything. Allah is Shafi (one who cures) …. If it is God's command, he/she will be cured.
>
> Doctors say that he is just a guest for a few days or months. You cannot say that if you believe in God. Can you give me a guarantee that the breath you take in would be out or in? Don't put your own opinions. I have my trust in Allah. He is beneficent and merciful. From a medical perspective, there might not be any hopes, but Allah will take care of him. Whatever happens, Allah would do better.

Performing prayers and practicing religious rituals were found to be an integral part of family caregivers' routines and a strong expression of their faith in and connectedness to God. Religious rituals included prayers, reciting the Holy Scripture from the holy book, listening to holy hymns and songs, going to shrines, giving holy water, blowing upon the sick, and attending religious gatherings. These activities brought solace to the participants. "I brought my daughter in a very bad condition," one of the participants recalled, "it was my prayers that prolonged her life. Allah will heal her."

Prayers were a form of communication and a demonstration of love, gratitude, and humility to God. In the face of adversity and grief, family caregivers said that prayers and others religious rituals helped them to cope and brought them peace and satisfaction. The following comments from two participants reflect those themes:

> He has a disease and I know it can't be cured. Offering my prayers [*Namaz*] and religious rituals make me strong.
>
> It is my prayers that give me support. I will fast. I will say *Tahajjud* [voluntary prayers by Muslims especially during the night time]. In Allah's praise, there is a cure always. May Allah take away this *takleef* [distress/affliction].

Prayers and religious rituals also had a significant impact on the caregivers' physical, psychological, and spiritual wellbeing. The caregivers found strength, spiritual satisfaction, and pleasure in prayers, as expressed by this participant: "Prayers make me fresh and enable me to continue with my routine tasks. It's a source of energy, pleasure, and strength to me."

One of the family caregivers who was suffering from a chronic illness said that prayers provided her with the strength and courage to manage her own illness as well as to cope with all the caregiving responsibilities she had because of her ill sister in the hospice:

> "Somedays, I feel so lethargic and weak. Then, suddenly after two days of fasting and regular prayers, I feel active again and am running around on my feet. Imagine how that would have happened. .... I gain strength from Allah through my prayers"
>
> I feel burdened when I do not pray. Allah says, the pleasure is in saying *Namaz* [formal prayer in Islam]; cry in front of me with humility. Many times, we do not remember Allah. But when we have troubles and difficulties, we pray to Allah…."

Participants said that if they were unable to say their prayers, they became restless. Prayers served as a means of peace and solace while caregiving for a family member at the end of life. As one of the participants said, "Prayers give peace of mind." Below are comments that the participants made about prayers:

> My biggest strength comes from Allah. Until I pray I remain restless. The days when I do not pray, I experience strange feelings, anxiety, and sadness. When I say my prayers, I refresh and reenergize myself.

> Last night, I reached home late at night. Due to cold weather, my cousins didn't allow me to shower and I couldn't pray. I felt so restless and couldn't sleep the whole night. I felt like crying and also got mad at my cousins…. If I miss my prayers I feel strange and sinking. I feel like something is missing.

Most Muslim participants mentioned that along with prayers, reciting Quranic verses were important sources of strength and comfort. "When I recite Quran or say my prayers, I seek blessings and mercy from Allah," one of the participants said. Another participant added that "The Quran contains the cure for everything." Most participants used to recite regular Quranic verses to give comfort and peace to their terminally ill family members. "We recite various prayers," said a participant who was caring for her mother-in-law. "We recite verses of the Quran in her ears, Surah Yaseen (Quranic verse). We have also told my mother-in-law to recite Quranic verses. It will give her solace and peace."

One family caregiver said that he/she read certain Quranic verses to mother-in-law because those verses have healing powers. She added:

> There are a lot of Quranic verses specifically for people living with cancer. We also keep reciting those. Whatever someone says we are to do…. if someone says recite this verse we do that to give her comfort. If there are any other prayers, we are willing to perform them to comfort her.

Reciting holy verses also provided comfort and support to family caregivers in the hospice as well as in their daily lives. "The recitation of the Quran in the hospice makes me feel like home."

Below are comments from other participants about reciting the Quran:

> Saying *Namaaz* [formal prayer] and reading the Quran gives me peace and eternal satisfaction. The more I do, the more I gain strength and courage.
>
> If I recite recite *Surah Maryam* [Quranic Verse] for 40 days regularly, I won't feel tired at all.

For some participants, reciting certain Quranic verses provided a sense of safety and security. One of the female family caregivers who had to leave her young children alone at home before visiting hospice to care for her husband said:

> Every day before leaving my children at home, I recite *Ayat-ul-Qursi* (Quranic verse) four times. I feel safe and secure. I believe it serves as a security guard for my home and my young kids. Allah keeps angels for our safety and security.

Healthcare providers also said that patients and family caregivers' religious values and beliefs should be respected all the time:

> We must not stop family caregivers if they want to perform any special prayers or any religious rituals for their dying family member…. we need to respect their values. We allow if they wish to bring a religious scholar into the hospice. We should allow them to offer their prayers. We should facilitate families in their beliefs and practices…. The *Quran Sharif* [holy book], *Sura Yasin, Punj sura* [Holy Scriptures], *jaye-namaz* [a special cloth that Muslims use while praying], rosaries, all these things are available here in the hospice.

Other than performing prayers and religious rituals, spiritual practices such as listening to music, walking in nature, and sharing laughter and stories were also found to be sources of spiritual satisfaction and comfort for family caregivers. These additional spiritual practices also helped the caregivers to cope and find strength in their caregiving roles and responsibilities. As one described:

> When I feel sad, I go out with my friends. I vent my sadness and grief…When I share my pain with others, it helps…. I feel relaxed and less burdened. Within the hospice, when I see others in pain, my pain seems less.

Family caregivers also reported that little words of praise from others encouraged and motivated them in their caregiving roles. Below are comments that the participants made about the theme of encouragement and motivation:

> When someone praises me, it makes me happy and reenergizes my efforts.

> My mother-in-law and other relatives say [to me] "You are the only one who can perform these tasks." Hearing such words from the family gives me a lot of courage and strength.

The professional healthcare providers also supported the value of communication and listening to the concerns and feelings of family caregivers in the hospice setting. They emphasized that families endure emotional turmoil when providing end-of-life care and, therefore, require continuous encouragement, support and guidance. Below are comments

from the healthcare providers in support of communication and comfort for the family caregivers:

> Patients and families get fresh and relaxed after talking to us. We should try to keep a friendly environment in the hospice. We should be nice, listen, and communicate to our patients and their families. If nothing else, we can at least give a smile to them. It is so encouraging.
>
> Sometimes we use humor and share jokes to provide comfort and relaxation. It makes them feel happy and satisfied.

Findings strongly support that the spirituality of family caregivers was evident throughout the caregiving process. Spirituality provided a major source of strength and resilience to help the family caregivers bear all the challenges and struggles of looking after an ill relative. Spirituality provided a sense of peace and comfort during the grieving process. Family caregivers experienced their spirituality in their strong bonds with family and others, by honoring family values, showing acts of compassion, and by providing selfless service and seeking God's blessings and grace. These spiritual acts and values enabled family caregivers to transcend their worries, grief, and loss and provided them with a strong spiritual outlook. Spirituality empowered family caregivers to continually grow and to rise above or self-transcend throughout the caregiving process.

Rise Above or Self Transcendence: "I see myself a better person"

All of the above themes of experiences of spirituality led to a central theme under study, Rise Above or Self Transcendence: *"I see myself a better person."*

Findings showed that family caregivers experienced their spirituality in several ways and underwent a change of worldview during the process of caregiving. The spiritual acts of love, sense of belongingness, compassion, and a firm belief in God's blessings and grace constantly helped them to transcend their worries and troubles and enabled them to find peace and satisfaction in their caregiving actions. Most family caregivers experienced

transcendence, harmony, and inner peace while caring for their dying family member. Below are comments about responsibility and self-development from two of the participants:

> One needs to develop positive thinking. Having positive thinking and faith, I could handle all my responsibilities.
>
> My father calls me lion…. “Say your prayers, my lion.” His words of love and affection give me courage and strength. My responsibilities are integral to my life and I should not leave those responsibilities for anyone or anything else.

Most participants described themselves as becoming a strong and different person after experiencing various adversities, sufferings, and challenges during the caregiving process as well as in their daily lives. Most participants contemplated that the odds of life turned them into a different individual. One of the participants stated, “Your prime trainer is your circumstances.”

Family caregivers used the Urdu word *Majboori,* which translates to hardships or helplessness in English. “Hardships/helplessness [*Majboori*] takes a person to a place where one would never imagine going,” said a participant who was taking care of her husband and had to sleep on streets during night time. “One might not prefer to go there, but many times your helplessness takes you to those places.”

Most participants said that they gained self-confidence and experienced self-growth. They said that although the hardships they endured had caused them pain, grief, and sorrow, these difficult times had also made them stronger in important ways. Their experiences of spirituality allowed them to gain self-awareness and discover hidden qualities in themselves, which led them to a higher level of learning and prepared them for the future. Here are comments that two of the participants made about their personal growth as a result of their caregiving experiences:

> I was shy and mostly homebound. Now I come and go from one place to another. Time causes one do things. Now the time is such that there is no one to go to places with my mother so I go with her. And I feel I should go.

> I have taken out the word failure from my dictionary. I have developed so much confidence in myself that now I can stand up in front of the president or any famous personality and I don't hesitate.

The majority of the participants saw end-of-life care as an opportunity to renew their relationships and develop meaningful engagement with the family, others, and God. In every situation, they turned towards God's grace and blessing and showed their submissiveness. With the passage of time, participants felt that they had developed a higher sense of humility and gratitude. Below are the sample of quotations from participants about faith and its significance in their lives.

> Truth, faith, and trust are the most important things in one's life. The path of truth is difficult.... and [so is] keeping the trust within ourselves. Allah (God) is watching everyone. Having faith and trust in Allah (God) keeps us alive. May God never break his trust in anyone. Everything breaks down then. I am alive with the faith that one day God will listen to me…. I don't have hopes from anyone except Allah. God is giving me the courage to face all the difficulties in my life."

> God creates trials and judges his chosen ones by setting adversity before them, and then He blesses those who demonstrate the courage and humility to face the adversities in their lives. One who overcomes the trials by continually seeking God's mercy and blessing grows nearer to God and attains spiritual upliftment.
> .
> Our faith should be strong. God never harms his worshippers. He tests us in different ways. This responsibility of caregiving is given by God and we must try to fulfill it in our best possible ways…. I just seek his prayers and hope that all difficulties will pass.

Participants found that the humanistic or spiritual values such as love, kindness, selfless service, faith and trust in the higher power ease the "path of truth" and keep them alive. Most participants expressed that "what you sow shall you reap." In other words, actions dictate consequences. "If you do well—you do well to yourself, likewise, if you do evil—you do evil to yourself." Participants affirmed that every person is accountable for his or her actions and behaviors. If a person shows kindness he/she will get kindness in return. Likewise, if he/she shows sinfulness then the future path will lead him/her towards destruction.

Family caregivers regarded death as a passage into the next life. Such thoughts and values transcended their own actions and behaviors and reinforced spiritual growth. “The thought of dying helps and brings you closer to God,” as one said. Participants stated that every individual is answerable to God for all his actions and deeds. A person should perform good deeds and serve and care for others to find peace and spiritual rewards in the afterlife.

Most participants voiced that their end-of-life care experiences allowed them to reflect on their own values and beliefs about life and death. They saw their end-of-life care as an opportunity to reflect on their actions, thoughts, and behaviors. “As a Muslim, when you care for others, you are confirming a place for yourself in heaven.” According to Islamic values and beliefs, heaven is a place where most loyal and pious people will dwell after their lives on earth have ended. According to the family caregivers, self-reflection fostered positive attitudes and values towards life and death and led to a positive spiritual outlook. It enhanced the caregivers’ humanistic values of love, caring, generosity, and humility towards their family and others. One of the participants expressed his desire to open his own hospital and provide free care to people:

> I wish to build my own hospital…a hospital where no one says that I am poor and cannot afford treatment. It’s my wish that those who are poor should get all the treatments that they need. I would look after them, talk to them and share their sadness and grief. Hopefully, Allah would do well.

Findings were evident that most family caregivers went through a constant process of self-transformation and personal growth while caregiving at the end of life. The spiritual and religious values and practices nurtured their hidden strengths, offered them hope, courage, and strength to deal with difficult situations in their lives and transcended their sufferings leading them to continually ‘rise above’ and experience self-transcendence.

Study findings also showed that there were a few participants who were unable to rise above. These participants often asked for existential explanations of their sufferings, such as “why us?” or “why me?” They shared feelings of anger, guilt, and self-blame often related to

what they saw as the unfairness of their situation. One of the participants, the mother of an 18-year-old daughter, showed immense grief and expressed her fear of losing her daughter. She was persistent in hoping for a miracle that could save her daughter's life. Another participant expressed her anger towards God saying, "Why [does] God give this disease to poor people?" Feelings of intense emotional distress, despair, and grief among those few participants were evidence of spiritual suffering and spiritual distress.

Section 4: Family Caregiver Expectations from Healthcare Providers

At the end of each interview, the participants were asked about their perceptions and suggestions about how healthcare professionals could help to facilitate their spiritual experiences in the hospice. A common theme that emerged from the analysis of the data was "We need your presence and a listening ear." This theme was kept separate from the central theme as it mainly included family caregivers' opinions and suggestions regarding how healthcare professionals can support family caregivers' spirituality during end-of-life care. The theme is described below:

Healthcare Professionals Care and Support: "We need your presence and a listening ear"

Family caregivers were asked, "How can healthcare staff support your spirituality while you are caring for your family member in the hospice?" Findings revealed a mixed reaction among family caregivers as to how they perceived the hospice staff's attitudes and behaviors. Some of the family caregivers said that they appreciated the staff in the hospice and that the staff members were very cooperative and friendly. Below are comments from three of the participants about the hospice staff:

> All the staff are very co-operative here. Here they do so much for us. They come to us, listen to us, and explain everything to us in a polite manner. All of the nurses and doctors are good and support us emotionally and spiritually. The staff are very good.
>
> They share jokes sometimes and it feels good to us. We laugh and smile together.
>
> The staff here always reply politely. I can imagine that this is not an easy job for them, but they do it very sincerely and deal with the patients very respectfully. We should praise them. It's not an easy job for them to do.

Some of the family caregivers stressed that staff must listen and respond to their concerns with a pleasant attitude and polite behavior, especially in a hospice environment. In the time of loss and grief, the family caregivers need extra support and

encouragement. Below are comments from two of the participants about what they need from the hospice staff:

> The doctors should communicate everything clearly and should ask about how the patient is feeling, what is bothering him, and what is giving him peace.
>
> If the staff is nice, then both patients and caregivers are satisfied. They need attention and it cures them. Otherwise, everything seems like it is failing [*sab khatam*].

Most family caregivers expected staff presence and support within the hospice. They said that they felt happy, relaxed, and satisfied if the healthcare staff took time to talk to them and listen to their concerns. When staff listened to their concerns, they felt the staff members' presence and support. The staff's pleasant behavior and communication provided a sense of comfort and peace. Talking and sharing with the staff helped the family caregivers to vent their feelings which in turn helped them to regain their own strength and the courage to continue with their caregiving tasks. They said it made them feel that "someone is there to listen, share, and help us" and that "it is just love and a caring attitude that gives us spiritual peace, and comfort - nothing else."

Family caregivers said that when doctors and nurses did not listen or explain things properly to them, they felt discouraged and lost hope. Adequate staff communication gave them hope and helped them in decision making. Below are comments they made about those experiences:

> Sometimes doctors and nursing staff discourage and lower our hopes. They don't appropriately explain to us the course of treatment which sometimes adds to our dissatisfaction and makes us anxious. Whatever they are doing, they should properly explain it to the family. Proper explanation gives us hope, comfort, and satisfaction."
>
> Communication is important, it helps us to decide for ourselves and our patient…. when staff talk and listen to us and take care of our family members, we don't feel stressed. Their attitude and behavior give us comfort and peace.

The analysis of the findings revealed that family caregivers expressed their needs that staff should demonstrate kind attitude and be empathetic towards their needs and

concerns. When staff was supportive and caring, this provided a source of hope, spiritual strength, and satisfaction for the family caregivers.

Summary of the Findings

Family caregivers felt the greatest sense of spirituality in their caregiver roles in the forms of love, belongingness, and attachment towards their family members near end of life. Honoring family values and elder care was highly regarded. Family caregivers displayed a great sense of compassion and altruistic values not only towards their immediate family members but also towards other within the community. Having a strong faith in God and performing spiritual practices were major sources of coping during times of distress, grief, and loss. Most family caregivers found that the spiritual experiences constantly helped them to "rise above" and "self-transcend" during stressful times of caregiving and other life situations. A few family caregivers did not describe experiencing self-transcendence as these participants were going through spiritual distress. Families expressed the need of spiritual support from staff and provision of better palliative care services.

Figure 1: Themes under Study

The study findings are presented in a digram below.

The themes are connected; they are not mutually exclusive. Collectively, they contributed to the central theme, rise above.

Chapter Five: Discussion and Implications

This chapter discusses the research findings about the experiences of spirituality among family caregivers and how these experiences influenced their caregiving actions and practices while caring for their terminally ill family member in a hospice setting. The discussion will focus on themes under the study which are: family love, attachment, and belongingness, honoring family values and dignity, acts of compassion and selfless service, and seeking God's kindness and grace. All these themes reflected the unique experiences of spirituality among family caregivers that led to the central theme i.e. rise above. Relevant scholarly work and literature were used to highlight what makes this study both similar to and unique among other studies and to show its contribution to the body of knowledge in the areas of nursing and health. The discussion of findings is followed by implications for practice, education, and research in the areas of spirituality and family caregiving. The strengths and limitations of the study are discussed at the end of the chapter.

The study was the first of its kind in Pakistan to explore the experiences of spirituality among family caregivers in a hospice setting. The findings represented the unique spiritual experiences of family caregivers in a Pakistani context and how these experiences shaped their caregiving actions and practices. Though the majority of the population in Pakistan is Muslim, the study adds to the richness of the data by including people from other religions such as Hinduism and Christianity. The spiritual experiences in the findings represent the hidden voices of the Pakistani family caregivers, the majority of whom were living with adversity, such as poverty and limited healthcare resources. Despite this adversity and their grief, the family caregivers continued to find comfort and peace in their caregiving actions and practices. Family caregivers described their roles as meaningful, fulfilling, and eternally satisfying.

The study findings clearly demonstrated that the experiences of spirituality such as a sense of love, belongingness, honoring family values, acts of compassion and selfless service for the family and others and having strong faith in God's kindness and grace constantly enabled family caregivers to transcend their grief and loss; foster ongoing satisfaction, peace, and courage; and bring about personal/spiritual growth and spiritual transformation. The four sub-themes mentioned at the beginning of this chapter led to the emergence of the core theme, "rise above," which describes the family caregivers' experience of achieving self-transcendence as a natural consequence of their own spiritual experiences and inner spiritual strengths. The family caregivers' spiritual experiences shifted their worldviews and modified their sense of self and their sense of self in relationship to others. Eventually, enabling them to grow and transform into stronger and better individuals.

The findings also signify that family caregivers' spirituality was strongly influenced by their cultural, religious, and personal values and beliefs. It is interesting to note that the participants described religion as organized prayers, rituals, and practices whereas spirituality was experienced as an internalization of humanistic values, meaningful and caring relationships, love and belongingness, and selfless service for humanity. The spiritual and humanistic values form a substantial part of the family caregivers' personalities and were reflected in several aspects of their lives. The discussion of the findings is presented below under separate headings.

Spirituality is experienced in Sense of Belongingness and Love for the Family

The study findings showed that the participants' experiences of spirituality included a deep sense of love and belongingness towards their dying relative, family, and others. Participants defined their spirituality as a feeling of relatedness, love, and belongingness rather than just finding meaning or purpose in life. The study findings add a wider perspective to the definition of spirituality used in the study by Puchalski et al. (2009), in

which a sense of connectedness and meaning-making were important aspects of spirituality. In this particular study, family caregivers described their spirituality as a strong sense of belongingness and love towards their patients, family, and the community. Belonging is a strong and inevitable feeling that exists in human nature. Belongingness is described as a human emotional need, an inherent desire to belong or to be an accepted member of a group, be that group family, friends, co-workers, religion, or something else (Hagerty, Lynch-Sauer, Patusky, Bouwsema, & Collier, 1992). Lane (1987) suggests that every human desire a sense of solidarity with other spirits, an identity of connectedness and belongingness towards others and the community. Vachon, Fillion, and Achille (2009) described such connectedness as a feeling of communion rather than a feeling of being alone. Hill (2006) calls belongingness a component of connectedness. However, one can argue that belongingness is beyond connectedness. A person's desire to belong or not to belong depends on his/her personal choice. A person might be culturally or genetically connected to a family or socially connected to a particular religion or community but may not have the sense of belongingness towards that family or the community. Thus, the feeling of belongingness is natural and is beyond the feeling of simply connectedness. The sense of belongingness experienced by the family caregivers in the hospice engendered love, kindness, and affection and was a strong motivation as evident in the study findings. Literature also supports that a sense of belongingness contributes to our emotional and spiritual wellbeing and enables us to maintain meaningful relationships with each other (Hill, 2006). Tan et al. (2011) in their qualitative study using hermeneutic phenomenology also found "spirituality as a web of relationships that gives coherence to our lives." Tan found that spirituality was expressed in the form of love, belonging, and attachment with others, and was integral to find meaning and purpose in one's experiences. However, unlike this study, the Tan study used a family meeting model

where both patients and families were invited to share their experiences of spiritual and psychosocial aspects of care. Most of the participants were Christian.

Spirituality is experienced in Family Relationships

Findings strongly suggested that family caregivers' spirituality was deeply rooted in their family relationships. Family relationships were seen as an integral and expressed as deep respect, care, and affection. The findings showed a strong sense of spiritual engagement among the family caregivers and their patients and with each other in general. The whole family was seen collectively struggling with and contributing to the care of their dying family member. Family relationships were highly valued and found in a strong sense of love and bonding. As one daughter said, "If I lose my father, it means to me like sun does not rise on that day." Family members were willing to sacrifice their time, energy, and resources in a desire to prolong their loved one's lives or in some cases to make every effort to let them die peacefully. In every aspect of care, family caregivers fostered human values of love and compassion for each other and preserved strong family relationships. Study findings showed that family caregivers considered such values highly spiritual. Similar findings were also reported by Penman et al. (2013) in a phenomenological study that looked at family caregivers and their patients with advanced cancer. The authors reported that patients and caregivers placed special emphasis on relationships and social networks, including networks with strangers. The patients' and caregivers' spiritual engagement with each other was associated with values of love and compassion, and maintaining relationships, and resulted in enhanced coping skills and personal transformation.

Study findings also showed that family caregivers viewed caregiving during end of life as an opportunity to deepen and strengthen their relationships. They found comfort and peace being with the family and doing their chores. Culturally assigned family roles and relationships, gender, and family expectations shaped caregiving roles and responsibilities.

The majority of the participants did not feel constrained by family caregiving roles; rather, they felt happy and honored and viewed caregiving as an opportunity to serve the family. Similar findings have been reported in several other studies (Buck & McMillan, 2008; Chang et al., 2012; Penman et al., 2013; Taylor, 2003; Taylor, 2006; Williams & Bakitas, 2012; Wong et al., 2009). Buck and McMillan (2008) found that being with the family was the highest reported spiritual need among family caregivers as compared to other spiritual needs such as reading a religious text, going to services, talking about spiritual issues, or reading inspirational materials. The help that family and friends received during caregiving was viewed as giving them strong social and spiritual resources that helped to combat the burden of caregiving (Burton et al., 2012). Maintaining strong relationships brought multiple benefits to the individual caregivers including faith, hope, peace, contentment, and serenity; what often resulted from this was personal growth and wellbeing (Eliason, Samide, Williams, & Lepore, 2010; Narayanasamy, 2007). Families preferred to be present for each other, journey together, engage in meaningful connections, and consider all these activities as multiple ways to express and experience love and spirituality (Edwards et al., 2010).

The findings of this study strongly support the values of “filial piety” and “dharma” among the family caregivers. Concepts such as filial piety and dharma emphasize the importance of virtues, ties, and order in the family system. These concepts demand serving and being obedient to ancestors, parents, and elders in return for their benevolence, affection, and care (Abdullah, Muhamad Shukri, & Othman, 2011; Hasnain & Rana, 2010). Similar findings have been shown in other studies by Mok et al., 2003; & Spitzer et al., 2003. Studies by Mok et al. (2003) and Spitzer et al (2003) were conducted among Chinese and South Asian communities that have ethnic and cultural beliefs similar to those of the participants in this study.

The concepts of filial duty and dharma carry strong notions of cultural and religious beliefs and values and can be found in Islam, Hinduism, and Confucianism. This study showed several examples of filial enactment where family caregivers were willing to make physical, financial, and social sacrifices for the care and comfort of their terminally ill family members in the hospice setting. Family caregivers reported sacrificing their basic needs such as eating and sleeping. Caregiving for the ill family member was preferred over other activities such as housework, childcare, and employment responsibilities. Findings showed that some family caregivers who lived far from the hospice preferred to sleep on the streets at night rather than leave their dying patients in the hospice. A profound sense of perseverance and devotion toward the family was evident overall. The values of love and belongingness, compassion, presence, journeying together, and sharing were meaningful and purposeful to family caregivers' existence and provided them with a sense of wholeness and integrity. Without those values, the participants reported, they would have felt lonely, inadequate, restless, and incomplete.

Spirituality is experienced in Honoring and Respecting Family Values

Another significant finding that was unique to this particular study was that of honoring family values. Honoring family values was considered highly significant among the family caregivers. Family caregivers expressed that not meeting or valuing the expectations of family could bring dishonor and disrespect and, therefore, should be avoided at all times. Being part of an extended family, every individual family member is obligated to participate in the family caregiving role. These values were strongly influenced by culture and religion.

It was interesting to note in the findings that caregiving roles were not gender-specific, a contrast to the findings by Spitzer et al. (2003), who showed that caregiving responsibilities in South Asian communities were often relegated to women and that the

women considered these responsibilities part of their moral and ethical selves. My study showed that both genders shared and honored the caregiving responsibilities equally. Among both genders, caring was regarded as profound and meaningful. The study findings also supported that family caregivers viewed their acts of love, honor, and sacrifice for the family as a legacy for their next generations, the children and grandchildren of the family. Family caregivers saw themselves as role models, setting an example of family values for subsequent generations. This particular finding was consistent with other studies (Hasnain & Rana, 2010; Isgandarova, 2012) that included Muslim participants from countries other than Pakistan.

Spirituality is experienced in Acts of Compassion and Selfless Service

Findings suggest that family caregivers showed strong values of compassion and selfless service or altruism. Altruism is an act of selfless service towards others whereas compassion can be defined as a recognition of another's suffering, a feeling of sorrow or concern for that suffering, and a desire and intention to end that suffering (Vieten, Amorok, & Schlitz, 2006). Love and compassionate values of caring were not limited to only family members but also to others including neighbors, friends, relatives, or community members. These inherent values were intrinsic to family caregivers and were spiritually engaging. They were sources of peace, serenity, and ongoing satisfaction among family caregivers. The findings showed that family caregivers interpreted the "act of serving others" as a "virus" or an addiction. Some participants described feeling restless or incomplete if they weren't able to care for others. Serving and caring for others were profound characteristics among most caregivers and were evident in their conscious and unconscious behaviors. By serving and helping others, family caregivers experienced intrapersonal and interpersonal relationships that involved a sense of relatedness to themselves, others, and the universe. Family

caregivers acquired a sense of wholeness and personal integrity by carrying such values within themselves.

The ethics of compassion and service among family caregivers were highly evident in the findings. Saslow et al. (2013) found that inherent compassionate values motivate families to go beyond their selfish motives and act altruistically for the care and service of others, which was similar to the findings of this study. My findings showed that despite adversity, family caregivers demonstrated a strong communal sense and were willing to look after, care for, and spend time with others. The family caregivers' acts of selfless care and compassionate service provided a sense of togetherness and prevented the families from experiencing isolation while experience pain and suffering. Moreover, these acts provided them with a deep sense of inner satisfaction and personal fulfillment.

Previous studies have shown a strong relationship between spirituality, altruism, and compassion (Greenwald & Harder, 2003; Huber & McDonald, 2012; Penman et al., 2013; Saslow et al., 2013; Young et al., 2015). However, very few of these studies were conducted among family caregivers in a palliative care setting. Penman et al. (2013), in their study of palliative care clients and caregivers, found that spirituality was strongly associated with human values of love, compassion, and altruism. Love and compassion were seen as acts of kindness and being present for others, and altruism was seen as giving preference to others' happiness and wellbeing over self. Both these spiritual qualities promoted improved life satisfaction, comfort, and peace among family caregivers. Mattis (2000), while studying the meaning of spirituality among African American women, also found that service for others was viewed as a social obligation, which motivated individuals to engage in activities and model behaviors that promote positive social relationships. Unlike the Mattis (2000) study, this study showed that among family caregivers, service for others was not only perceived as a social obligation but as a moral and ethical responsibility. Serving and caring for the family

and others were considered blessed opportunities. Family caregivers cared for their family members and others out of love and affection and not merely due to a social obligation. Such practices and values were inherent and highly influenced by the participants' personal, religious, and cultural values and beliefs and had fostered a sense of personal fulfillment, peace, and satisfaction.

The literature shows that various religious and cultural traditions promote the teachings and practices of compassion, altruism, and self-sacrifice. Islam, Christianity, and Hinduism place a high value on altruistic values and acts of self-sacrifice, and service towards each other within the society. In Islam, altruism is referred to as the concept of 'īthār' (إيثار), which translates as "preferring others to oneself" or selflessness. In Hinduism, the word for altruism is *seva,* Sanskrit for "being of selfless service to the needs of others." In Christianity, 'Caritas' a Latin word meaning eternal love, unconditional love or love for humankind is commonly referred to as altruism. Study findings suggested that regardless of their religious background, people who are altruistic share similar values.

Study findings also showed that acts of love, compassionate care and selfless service involved transcendent dimensions of spirituality that led to a spiritual transformation and, subsequently a greater sense of self (Delgado, 2005; Greenwald & Harder, 2003; Saslow et al., 2013; Vieten, Amorok, & Schlitz, 2006). While serving and caring for the family and others, family caregivers experienced closeness, affection, and a greater sense of connectedness towards each other and God. Vieten et al. (2006) suggest that individuals experiencing pain and suffering often internalize compassionate values and demonstrate altruism towards others and the community. Study findings suggest family caregivers experienced hardship, grief, and painful situations and therefore were able to recognize the pain and suffering of others. They developed an elevated feeling of compassion and empathy

towards others (Delgado, 2005). Religious teachings, family values, and cultural beliefs also contributed to the family caregivers' values of compassion and selfless service.

Spirituality is experienced in Gratitude and Faith in God

The findings showed that family caregivers had a higher sense of gratitude for and faith in God's will and blessings. Family caregivers had a strong belief that all human actions and deeds are dictated by God's will and commands. They said they believed that life and death can be determined by no one except Allah or God who is merciful and benevolent. Findings showed that family caregivers strongly believed that life and death decisions lie in the hands of God and therefore, it is important to preserve human life until the individual's last breath. Families did not want or allow healthcare providers to talk about a time of death or dying with the patients. Families said they believed that such conversations would take away the patients' hopes of living and the strength that they would need to get through this difficult period. Family caregivers said they believed that a person's future is decided by God rather than by a person and, therefore, it is best to trust God and have faith in His commands. Family caregivers said that they had a trusting relationship with God that constantly nurtured their meaning and hope in life.

The findings also showed that faith in God enabled family caregivers to find comfort and peace. Family caregivers were better able to cope with grief while handing over the difficulties of end-of-life care experiences to God. Nunez, Holland, Beckman, Kirkendall, and Luna (2017) found similar views among Hispanic family caregivers in a hospice setting. Gonzalez et al., (2016) found that fatalism intertwined with religiosity/spirituality is a complex phenomenon and such beliefs often help to provide emotional and spiritual comfort while someone is experiencing life-limiting illness or is at the end of life. However, the study was limited in that it looked at only women from three cultures: Chinese-American, Korean-American, and Mexican-American.

Findings suggest that personal hardships and difficulties, including life-threatening illness in the family, further strengthened participants' faith in God and enabled them to transcend their stresses, worries, and grief. They viewed these experiences as spiritually awakening. They reported that "the thought of dying helps," as they see it as an opportunity to reflect on their own deeds, actions and behaviors. They had a strong faith and belief that all hardships and struggles are God-given and are meant to lead them to examine their spiritual strength, humility, and submissiveness to God. Participants affirmed that the "path of truth is difficult." However, they agreed that having strong faith in God and abiding by religious and spiritual beliefs would enable them to endure suffering, find meaning in that suffering, and practice the spirit of compassionate care at the end of life. Consistent with the study findings, Reed and Rousseau (2007) found that spirituality "transcend[ed] life limiting illness" among patients and their family caregivers. They found that the patients and family caregivers, felt a "pull towards believing something unforeseen," had "a firm relationship with a higher being," and expressed a "yearning towards spiritual beliefs" and believing "unequivocally in life after death." Similarly, Paiva et al. (2015) and Sterba et al. (2014) found that spirituality enabled family caregivers to rethink life issues and their quests to connect with their religion.

Study findings also demonstrated spiritual reciprocity as a driving force, a source of motivation, and encouragement among participants in their caregiving actions and practices. Study participants referred to spiritual reciprocity as the acknowledgment of the belief that God is eternal and omnipotent and has control over every individual's life. Therefore, one should remain grateful for God's blessings and should refrain from blaming God and questioning His will and decisions. Family caregivers said, "what you sow shall you reap," meaning that one's actions and behaviors determine one's future and fortune. Family

caregivers strongly believed that their caregiving values and actions would make God happy and in return, would bring them spiritual rewards and blessings in the afterlife.

The study findings showed that spirituality and faith largely influence individual and family values and choices about end-of-life care. Faith in God, and religious and spiritual beliefs nurtured a sense of gratitude, enhanced closeness to God, and enabled self-reflections among family caregivers. These qualities also provided the caregivers with comfort and engendered courage and strength during the challenging times of caregiving in the hospice setting and during the grieving process.

Spiritual Practices as Major Sources of Coping among Family Caregivers

Spiritual practices include prayers, religious rituals and practices, reading holy books, listening to religious hymns, socializing with friends and family, and walking in nature. A major part of the family caregivers' descriptions of spiritual practices focused on prayers and religious rituals.

Findings strongly suggested that family caregivers found strength, peace, comfort, and coping skills through prayers and religious rituals such as reciting the Holy Quran, listening to holy hymns and songs, giving holy water and blowing upon the sick, and attending religious ceremonies. The family caregivers said that they saw prayer and performing religious rituals as ways to express their humility and gratitude for God's blessings. Family caregivers said that they believed that they can receive God's grace and blessings by being submissive and asking God's forgiveness. Prayers were a routine part of their lives. Most family caregivers said that without prayers, they felt restless, disrupted, and incomplete. Prayers provided the family caregivers with courage and made them resilient, which helped them to face difficult situations.

Another unique and interesting finding in the study was that family caregivers reported that prayers and religious rituals enhanced their physical, psychological, and

spiritual wellbeing. Family caregivers who were suffering from chronic illnesses said that praying gave them comfort as well as the physical strength they needed for caregiving. The literature suggests that faith and spiritual practices serve as protective factors against spiritual distress, especially among family caregivers (Deal, 2011, Boston & Mount, 2006; Delgado-Guay et al., 2013). Research has shown that participating in religious and spiritual practices helps caregivers to transcend their known and unknown fears and anxieties during end-of-life-care (Penman & Ellis, 2015), fostering resilience (Nunez et al., 2017) and guiding them in illness management and other health-related decision-making (Ko, Roh, & Higgins; 2013; Reed & Rousseau, 2007; Sterba et al., 2014), and improving the quality of life and wellbeing of family caregivers (Buck & McMillan, 2008; Gill, Kaur, Rummans, Novotny, & Sloan, 2003; Lee, et al, 2015; Leow, Chan, & Chan, 2014; Tang, 2009).

Rise Above or Self-Transcendence

Findings suggested that experiences of spirituality often enabled family caregivers to find meaning in both past and present situations. Hardships and struggles allowed most of the participants some control over the unknown, motivated them to grow, and eventually helped them to self-transcend and self-transform into better versions of themselves. There were few participants who experienced spiritual distress and required spiritual resources that could help them develop effective coping strategies and locate their hidden strengths and inner resources that could improve their resiliency and perhaps later foster personal/spiritual growth. Deal (2011) suggests that a healing environment includes listening to and witnessing the suffering of the others, connecting suffering and spirituality, and inviting self-reflections on the individual person's stories. These strategies can assist in overcoming spiritual distress or suffering and can promote self-transcendence.

In the findings, it was evident that family caregivers faced various challenges due to poverty and poor socio-economic conditions, such as lack of affordability of healthcare

resources, food, and transportation. Due to poverty, family caregivers said, they were unable to provide timely treatment and adequate care for their dying family member. Despite poverty, suffering, grief, and loss, family caregivers' experiences of spirituality served as a motivation, fostered resiliency, and enabled them to achieve the sense of a higher self or self-transcendence. Participants viewed adversities of life and sufferings as a precursor to personal spiritual transformation (Deal, 2011) which can in some way also enhance one's search for divine truth or transcendence (Reed & Rousseau, 2007). Sinclair, Raffin, Pereira, and Guebert (2006) support a similar view and described suffering and painful circumstances as a "spiritual calling" that can serve as a catalyst for personal spiritual journeys. Reed (2014) also asserts that the inner strength of individuals enables them to expand their self-boundaries and develop wider perspectives to discover or make meaning of an experience.

Study findings supported that religion and spirituality can influence the way individuals perceive suffering and enable them to find meaning in their suffering and then eventually lead them to a transcendent experience of spiritual growth (Agrimson and Taft, 2009; Bhatnagar, Gielen, Satija, Singh, Noble, & Chaturvedi, 2017; Daaleman et al., 2008; Deal, 2011; Delgado, 2005). Faith and spirituality enabled people to find meaning in their suffering rather than simply justifying it. Spirituality enhanced deepening of self, a profound connectedness to life, and an awareness beyond self (Wayman & Gaydos, 2005). Previous studies on family caregiving have also reported that families acquired strength through adversity and viewed caregiving for their loved one at the time of life limiting illness as an opportunity for spiritual growth (Delgado-Guay et al., 2013; Mok et al., 2003; Paiva et al., 2015; Penman et al., 2013; William & Bakitas, 2012; Wong et al., 2009). Spirituality has been valuable in providing support for people coping with life-threatening illness; it helps them to maintain confidence, is a source of comfort, reduces stress, increases peace, and

helps them to foster a positive outlook (Ando et al., 2010; Coughlin, 2008; Reed & Rousseau, 2007, Wong et al., 2009).

Many psychologists and sociologists claim that self-transcendence usually occurs during old age or end of life (Deal, 2011, Delgado, 2005; Reed and Rousseau, 2008). The authors take a developmental life span perspective. In contrast, this study showed that spiritual inquiry, spiritual transformation, and self-transcendence can be experienced at any age or time in an individuals' life. Most of the family caregivers in the study were young or middle aged. Thus, it can be argued that the experience of self-transcendence depends on the person's inner strength, support systems, and response to circumstances rather than on age or when in the life-cycle it occurs.

To summarize, life challenges, suffering, and misery can motivate self-transcendence and promote physical, psychological and spiritual well-being among individuals and is independent of age or other developmental considerations. Findings support that the family caregivers went through a constant process of "spiritual transformation" or "unfolding mystery" (Reed, 2014) where they courageously dealt with multiple uncertainties and challenges in life. The family caregivers' spirituality imbued in their deep sense of love and belongingness, compassionate values of caring, and firm belief in God, provided them with the inner strength to endure suffering throughout the family caregiving process and enabled them to discover meaning and purpose in life. Most of the participants said that their spiritual experiences positively transformed their personalities and now they see themselves as stronger, confident, resilient, and self-effacing.

Role of Healthcare Professionals in Spirituality of Family Caregivers

The study also asked family caregivers about the role of healthcare professionals in enhancing caregivers' spiritual experiences during end-of-life care. The findings revealed that family caregivers wanted the healthcare professionals to display a caring, supportive, and

empathetic attitude. The family caregivers provided a range of qualities that the healthcare professionals could display that would promote spiritual care. These included a positive attitude, empathetic communication, a listening ear, and respect for the families' spiritual values and beliefs. Family caregiver said that the staff's positive attitude, good communication, active listening, and use of humor instilled strength, hope, and courage in their caregiving activities. It also gave them a sense of comfort and peace. Similar findings have been reported in previous studies (Daaleman et al., 2008; Kim, Hayward & Reed, 2014; Sinclair, Bouchal, Chochinov, Hagen, & McClement, 2012; Taylor, 2003; Taylor & Mamier, 2005). The literature supports that nurses cannot always alleviate suffering, but they can witness the patient's suffering by careful listening, creating a healing environment, and inviting reflections from their patients or families to promote supportive care with authenticity and compassion (Deal, 2011). Spirituality should be embedded in nurses' routine acts of caring and demonstrated in their small daily acts of kindness and of love (Sinclair, Raffin, Pereira & Guebert, 2006). Nurses can be role models of care for families. Their caring behaviors can have a profound impact on families (Deal, 2011).

Findings also suggest that it is important to address the family caregivers' spiritual needs and to facilitate resources to prevent isolation and spiritual distress among them. Spiritual needs involve love, belongingness, and supporting the religious activities of family members. Previous studies also suggest that healthcare professionals need to identify spiritual needs through proper assessment and communication to support compassionate care for family caregivers (Buck & McMillan, 2008; Ross & Austin, 2015). Study findings showed that available resources in the hospice, such as the availability of religious books, playing religious hymns, and allowing religious scholars in the hospice, provided caregivers with spiritual support, peace, and comfort. A separate room for family grief counselling and warm water supply for family caregiver in the facility, if provided can further add to their

comfort. Increased nurse-patient ratios will allow nurses more time to provide spiritual and emotional support to the patients as well as to the family caregivers.

As stated earlier, family caregivers voiced their concern that staff must respect their spiritual values, beliefs, and preferences, especially while talking to them about issues and decisions related to death and dying. The study showed that health professionals need to recognize various spiritual concerns of patients and family caregivers during end-of-life care to provide culturally competent and supportive care in the hospice setting (Bullock, 2011; Hawley & Morris, 2017; Ohr, Jeong, & Saul, 2017; Reed & Rousseau, 2007; Volker, 2005). Studies have emphasized the need for improved communication between nurses and family caregivers as it will help family caregivers to make appropriate decisions regarding treatment choices and care in the hospice setting (Bernard et al., 2014; Buck & McMillan, 2008; Chang et al., 2012; Delgado-Guay et al., 2013; Jaul et al., 2014; Koenig, 2005; Ross & Austin, 2015; Skalla et al., 2013; Sterba et al., 2014). Consistent with the literature, findings also suggest the need to look at barriers to spiritual care. These barriers include a lack of time, lack of training and education regarding spirituality, lack of cultural competency, and a lack of organizational policies and practices to promote spiritual care in palliative care settings (Edwards et al., 2010). To promote families' health and spiritual wellbeing in a hospice setting, health professionals need to listen to family caregivers and understand the crucial role of spirituality.

The study findings also make it clear that health personnel and stakeholders must immediately prioritize the need for effective and efficient palliative and hospice care in Pakistan. Palliative care is essential for both patients and their families, especially in a hospice setting. Better access and effective provision of palliative care services can aid families and enhance their family caregiving experiences. Palliative care services can be a

major resource to relieve suffering, provide comfort, and promote quality care of the dying patients and their families at the end of life.

Summary of the Discussion

This unique study of experiences of spirituality among family caregivers in Pakistan informs the importance of facilitating the experiences of spirituality among family caregivers in a hospice setting. Study findings strongly support that family is integral to care in a Pakistani cultural context. Understanding the spiritual experiences, values, and beliefs of family caregivers is essential to provide holistic and quality care in a palliative care setting.

The study findings showed that spirituality was embodied in every aspect of the family caregivers' lives and shaped their caregiving actions, behaviors, and practices in a hospice setting. The family caregivers' experiences of spirituality were found to be beyond meaning-making and a sense of connectedness. The spiritual experiences of the family caregivers were reflected in their strong sense of love and belongingness towards family and others, respect and honor of the family, compassion and selfless service towards family and others, and a firm belief in God and spiritual practices. Spirituality was seen as a major source of coping and resiliency among family caregivers. Despite adversity, poverty, limited resources, and other challenging circumstances, spirituality enabled family caregivers to nourish and find comfort in their caregiving practices. Although some of the family caregivers experienced spiritual distress, most family caregivers found their spiritual experiences constantly engendered personal growth and self-transformation and enabled them to become stronger, more courageous, and eventually more forbearing individuals.

Study also suggested that familial, cultural, and religious values influence experiences of spirituality. The values of compassion, altruism, filial piety and dharma were evident in caregiving practices and reflected family caregivers' spiritual values and beliefs. Faith in God and other spiritual practices were seen as a protective factor and found to be essential

coping resources that helped the family caregivers to endure suffering, grief, and loss. Spirituality also had a major impact on family caregivers' communication preferences and decision-making during the caregiving process near the end of life. Spiritual reciprocity was seen as a driving force that helped the family caregivers to endure the challenges of caregiving and other difficult life situations. Family caregivers' inherent spiritual and humanistic values and beliefs served as a mediator for a constant process of self-transformation in the family caregivers' lives and eventually lifted them towards a higher self or self-transcendence. Study findings inform healthcare providers to recognize the importance of spirituality and provide effective spiritual care for patients and families. This unique study about the experiences of spirituality among family caregivers provides valuable information that should be incorporated while developing spiritual care interventions for families in the palliative care in Pakistan.

Strengths and Limitations of the Study

Findings of the study present a novel perspective of spirituality among family caregivers from a developing country like Pakistan, where healthcare resources are limited, and palliative care services are minimal. Consequently, it informs and challenges researchers' dominant discourses about family caregiving that are primarily shaped from Western countries where there are more resources and mainly a publicly funded healthcare model. The study findings can be transferrable within similar settings and contexts as thick descriptions of data contain common conceptual linkages and commonality of the patterns generated in the study. As a researcher using interpretive description approach, I had an interpretive authority over the findings to decide the extent of interpretation and direction of the research. Nonetheless, to ensure credible and rich findings in the research, I followed appropriate and transparent analytic techniques. I made regular analytic notes and dated thematic lists and emergent patterns in the data, ongoing memos, field notes, and in reflective

and reflexive journals. I also kept a detailed audit trail of the research process. I conducted regular and ongoing consultations and obtained feedback from my supervisors. Furthermore, to avoid socially acceptable answers from the participants in the interview, I used a well-designed and thorough interview guide. The interviews were conducted as per availability and mutual agreement with the participants. I established rapport with the participants, showing respect, using effective communication techniques, and maintaining ethical principles throughout the study.

Translating the interviews from Urdu to English might have resulted in losing some of the meaning and the essence of actual words in the data. To overcome this limitation, I kept some words in their original language in the translation. In addition, I faced certain communication challenges while discussing experiences of spirituality. Therefore, I remained sensitive and respectful, using ethical guidelines during all interactions with the participants. Throughout the study process, I maintained a reflective journal to limit my personal biases, opinions, and feelings in the study.

Study Implications

The findings show that spirituality is an integral aspect of care and plays a significant role in supporting families in a hospice setting. Based on the findings, several implications are suggested in the areas of practice, education, and research.

Implications for Practice

Caring for a terminally ill family member in hospice involves unique challenges. Spirituality can be a major resource for family caregivers, to help them cope and find strength and peace during periods of grief and loss when there are limited resources. Healthcare providers need to internalize the significance of spirituality and should adopt a holistic and a family-centered approach in a hospice setting. Healthcare professionals need to develop family interventions that facilitate spiritual growth and self-transformation.

Spirituality is highly subjective and is influenced by personal, religious, and cultural values. Findings suggest that healthcare professionals should obtain a spiritual history and carefully assess the patient's and families' spiritual, religious, and cultural values and beliefs to avoid any biases and stereotypes. Healthcare professionals need to be culturally sensitive and show respect for the family's values, preferences, and choices at end-of-life care to promote comfort and peace among families and assist in their caregiving activities/decisions. Having knowledge of the family caregivers' spiritual values and beliefs will help the professionals to refer the family caregivers to spiritual advisors and plan other effective family care interventions and support the families' spiritual wellbeing in a palliative care setting.

The findings also suggest that family care interventions should focus on promoting a sense of belongingness, love, and compassion among family caregivers. Staff need to be comfortable generating sensitive end-of-life discussions including spiritual issues and concerns of patients and their families. Such interventions require proper knowledge of

spirituality, spiritual values, and needs as well as effective communication and interpersonal skills. Effective communication training sessions around end-of-life care issues and concerns will help staff to clarify their understanding about spirituality and help them to facilitate discussions of spirituality and spiritual care preferences for the family caregivers in the hospice setting. Hospice staff should have regularly scheduled training and educational sessions about spiritual assessment tools, spiritual history, and spiritual care. Adequate training will enable staff to recognize the family caregivers' spiritual values, concerns, and preferences and help them to formulate relevant and effective interventions to facilitate a positive spiritual outlook and spiritual growth among family caregivers in the hospice setting.

Study findings suggested that spirituality influences family caregivers' decision-making at the end of life in a hospice setting. Therefore, healthcare professionals should not only assess the religious and spiritual beliefs and values of family caregivers but also need to know how family caregivers perceive those spiritual values and beliefs. Such interventions will help health care professionals to support family caregivers in decision-making and to facilitate a smooth transition among families at end-of-life care. Findings support that effective spiritual care can promote spiritual growth and self-transformation among families in a palliative care setting.

Included in the findings are suggestions for stakeholders for modifications and improvements in the hospice setting to facilitate effective spiritual care among families. These include allocating adequate nurse-patient ratios, providing a separate family counselling or bereavement room, and ensuring the availability of volunteers, a social worker or a psychologist in the hospice setting. Improvements can be made to basic facilities in the hospice. These improvements can include having warm water in the bathrooms and providing other means for self-care. Hospice facilities can provide comfort and enhance the

family caregivers' spiritual satisfaction by adding a religious advisor or instituting faith-related practices.

Implications for Health/Nursing Education

Spirituality is an essential component of palliative care and must be included in health curricula. In Pakistan, neither the nursing nor medical school curricula offer courses and training in spirituality, spiritual assessment, or spiritual care. It is recommended to include those concepts/courses in the health curriculum across the country. Accredited spirituality courses should be included in medical and nursing school curricula, both as theoretical and clinical components.

The findings suggest that a strong relationship exists among spirituality, culture, and religion. The courses should include concepts of cultural safety and cultural competency in addition to spirituality and palliative care concepts. These courses should be offered in the curricula of various health disciplines. This will allow healthcare professionals to understand the concepts of spirituality and palliative care within the proper context and to formulate spiritual care interventions according to the population's needs.

Workshops or training sessions about spirituality in palliative care should be designed and offered to healthcare professionals currently working with terminally ill patients and their families in acute, hospice, or other palliative care settings. Continuing education sessions about communication techniques, cultural safety, and addressing spirituality among family caregivers should be provided to the hospice staff on a regular basis to reinforce the importance of spirituality and spiritual care for the families in the hospice setting.

As Pakistan is a poor country, available funding and training support for educating healthcare professionals in the areas of family caregiving and spirituality can be sought from other palliative care or spirituality organizations, educational institutions, and universities

from developed countries. With the increase in technology, online courses can be offered to healthcare professionals.

The study findings strongly imply that there is a crucial need to create awareness and training at all levels to give priority to this important area of spirituality in family caregiving and to mobilize spiritual resources at end-of-life care. Such efforts will improve the standards of health and enhance quality care in the palliative care setting in Pakistan. Family is an essential resource of care in Pakistan. Such measures will assist families in supporting their spirituality and family caregiving activities.

Implications for Research

This study focused on examining the experiences of spirituality among family caregivers at end-of-life care in a hospice setting. Further longitudinal research can be done at various intervals during the trajectory of life-limiting illness to identify similarities or variations in the experiences of spirituality among family caregivers.

Findings suggest recognizing spiritual needs and concerns to prevent spiritual distress among family caregivers. Future studies are recommended to specifically examine those spiritual needs and concerns to further assist families in end-of-life care.

In Pakistan, palliative care is provided in acute care, hospice, and home care settings. It can be assumed that family caregiving and spiritual experiences of family caregivers may vary in those settings. Therefore, studies are recommended in different settings and among different populations to further broaden our understanding of spirituality, spiritual concerns, and spiritual needs among family caregivers in Pakistan.

Future studies using different methodologies are also recommended. Also, studies targeting family caregivers from different cultures, ethnicity, and religions in Asia can be conducted to further generate knowledge around spirituality.

This study did not aim to establish any associations between experiences of spirituality and spiritual wellbeing. Future quantitative studies can be conducted to establish those associations or causal relationships between experiences of spirituality and spiritual wellbeing.

In this particular study, healthcare professionals were interviewed briefly to support/supplement the family caregivers' data. Future studies are recommended to identify the health care professionals' attitudes and perceptions of spirituality in the hospice or palliative care setting.

Conclusion of the Study

This particular study on the experiences of spirituality among family caregivers in a hospice setting was one of a kind in a Pakistani context. The study reported the enriching spiritual experiences of family caregivers that signify the importance of understanding spirituality in caregiving near the end-of-life in different cultures. In Pakistan, culturally, the family plays an integral role in caregiving, especially in a palliative care setting. Findings show that families face multiple struggles and go through various stressors living in poor socio-economic conditions and limited healthcare resources. Despite all the challenges, spirituality was found to be a major resource for coping and strength among family caregivers. Family caregivers uncovered a deep sense of belonging and attachment towards their patients and family. The spiritual experiences such as love, care, respect, service for the family and others and faith in God's blessings and grace gave meanings, purpose, and sense of connectedness in their lives and facilitated personal and spiritual growth. These experiences opened the doors for them to rediscover, deepen or reshape their own attitudes and behaviors, and gave them courage, inner peace, and satisfaction, consequently empowering them to self-transcend and rise above. The study findings strongly support incorporating spirituality into palliative care areas to promote spiritual wellbeing of both

patients and their families. In the end, I would like to quote: "Everyone will experience the loss of a loved one. It is universal. Understanding how different cultures cope and the needs that they have doesn't just influences nursing care-it directs it." (personal communication – Beyerman, K-Jan 3, 2018).

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Appendix A: Information Script and Verbal Consent for Family Caregivers

Title of Study: Experiences of Spirituality among family caregivers of palliative care patients in a hospice setting in Pakistan

Principal Investigator: Nasreen Lalani, RN, MScN, PhD Candidate

Introduction:
Assalam u-Alaikum. I am Nasreen Lalani. I am conducting interviews about your experiences as a family caregiver in a hospice setting. I am conducting this as part of my research as a PhD student at University of Alberta, Canada. I am working under the direction of Dr. Wendy Duggleby and Dr. Joanne Olson, Faculty of Nursing, University of Alberta. Your name was suggested to me by the staff (name) in the hospice/other participant who know about my research.

What will happen during the study?

I'm inviting you to do a one-on-one interview [face –to-face] that will take about 60-90 minutes. I will ask you questions about your experiences as a family caregiver, how you feel being in this role, what gives you meaning being in this role. During the interview, I will take handwritten notes to record your answers as well as use an audio recorder to make sure I don't miss what you say. We can set up a time and place that works for us both.

Are there any risks to doing this study?

There are no known risks to you for participating in this study. However, you may feel uncomfortable talking about your experiences. If you need to take a break or stop completely, please feel free to inform me. If you feel stressful, we can arrange for a counselling with the staff available in the hospice.

Are there any benefits participating in the study?

It is unlikely that there will be direct benefits to you, however, it may allow you to ventilate your feelings and experiences towards care. Your participation will help researchers and healthcare professionals to integrate these experiences and aspects of spirituality while developing family care interventions in the future.

Will my information be kept confidential?

I will keep the information you tell me during the interview confidential. Information I put in my report that could identify you will not be published or shared beyond the research team unless we have your permission. Any data from this research which will be shared or published will be the combined data of all participants. That means it will be reported for the whole group not for individual persons.

Your participation is voluntary:

Your participation in this study is voluntary.

You can decide to stop at any time, even part-way through the interview for whatever reason, or up until approximately six months.

If you decide to stop participating, there will be no consequences to you.

If you decide to stop, I will ask you how you would like us to handle the data collected up to that point.

This could include returning it to you, destroying it or using the data collected up to that point.
If you do not want to answer some of the questions you do not have to, but you can still be in the study.
If you have any questions about this study or would like more information you can call me at (0301) 824-1899.

If you have any concerns about your rights as a study participant, you may contact Ethics Board Bait-ul-Sukoon Cancer Hospital and Hospice Care Center, Karachi, Pakistan at +92 21 34553834.

Part 1 (To be completed by the researcher)

Title of Project: Experiences of Spirituality among family caregivers of palliative care patients in a hospice setting in Pakistan

Principal Investigator: Nasreen Lalani Phone Number: +92 301 8241899
Co-Supervisors: Dr. Wendy Duggleby Phone Number: +1 780-492-8660
Dr. Joanne Olson Phone Number: +1 780-492-6252

Part 2 (to be completed by the research participant)

	Yes	No
Do you understand that you have been asked to be in a research study?		☐
Have you understood the information about the study?		☐
Do you understand the benefits and risks involved in taking part in this research study?		☐
Have you had an opportunity to ask questions and discuss this study?		☐
Do you understand that you are free to withdraw from the study at any time, without giving a reason and without affecting conditions of your employment?		☐
Has the issue of confidentiality and anonymity been explained to you?		☐
Do you understand that the conversations will be recorded?		☐
Do you understand that portions of the final research may be published in professional journals or presented at conferences?		☐ ☐
Who explained this study to you?		☐ ☐

____

I agree to take part in this study: Yes ☐ No ☐

(Printed Name) __________________________ Telephone: ______________

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

____

Appendix B: Demographic Data Sheet for Family Caregivers

Title of Study: Experiences of Spirituality among family caregivers of palliative care patients in a hospice setting in Pakistan

Please provide me with some of your personal information.

It will take about five minutes to complete this data sheet. I will handle all information provided in a confidential manner.

Thank you in advance for completing this data sheet.

Code # ___________ Gender: Female __________ Male ___________

Marital Status: Married☐ Unmarried☐ Divorce☐ Separated☐

Age range in years: 20-30☐ 30-40 ☐ 41–50 ☐ 51–60 ☐61–70 ☐ 70–75☐

Education: Never been to school ☐ Primary ☐ Secondary ☐ Higher Education ☐

Occupation: Labour ☐ Skilled Worker ☐ Housewife☐ Retired☐ Other☐

Religion: Muslim☐ Christian ☐ Hindu☐ Other☐

What is your relationship to the patient?
Mother☐ Father ☐ Sister☐ Brother☐ Spouse☐ Son☐ Daughter☐
Friend☐ Relative☐ Other☐

How long have you been caring for your sick family member? ______

Do you yourself suffer from any illness/disability? ---------------

How many family members are there in your household? ___________

Monthly Income Range (in PKRs): 1000-3000☐ 3000-5000☐ 5000-10,000☐
>10,000☐

Appendix C: Interview Guide for Family Caregivers

- Tell me about your experiences while caring for your family member in a hospice setting?
- How would you define or describe spirituality?
  Prompt: What does spirituality mean to you?
- How do you think your own spirituality affects your caregiving experience?
- Tell me about spiritual practices that have helped you in your caregiving process? or provided you comfort/strength in your caregiving practices?
- Tell me whether religious practices/prayers/ rituals help you (or not help you) in your caregiving practices?
- How do you think healthcare professionals can help to support you in your faith/spirituality in a hospice setting?
- **Probes** will be added in the interview process such as tell me more about it, would you clarify or explain it more for me, tell me more detail about it, I would like to hear more, share any other examples, what makes you feel that way?

Appendix D: Information Letter and Informed Consent for the Healthcare Professionals

Title of Study: Experiences of Spirituality among family caregivers of palliative care patients in a hospice setting in Pakistan

Principal Investigator: Nasreen Lalani, RN, MScN, PhD Student

Co-Supervisors:
Dr. Wendy Duggleby, PhD, RN, AOCN
Professor and Nursing Research Chair Aging and Quality of Life
Director Innovations in Seniors Care Research Unit
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Dr. Joanne Olson, PhD, RN, FAAN
Professor & Director, Quality Assurance & Enhancement
Faculty of Nursing, University of Alberta
4-299 Edmonton Clinic Health Academy (ECHA)
11405 - 87 Avenue,
Edmonton, Alberta, Canada. T6G 1C9
Tel: 780-492-6252
Email: joanne.olson@ualberta.ca

Background
Family go through several experiences while giving care to their family member who are seriously ill and cared for in a hospice setting. Spirituality helps them to cope with their experiences. We are conducting a research study to learn about such experiences of spirituality at end of life care. Healthcare professionals work closely with the patients and their families. Healthcare professionals can guide and support families in the family caregiving practices. The purpose of this research is to explore caregiver's experiences of spirituality and its significance at the end of life. The study will also guide Healthcare professionals to include spiritual care for the families.

Study Procedures
This letter outlines important information to help you decide whether you would like to take part in this research. If you agree, I will ask you to participate in an interview. During the interview, we will talk about your perceptions as a healthcare professional regarding the significance of spirituality in family caregiving. The interview will take around 1 to 2 hours of your time. It will be held at our mutually agreed time at the hospice care facility. I will also ask you to give me some basic information about yourself (e.g. age, gender, and years of experience).

Potential Benefits
Your participation might not benefit you individually. However, your participation will help us to understand the role and significance of spirituality among family caregivers as

perceived by the Healthcare professionals. The study will help Healthcare professionals to integrate spirituality in family caregiving interventions.

Potential Risk

There are no known risks to you for participating in this study. However, some individuals may feel uncomfortable talking about their experiences. If you need to take a break or stop completely you will be able to do so. I will make every attempt to meet with you in the hospice or palliative care facility of the hospital.

Confidentiality

The interviews will be audio-taped and then typed. All information you provide in the interview will be kept confidential. Information that revealed your identity (e.g. your real name) will be removed from the records. Your name will not be used in the tape, notes and typed interviews. Instead, you will be assigned a code which is only known to the members of the research team. Your name will be recorded only on the consent form. The consent form will be locked in separate place than the interview data. All information will only be accessible to research team members or ethics board on request. Data will be stored in the shared drive of a computer. All the data in the shared drive will be password protected. I will keep your records for at least five years after the study has been completed. My co-supervisors in Canada will also keep an electronic copy of the data for the same period of time. I may contact you again if I need more clarifications about the information you have provided to me. If you wish, you will have the option of seeing and changing the typed version of your data.

Voluntary Participation

Your participation in the study is voluntary. You may withdraw from the study at any time without giving me a reason. You are free not to answer any part of the study. You can ask me to stop the interview at any time and you may refuse to answer any question.

Future Use of Data

The information collected for this study will be used to publish papers or presentations. The data may be used for future research. Your name will be kept strictly private in any of these situations.

Additional Contacts

If you have any questions about the study, feel free to contact any time. You may ask questions to Nasreen Lalani, Tel: (301)828-4319 or e-mail at nasreen@ualberta.ca or Dr. Wendy Duggleby, Tel: (780)492-8660 or Dr. Joanne Olson Tel: (780)492-6252

If you have any concerns about your rights as a study participant, you may contact Health Research Ethics Board at the University of Alberta at (780) 492- 0459. This office has no direct affiliation with the study investigators.

Please keep a copy of this letter for reference.

Participant initials: _________________Witness initials: ………………

Flesch-Kincaid Grade level is 8.9

Consent Form for Healthcare Professionals

Title of Study: Experiences of Spirituality among family caregivers of palliative care patients in a hospice setting in Pakistan

Principal Investigator: Nasreen Lalani Phone Number: +92 301 8284319
Co-Supervisors: Dr. Wendy Duggleby Phone Number: +1 780-492-8660
Dr. Joanne Olson Phone Number: +1 780-492-6252

Part 2 (To be completed by the Healthcare Professionals):

	Yes	No
Do you understand that you have been asked to be in a research study?		☐
Have you read and received a copy of the attached Information Sheet?		☐
Do you understand the benefits and risks involved in taking part in this research study?		☐
Have you had an opportunity to ask questions and discuss this study?		☐
Do you understand that you are free to withdraw from the study at any time,		☐
without giving a reason and without affecting conditions of your employment?		☐
Has the issue of confidentiality been explained to you?		☐
Do you understand who will have access to the research information?		☐
Do you agree to have the interview audio-taped?		☐
Who explained this study to you?		☐
____		☐
		☐
I agree to take part in this study.		☐

Signature of Research Participant__________________________
(Printed Name) __________________________ Telephone: ________________
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 ______________

Appendix E: Demographic Data Sheet for Healthcare Professionals

Title of Study: Experiences of Spirituality among family caregivers of palliative care patients in a hospice setting in Pakistan

Please provide me with some of your personal information.

It will take about five minutes to complete this data sheet. I will handle all information provided in a confidential manner.

Thank you in advance for completing this data sheet.

Code # ___________ Gender: Female __________ Male _________

Marital Status: Married☐ Unmarried☐ Divorce☐ Separated☐

Age range in years: 20-30☐ 30-40 ☐ 41–50 ☐ 51–60 ☐61–70 ☐ 70–75☐

Religion: Muslim☐ Christian ☐ Hindu☐ Other☐

Title/Designation: Consultant/Physician ☐ Medical Doctor ☐
Registered Nurse (RN) ☐ Nursing Assistant (NA) ☐ Social Worker ☐ Psychologist ☐

Qualification: Diploma ☐ Undergraduate/Bachelors☐ Graduate/Masters or PhD☐

Years of Experience: 2-4years☐ 4-6years ☐ 6-8years☐ 8-10years☐ >than 10years☐

Years of Experience in Palliative care setting: 2-4years☐ 4-6years ☐ 6-8years☐ 8-10years☐ >than 10years☐

How long have you been working in this facility: _____________years

Do you have any specialized training in palliative care? Yes ☐ No ☐

If yes, what was the duration of the training? ____________

Any other specialized course in the field of palliative care? Please specify: _________

Appendix F: Interview Guide for Healthcare Professionals

- How would you define spirituality and religion?
- In your opinion, how does spirituality help family caregivers in coping with their caregiving activities?
- How do you think healthcare professionals can support family caregivers' spirituality in a hospice setting?
- What are some of the strategies that can help healthcare professionals to integrate various aspects of spirituality in a palliative care/hospice setting?