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Primary Caregivers Caring for a Child at End of Life in Saudi Arabia

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PRIMARY CAREGIVERS CARING FOR A CHILD AT END OF LIFE IN SAUDI ARABIA

by

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ABSTRACT

PRIMARY CAREGIVERS CARING FOR A CHILD AT END OF LIFE IN SAUDI ARABIA

by

Shahad Hafez

The University of Wisconsin-Milwaukee, 2020
Under the Supervision of Professor Julia Snethen

Background/ Significance: Caring for children at end of life (EOL) can be devastating for primary caregivers who are providing the physical, social, and emotional needs of their dying child. Limited information was found on resources in Saudi Arabia to manage the impact on primary caregivers from caring for a child receiving end of life care (EOLC).

Purpose: Explore the experiences of primary caregivers caring for a child at EOL in Saudi Arabia.

Conceptual framework: The conceptual framework for this investigation was comprised of concepts related to EOLC including holistic health, support system and religion.

Method: A phenomenological investigation was conducted in Saudi Arabia. The participant inclusion criteria: female primary care givers, 18 years of age and older, with children under 15 years, who are receiving EOLC. An interview guide was used for conducting in-depth individual interviews. The data was analyzed using thematic analysis, and the analysis was conducted within and across all interviews.

Results: Participants were female primary caregivers (N = 24), who met the inclusion criteria. The findings suggest that primary caregivers caring for a child at EOL experienced biopsychosocial and financial alterations. Additionally, religion/Islam, support system, and culture were factors that impacted the participants' experiences.

Conclusions: This study has implications for nursing education, practice, policy, and research regarding EOLC. Furthermore, it will guide future research on EOLC in Saudi Arabia and countries worldwide.

To

my Parents,

my Sisters,

my Brother,

my Friends,

my Family in the U.S.,

and my Major Professor

TABLE OF CONTENTS

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Chapter 1

Introduction

Primary Caregivers Caring for a Child at End of Life

Taking care of a child at end of life (EOL) is a challenging experience (Gothwal et al., 2015). In Saudi Arabia, mothers are the primary care givers for their children regardless of the type or severity of the child's illness (Saad, 2016). As the primary care giver, mothers intimately experience their child's life limiting illness (Khraisat et al., 2017). Mothers whose child is dying experience the physical role of the primary care giver while also grieving the loss of their child (De Vos et al., 2015). Facing the death of a child can be traumatic, impacting the mothers psychologically, physically, and socially (Khraisat et al., 2017).

Globally, studies have been conducted on EOL, EOLC, and the experiences of patients, family members, and healthcare professionals (Atout et al., 2017; De Vos et al., 2015; Haley & Walker, 2016; Mc Andrew & Leske, 2015; and Zimmermann et al., 2016). Nevertheless, studies conducted on EOL in Saudi Arabia are limited. Generally, EOL studies conducted in Saudi Arabia focus on the religious (Islamic) perspectives, healthcare professionals' beliefs and opinions, and family members' experiences (Al Ayed & Rahmo, 2014; Al Dawood et al., 2012; Hammami et al., 2015; Katooa et al., 2015; Miller et al., 2014). No investigations were found in Saudi Arabia exploring mothers' experiences as primary care givers for their dying child. Additionally, nothing was found in the literature on the psychological, social, and physical impact on Saudi Arabian mothers on managing the care of a dying child.

Background

End of Life and End of Life Care

The American Psychological Association (2018) defined EOL as the period when healthcare providers expect death within six months. End of life represents a unique period that is disease centered and time based (Hui et al., 2014). A disease centered EOL refers to when the patient is in the irreversible stage of the disease prior to death (Hui et al., 2014). The time-based EOL perspective refers to the hospice admission criteria requirement that the patient's life expectancy to be six months duration or less (Hui et al., 2014).

The National Cancer Institute (NCI) (2018) defined EOLC as the care provided to individuals who are at EOL and stopped treatments to cure or manage their illness. According to the NCI (2018) EOLC is the emotional, social, physical, and spiritual support provided to dying individuals and their families. The goal of EOLC is to provide comfort to the dying individual by managing their pain and other undesired symptoms (NCI, 2018).

Hospice care provides comfort care to patients who have a life expectancy of six months or less (Vitas, 2018). Patients in hospice care do not receive curative treatments because their illness has no cure (Vitas, 2018). Hospice care and EOLC are intertwined. Patients are receiving comfort care (with no curative treatments) at their last hours, days, weeks, or months of life (Americare, 2016). After the failure of curative treatments, palliative care can lead to hospice and EOLC (Center for Hospice Care, 2018). Palliative care is the comfort care provided to the patient to relieve undesired symptoms (pain, nausea, shortness of breath etc.) (Vitas, 2018). Palliative care should be provided at the time of diagnosis, during curative treatment, and at EOL (Vitas, 2018).

End of Life Care in Children

It has been reported that pediatric EOLC is different than adult EOLC (Johnston et al., 2017). Children suffer from terminal illnesses longer than adults (Keegan et al., 2016). Children receiving hospice care are admitted on an average of 103 days, whereas adults are admitted on an average of 66 days (Dingfield et al., 2015). In general, pediatric mortality rates are lower than adult mortality rates (Hall et al., 2013). Unlike adults, sometimes children cannot express their needs at EOL (Johnston et al., 2017). According to Wolfe et al. (2015) children diagnosed with advanced cancer experience pain (48 percent), fatigue (46 percent), and irritability (37 percent).

Children suffering from a terminal illness have limited treatment options compared to adults (Johnston et al., 2017). The majority of children diagnosed with a terminal illness receive palliative, hospice, or EOL care (Johnston et al., 2017). Similar to adult EOLC, healthcare professionals provide care to both the child and family members (Dingfield et al., 2015). Family members included in pediatric EOLC are parents and siblings (Johnston et al., 2017). Children generally die in hospitals rather than their homes, as needed, pediatric EOLC is available in hospitals, and parents are concerned about the impact of the child's death on the siblings (Hall et al., 2013; Johnston et al., 2017).

Significance

According to the World Health Organization (WHO) (2019) in Saudi Arabia the mortality rates of children in 2015 was 17 percent. The 17 percent mortality rate is equivalent to 15 deaths per 1000 births (WHO, 2019). The common causes of childhood death under the age of five are prematurity, congenital anomalies, injuries, and pneumonia (WHO, 2019). Adolescents between the ages of 12-18 main causes of death is road traffic accidents followed by leukemia, congenital anomalies, and lower respiratory infections (DeNicola et al., 2016). Unfortunately, no recent studies were found identifying the common causes of childhood death between the ages of five and 12 in Saudi Arabia. However, in the United States, the common causes of childhood death between the ages of 5 and 14 in 2016, are cancer, unintentional injuries/ accidents, and intentional self-harm/ suicide (Jiaquan et al., 2018).

Studies in Saudi Arabia are generally quantitative, with limited qualitative studies. Studies were found in the literature on EOL from the religious (Islamic) perspective and healthcare providers views and opinions. Limited studies focused on family members caring for their loved one at EOL. Family members are reported to be involved in the EOLC decision making process, with parents making EOLC decisions on behalf of their children (Alkabba et al., 2012; Gothwal et al., 2015). Al Dawood et al. (2012) found that families are not aware of the care and support they could receive from the healthcare system. No studies were found regarding the experiences of mothers caring for a child receiving EOLC. This qualitative study about mothers' experiences caring for children receiving EOLC will provide insight into the EOLC experience. Additionally, the study will address a gap in the literature regarding EOLC with children.

Saudi Arabian Culture and Traditions

Overall, Saudi Arabian families are large in size having many children; and parents and grandparents are expected to remain in their children's lives as they get older (Hope College, 2016). As children grow older and get married, they reside close to their parents to maintain their relationship; children are expected to treat their parents well (Hope College, 2016). Distant families and in-laws have strong familial bonds; and are considered members of the family (Hope College, 2016).

Saudi Arabian families are generally patriarchal (Murphy, 2014). The father in the family is head of the authoritarian hierarchy of the family structure; alternately, the older male in the family is the authoritarian figure (Murphy, 2014). The guardianship law in Saudi Arabia requires all women, regardless of age, to have a male guardian (Murphy, 2014). The male guardian must give women permission to travel, go to school or work, and get married (Murphy, 2014). In Saudi Arabia women have less authority, fewer rights, and limited roles than men (Garcia & Troisonne, 2016). Recently, King Abdullah Al-Saud has ordered that women be allowed a greater role in Saudi Arabian society (Garcia & Troisonne, 2016). The goal of the king's order is to develop and grow gender equality in the country (Garcia & Troisonne, 2016).

Islam

Islam is a monotheistic religion that provides a foundation for human conduct, laws and regulations, behaviors, and lifestyle (Bamousa et al., 2016). Saudi Arabia is an Islamic country where Islam shapes the culture. Thus, understanding Islam's rules, laws, and values regarding illness, death, and EOL are fundamental to understanding the Saudi Arabian culture, laws and Muslims' perspectives towards EOLC.

Illness and Death in Islam

Muslims believe that suffering from an illness as an atonement for one's sins (Chamsi-Pasha & Albar, 2016). It is believed that suffering patients and their families who care for them will be rewarded by *Allah* in the hereafter (Chamsi-Pasha & Albar, 2016). Therefore, in Islam, taking care of the ill is a high obligation (Chamsi-Pasha & Albar, 2016). Muslims trust that *Allah* is merciful, has the ultimate wisdom, and is the healer for all physical and psychological illnesses (Chamsi-Pasha & Albar, 2016). Islam encourages using advances in healthcare for treating curable illnesses; however, using passive or active medical procedures to end someone's life is forbidden (Chamsi-Pasha & Albar, 2016). Muslims believe that incurable illnesses are *Allah's* will and he will end the person's life at the right time (Chamsi-Pasha & Albar, 2016). *Allah* said *"Wa asbiroo inna Allah ma'a alsabireen*" (Holy Quran: Al Anfal verse 46, Chapter 10), meaning that God is with those who patiently persevere (Almaany, 2017). So, patience is highly appreciated and fortified in Islam, especially when suffering from an illness (Chamsi-Pasha & Albar, 2016).

In Islam, an individual's life is "sacred but finite in duration" (Steinberg, 2011, p. 155). Muslims believe that death is an inevitable destiny, and predetermined only by *Allah* (Tayeb et al., 2010). Therefore, people in Saudi Arabia avoid talking about EOL decisions or death (Tayeb et al., 2010). As humans we cannot interfere with fate as it is beyond our control (Tayeb et al., 2010). Muslims in general are accepting of death; which influences how the patient, family, and healthcare providers view death (Silbermann et al., 2012).

EOLC Options in Islam

Based on the Islamic laws, there are limited EOLC options allowed for Muslims. Full support requires providing the patient with all required medical care including cardiopulmonary resuscitation (CPR) (Aldawood et al., 2012). Do not resuscitate (DNR) orders requires providing the essential ICU management excluding CPR (Aldawood et al., 2012). Palliative care is an approach that improves the patient's quality of life related to a life-threatening illness (WHO, 2016); for example, providing pain management for a cancer patient. Lastly, withdrawal from life support, if the patient has a poor quality of life (Saeed et al., 2015). There has been concerns related to futile medical therapy where the patient's life is prolonged with no benefits for their quality of life (Chamsi-Pasha & Albar, 2016). Islamic scholars (*Ulamá)* agree that delaying death with hopeless therapy is unacceptable (Chamsi-Pasha & Albar, 2016). In situations where the patient is receiving futile treatment, withdrawal from life support is encouraged (Chamsi-Pasha & Albar, 2016).

Children and Parents in Islam

In Islam, the children's age group encompasses infancy until puberty (Stacey, 2017). Children are a source of pride and joy (Quran Reading, 2018). Parents need to be thankful for having a child since not everyone can conceive children (Quran Reading, 2018). Children could also be source of distress and allurement; because, with children comes great responsibility (Quran Reading, 2018). In Islam, parents are responsible for providing security, respect, love, mercy, and care (Quran Reading, 2018; Saad, 2016; Stacey, 2017). Parents need to protect their children from moral and physical harm, choose a good name for their children, treat their children with leniency and strictness, and raise their children to be Muslims (Quran Reading, 2018; Saad, 2016; Stacey, 2017). Children are required to be respectful, obedient, and kind to their parents even in adulthood (Stacey, 2017).

Losing a child is one of the most difficult and painful experiences parents go through (Khraisat et al., 2017; Saad, 2016). Parents are rewarded from *Allah* for accepting the loss of a child and being patient by giving them salvation in the afterlife (Saad, 2016). Parents therefore need to be reminded that the devastating loss of their child will bring them the infinite gain in the end (Saad, 2016). Additionally, Muslims believe that all dead children go to Paradise and will reunite with their parents in afterlife (Saad, 2016). According to the Islam Way (2014) children in Paradise are full of joy and happiness, and able to walk around freely without disruption. Children who die before their parents could be the reason their parents are allowed to join them in Paradise (Islam Way, 2014). Prophet *Mohammed* (peace be upon him) said that “the children are the da’amees (small fish) of Paradise. Each of them will meet his father or his parents and take him by his cloth- or by his hand- and never stop until *Allah* permits both of them into Paradise” (Muslim) (Saad, 2016, para. 5).

End of Life Decision Making in Saudi Arabia

There have always been ethical dilemmas regarding EOL decision making in Saudi Arabia (Chamsi-Pasha & Albar, 2016). Usually, several individuals are involved in the decision-making process which makes it more complicated. Individuals involved in the decision-making process in Saudi Arabia are the patient, family members, and healthcare providers (Saeed et al., 2015). According to Hammami et al. (2015) patients at EOL prefer to have a shared decision with family members and physicians, rather than making EOLC decisions themselves. In Saudi Arabia, EOLC decisions are made by physicians and not family members; because, family members are considered unqualified to make EOLC decisions (MOH, 2018). However, if the patient is a child, the patient's guardian (their father or older brother) opinion could be considered in the decision-making process (MOH, 2018).

End of life care policies in Saudi Arabia are based on Islamic *Fatwás*. The main *Fatwá* followed in Saudi Arabia regarding EOLC decisions is *Fatwá* no. 12086 (Saeed et al., 2015). *Fatwá* (No. 12086) was developed in 1989 stating that "if three knowledgeable and trustworthy physicians agreed that the patient condition is hopeless; the life-supporting machines can be withheld or withdrawn. The family members' opinion is not included in decision making as they are unqualified to make such decisions" (Saeed et al., 2015, para. 1).

Pediatric End of Life Care Policy in Saudi Arabia

The Ministry of Health (MOH) in Saudi Arabia (2018) have developed a policy regarding withholding or withdrawing life support from patients in the pediatric intensive care unit (PICU). The policy indicates that it is allowed to withhold or withdraw life support if the pediatric patient has suffered brain death (MOH, 2015). There are other criteria that need to be met to apply the policy (MOH, 2018). The criteria identified by MOH (2018) include: the brain death diagnosis must be supported by two physicians, and one of them should be a neurologist or a neurosurgeon. The assigned physician would document in the patient's record the causes of brain death. A patient must be pronounced brain dead before disconnecting the ventilator. The brain death law has to be explained to the family and other interested people before the procedure is applied. After that, the agreement of two physicians (neurologist or neurosurgeon and a pediatrician) must be obtained if life support machines are being withheld or withdrawn. The second neurologist or neurosurgeon should not be a practice associate of the pediatrician. In addition, the patient’s medical record must indicate that there has been no expressed intention from the patient that life support machines be initiated or maintained in such circumstances. The patient’s medical record need to reflect that the patient’s family, guardian or conservator (male), agrees in the decision to withhold or withdraw life support. Finally, the dignity and comfort of the patient should be maintained if death does not occur after withholding or withdrawing life support machines.

Mothers’ Involvement in End of Life Care Decision-Making

Generally, the father’s opinion regarding the child’s EOLC is favored over the mothers (Ramsey & Matt, 2016). Nonetheless, the EOLC decision is made by three qualified physicians, referring to Fatwá (no. 12086). It is recommended that both parents make EOLC decisions on behalf of their child, with consideration of healthcare providers’ opinions. Parents need to provide consent and agree on the same decision, instead of giving the responsibility to one parent to make the decision. Studies found that a child’s EOLC is a group decision that includes parents, healthcare providers, and sometimes the child (Lichtenthal et al., 2015; Ramsey & Matt, 2016).

In Saudi Arabia, mothers are known to be the primary care giver for their children (Katooa et al, 2015). Mothers are involved caring for their child and thus intimately experience their deterioration during their child’s illness (Katooa et al., 2015). According to Katooa et al. (2015), mothers were found to stay longer hours with their children during the hospitalization than fathers. Consequently, mothers are the closest to their children and know them best

(Arabiat et al., 2013). Therefore, mothers are best positioned to be involved in the decision-making process related to her child's EOLC.

Mothers' experiences with their children at EOL have been presented in the literature (De Vos et al., 2015; Haley & Walker, 2016; Khraisat et al., 2017; Lou et al., 2015; and Ohs et al., 2015; Temsah, 2018; Willems et al., 2014). Mothers in multiple studies stated that caring for their children at EOL affected them psychologically, physically, socially, and financially (Atout et al., 2017; De Vos et al., 2015; Haley & Walker, 2016). Moreover, mothers expressed that their spiritual beliefs, culture and traditions, family and friends, and healthcare system influenced their experience (Haley & Walker, 2016; Hemingway & Seymour, 2017; Khraisat et al., 2017). However, the experiences of mothers with their children at EOL has not yet been explored in Saudi Arabia.

Purpose and Research Questions

The purpose of this study is to explore the experiences of primary caregivers caring for a child at EOL in Saudi Arabia. The research questions are: (1) How does caring for a child receiving EOLC impact the primary caregivers' psychological, physical, social, and financial status? (2) What are the factors that influence the experiences of primary caregivers caring for a child receiving EOLC in Saudi Arabia?

Definition of Terms

Theoretical Definitions

End of life. The period when healthcare providers expect the death of the patient within six months (APA, 2018).

End of life care. Care provided to individuals who are at EOL and stopped treatments to cure or manage their illness (NCI, 2018).

Mother. The biological female parent that protects and care for her children (Mangeli et al., 2018).

Mother figure. Individual that embodies the qualities of a mother.

Child. Individual below the age of 18 (Unicef, 2019).

Operational Definitions

End of life. Final months, weeks, days, or hours of the person's life where it is medically clear that death is imminent.

End of life care. The emotional, social, physical, and spiritual support provided to dying individuals and their families (NCI, 2018).

Mother. The biological, adoptive, or step female parent that protects, cares, and loves her children unconditionally.

Mother figure. Woman that embodies the qualities of a mother, such as a grandmother, aunt, or older sister.

Child. Individual between the ages of one day and 14 years.

Conclusion

Studies are needed to explore mothers caring for children receiving EOLC. There are studies conducted globally on EOLC (Al Ayed & Rahmo, 2014; De Vos et al., 2015; Haley & Walker, 2016; Khraisat et al., 2017; Lou et al., 2015; Ohs et al., 2015; Temsah, 2018; Willems et al., 2014); but, limited number of studies conducted in Saudi Arabia. An additional gap in the literature is the type of studies that have been conducted in Saudi Arabia, as studies in Saudi Arabia are overwhelmingly quantitative, focused on healthcare providers, and adult patients. There is limited information is available about children and their family members' experiences at

EOL/ EOLC in Saudi Arabia. A qualitative research study will provide additional insight into mothers’ experiences with their children at EOL.

Moreover, Saudi Arabia is an Islamic country where Islam shapes the culture and traditions. So, illness is viewed as an atonement for one’s sins; and death is defined as the complete separation of the spirit from the body. Based on Islamic laws there are limited EOLC options allowed. Therefore, in Saudi Arabia full support including CPR, DNR orders, palliative care, and withdrawal from life support are the only options allowed at EOL. Furthermore, Islam highlights the importance of family, and how children should be treated with care. Caring for an ill or dying child is highly rewarding for parents, as it is explained in Islam. In my study, the aim is to explore the experiences of mothers caring for a child receiving EOLC within the Saudi Arabian healthcare system.

Chapter 2

Systematic Review

Manuscript 1

Abstract

Background: The mother feels complete when she fulfills her role in protecting her child from harm. If a child is diagnosed with a terminal illness and reaches EOL, the mother's life is affected negatively. The mother is affected mentally, psychologically, and physically because her child is dying.

Objectives: Explore the recent studies that focused on experiences of mothers caring for a child receiving EOLC at home or a healthcare facility.

Data sources: An electronic search was done in multiple databases, including the University of Wisconsin-Milwaukee library, PsycINFO, PubMed, CINAHL, and Academic Search Complete.

Study eligibility criteria: Studies published within the past five years, studies about EOL/ EOLC, hospice cate, pediatric care, quantitative, qualitative, and mixed methods studies.

Synthesis methods: Thematic synthesis following PRISMA guidelines.

Results: Four themes emerged from the thematic synthesis. The main themes included decision making challenges, communication with healthcare professionals, parents' support system, and grief.

Limitations: Parents were included in most studies. However, the number of mothers exceeded the number of fathers. Some researchers mentioned that there was no diversity between their participants (most participants were Caucasian).

Conclusion: There is limited information available about children and their family members' experiences at EOL/ EOLC in Saudi Arabia as it was presented in other countries. Based on this systematic review, more studies are needed related to children at EOL in Saudi Arabia.

Keywords: end of life, parents, mothers, pediatric end of life care

Mothers Caring for a Child Receiving End of Life Care

Studies have been conducted globally exploring parents/ mothers' experiences with their children who are at EOL (Arutyunyan et al., 2018; Arruda-Colli et al., 2016; Atout et al., 2017; Baughcum et al., 2017; De Vos et al., 2015; Haley & Walker, 2016). Individuals at EOL experience mental, psychological, physical, social, financial, and spiritual alterations during that period (Arruda-Colli et al., 2016; Atout et al., 2017; Lou et al., 2015). However, limited information was found focused on the experiences of mothers caring for their child at EOL and EOLC. Therefore, the aim of this systematic review is to explore recent studies that focused on experiences of mothers caring for a child receiving EOLC at home or within a healthcare facility. A secondary aim was to review the current studies conducted in Saudi Arabia regarding EOL and EOLC.

Background

End of Life Definitions

End of life is a unique healthcare situation concentrated on two main perspectives, disease centered and time-based centered (Hui et al., 2014). The disease centered perspective focuses on the irreversible stage of the disease prior to death (Hui et al., 2014). The time-based perspective emphasizes the hospice admission criteria of a life expectancy of six months or less (Hui et al., 2014). Several definitions for EOL have been presented in the literature. The American Psychological Association (2018) defined EOL as the period when healthcare providers expect death within six months. End of life care (EOLC) was defined by the NIH (2018) as the medical care and support provided to individuals around their time of death. The National Cancer Institute (NCI) (2018) further delineated that EOLC is the care provided to individuals who are at EOL and stopped treatments to manage their illness. According to the

NCI (2018) EOLC is the emotional, social, physical, and spiritual support provided to dying individuals and their families. The goal of EOLC is to provide comfort to the dying individual by managing their pain and other undesired symptoms (NCI, 2018).

Parents

In general, parents report feeling responsible for the health and illness of their children (Pease & McMillin, 2018). As the primary caregivers and protector of their child (Pease & McMillin, 2018), when a child gets diagnosed with a terminal illness, the family's life change (Youngblut et al., 2017). The parental relationship becomes more collaborative (Pease & McMillin, 2018), as parents try to cope with their child being at EOL (Youngblut et al., 2017). De Vos et al. (2015) indicated that parents experience distress, fear, despair, helplessness, and grief when their child is dying. Death of a child is a devastating, difficult, and extremely painful experience for parents (Youngblut et al., 2017).

Siblings

A child's EOL is impacted positively by the presence of their siblings (Baughcum et al., 2017). It was reported that siblings distracted the child from the undesired symptoms of the illness and treatments (Baughcum et al., 2017). The siblings were considered a support system for the dying child and parents (Widger et al., 2015). Moreover, siblings experience fear, stress, and grief when the child is at EOL (Youngblut et al., 2017). Some siblings reported feeling neglected from parents while caring for the terminally ill child (Arruda-Colli et al., 2016). Therefore, the death of the child is a life changing experience for siblings (Baughcum et al., 2017; Youngblut et al., 2017).

Mothers

Motherhood is a turning point in a woman's life (Mangeli et al., 2018), as the maternal role becomes part of her new identity (Mangeli et al., 2018). As a mother, women grow attached to their child and overtime develop a strong bond (Mangeli et al., 2018). Mothers report feeling complete when they fulfill the role of protecting the child from harm (Mangeli et al., 2018). When a child is diagnosed with a terminal illness, the mother's life is negatively affected (de Andrade et al., 2017). Mothers can experience mental, psychological, and physical changes due to the pending loss of her child (Arruda-Colli et al., 2016; Atout et al., 2017; Lou et al., 2015). According to Mangeli et al. (2018) mothers report that when their child is at EOL they feel like their bond between themselves and their child is starting to break. The mother's dream of seeing her child grow and develop into adulthood is lost (Rahman & De Souza, 2014). A mother is forced to deal with the new reality of being a mother of a dying child, all the while hoping to survive a devastating period in her life (Mangeli et al., 2018).

Studies have shown that it is difficult for parents to be present with their child at EOL (Arruda-Colli et al., 2016; Atout et al., 2017; De Vos et al., 2015; Lou et al., 2015; Ohs et al., 2015). Youngblut et al. (2017) reported that the mother's pain, distress, and grief are greater than that experienced by father's. Mothers adapting to their child's being at EOL was found to be more difficult than fathers' adaptation (Youngblut et al., 2017). After the death of a child, mothers' coping and accepting of the fact could take a long time (Pease & McMillin, 2018; Youngblut et al., 2017). Mothers have expressed feeling guilt, despair, regret, and even thoughts of self-harm after the loss of their child (Youngblut et al., 2017). According to Arruda-Colli et al. (2016) mothers feel they have failed and not fulfilled their maternal role requirement to protect their child from harm. Conversely, some mothers identify positive elements within the tragic experience (Youngblut et al., 2017). Among the positive elements were mothers becoming more forgiving, empathetic, and hopeful after their child's death (Laasko et al., 2002).

Methods

The search strategy for this systematic review included an electronic search in the following databases, the University of Wisconsin-Milwaukee library, PsycINFO, PubMed, CINAHL, and Academic Search Complete. Keywords used in the search included end of life, end of life care, palliative care, death, terminal illness, family, parents, children, pediatrics, and neonates. The inclusion criteria included (a) studies published in English (b) within the past five years, (c) studies about EOL/ EOLC, (d) palliative care, (e) hospice care, (f) pediatric care, (g) quantitative studies, (h) qualitative and (i) mixed methods studies. The exclusion criteria included studies focused on pediatric acute or chronic illnesses. The electronic search revealed a total of 153 studies. Out of the 153 studies, 89 studies were duplicates and most studies were excluded due to not meeting the inclusion criteria. The total articles screened were 40, and 11 studies were accepted (see Figure 1.2).

Analysis

Thematic synthesis was used in this systematic review and was organized based on the PRISMA guidelines (Moher et al., 2009). For the thematic synthesis the 11 studies included in this systematic review were organized in an evidence table (see Table 1, Table 2). Quantitative, qualitative, and mixed methods studies were organized alphabetically based on the author's names. For convenience, the evidence table included the author's name, year of publication, country where the study was conducted, study design, sample, data collection method, analysis, study findings, and the strengths and limitations of the study. Therefore, the main concepts of each study were highlighted, allowing for the identification of the similarities and differences between the studies. The quantitative, qualitative, and mixed methods studies revealed the objective and subjective concepts related to EOL. The researchers in the studies explored different concepts about EOL such as, EOLC, EOL decision making, terminal illnesses, psychological and mental status, spirituality, and communication at EOL.

Findings

Four themes emerged from the thematic synthesis. The themes were not only related to mothers' experiences. The themes that emerged were related to parents and family members who had an experience with a child at EOL. The main themes included: decision making challenges, communication with healthcare professionals, parents' support system, and grief.

Decision-making Challenges

Parents faced challenges while making EOLC decisions on behalf of their child (Atout et al., 2017; De Vos et al., 2015; Ohs et al., 2015; Popejoy, 2015; Zimmermann et al., 2016). Parents struggled to decide who should be responsible to make the EOLC decision for their child (Ohs et al., 2015). Other parents believed that EOL decisions are shared between the parents and healthcare professionals (Ohs et al., 2015; Zimmermann et al., 2016). Sometimes parents believed that physicians should make the EOLC decision for the child, since physicians are qualified and more knowledgeable about medical diagnoses (Atout, et al., 2017; De Vos et al., 2015). Also, parents preferred that physicians made the EOLC decision for their child to avoid future guilt (Atout et al., 2017). According to Popejoy (2015) making EOLC decisions required discussing the options available, timing of the discussion, decision makers, and the values of parents of the child receiving EOLC.

Communication with Healthcare Providers

Communication between parents and healthcare professionals was essential while providing EOLC for a child (Baughcum et al., 2017; De Vos et al., 2015; Zimmermann et al., 2016). Healthcare professionals (physicians and nurses) communicated with parents to help them make EOLC decisions on behalf of their dying child (Baughcum et al., 2017; De Vos et al., 2015; Zimmermann et al., 2016). The conversations between parents and healthcare professionals focused on the child's diagnosis, prognosis, and EOLC options available (De Vos et al., 2015). Parents expressed that communicating with healthcare professionals helped them in the EOLC decision making process (Zimmermann et al., 2016). Ongoing communication between children, parents, and healthcare professionals helped form a working relationship when providing EOLC (Baughcum et al., 2017).

Parents Support System

Parents required a support system while caring for a child at EOL, (Baughcum et al., 2017; De Vos et al., 2015; Haley & Walker, 2016; Katooa et al., 2015; Zimmermann et al., 2016). Parents' support came from each other, family members, and healthcare professionals (Baughcum et al., 2017; De Vos et al., 2015; Haley & Walker, 2016; Katooa et al., 2015; Zimmermann et al., 2016). Parents found it helpful to share their emotions, grief, fear, despair and frustration with others (De Vos et al., 2015). Expressing emotions helped parents to power through the hard times with their child at EOL (Haley & Walker, 2016). The support parents required from family members and healthcare professionals provided them the strength to make EOLC decisions for their child (Zimmermann et al., 2016). Parents felt supported by sharing their experience with other parents going through the same situation (Atout et al., 2017). Additionally, parents found support through spirituality (Arutyunyan et al., 2018; Haley &

Walker, 2016). Parents appreciated the privacy they were provided to practice their spiritual beliefs that supported them wile caring for their child at EOL (Arutyunyan et al., 2018).

Grief

Grief was a common emotion expressed by parents with a child receiving EOLC (Arruda-Colli et al., 2016; Atout et al., 2017; De Vos et al., 2015; Lou et al., 2015; Ohs et al., 2015). Parents reported feeling grief before the death of their child (Arruda-Colli et al., 2016). The grief process started when parents saw the deterioration of their child's health (Lou et al., 2015). As the parents grieved, they lost hope for finding a cure, developing fear, and frustration (De Vos et al., 2015; Lou et al., 2015). Parents feared the loss of their child and frustration for not being able to help their child to survive (De Vos et al., 2015). Even though parents were losing their child over time, it was hard to let go and say goodbye (Ohs et al., 2015).

Quality Critique

The studies included in this systematic review were six qualitative studies, three quantitative studies, and two mixed methods studies (see Table 1.2 and Table 2.2). The studies were conducted in different countries including: Saudi Arabia (Katooa et al., 2015), Jordan (Atout et al., 2017), Brazil (Arruda-Colli et al., 2016), Netherlands (De Vos et al., 2015), Taiwan (Lou, Mu, Wong & Mao, 2015), England (Popejoy, 2015), Switzerland (Zimmermann et al., 2016), and the United States (Arutyunyan et al., 2018; Baughcum et al., 2017; Haley & Walker, 2016; Ohs et al., 2015). The studies were conducted by researchers representing different disciplines, including nursing and medicine.

Qualitative Studies

Overall, the qualitative studies aimed to explore the experiences of parents (mostly mothers) and healthcare professionals caring for a child receiving EOLC. The experiences of parents and healthcare professionals included their attitudes towards illness and death, spiritual beliefs, perspectives towards EOLC, decision-making process, communication skills, and coping mechanisms while caring for their child at EOL. Across the studies the data was collected with semi-structured in-depth interviews. The number of participants included in the qualitative studies ranged between one and 83 participants (mothers, fathers, nurses, and physicians). The data was collected by multiple researchers which reduced research bias. According to Noble and Smith (2015) including other researchers will decrease the chance of bias and enhance the trustworthiness of qualitative research. Furthermore, most of the data in the studies were analyzed using a constant comparative method to analyze interviews. A single study used Colaizzi’s method for analyzing the phenomenological data collected (Lou et al., 2015).

Quantitative Studies

The quantitative studies explored different concepts related to a child receiving EOLC. The concepts explored included parents’ experiences with their child at EOL, communication and barriers between parents and healthcare professionals at EOL, and parents’ coping patterns while caring for an ill child. Across the studies data was collected through observation and questionnaires. The number of participants included in the quantitative studies ranged between 122 and 186 participants (mothers, fathers and nurses). Most researchers used SPSS to analyze their data (descriptive and inferential statistical analysis). However, the findings could not be generalized to a population of mothers because of the small sample size (Haley & Walker, 2016; Katooa et al., 2015).

Mixed Methods Studies

Both mixed methods studies explored the experiences of parents caring for a child at EOL. Researchers collected the data with in-depth interviews and surveys. The number of participants in both studies ranged between eight and 45 participants (mothers and fathers). Then the data was analyzed using constant comparative analysis, content analysis, or independent sample *t* tests and X^2 analyses. In-depth interviews and survey distribution are common effective data collection methods used in mixed methods studies (Creswell & Creswell, 2017).

Discussion

Studies in this systematic review indicated the complexity of caring for a child at EOL. Parents found it challenging to be with their dying child receiving EOLC. Most parents struggled in the EOLC decision making process (Atout et al., 2017; De Vos et al., 2015; Ohs et al., 2015; Popejoy, 2015; Zimmermann et al., 2016). Parents believed that it was easier to make a group decision regarding their child's EOLC, with other family members and healthcare professionals (Ohs et al., 2015; Zimmermann et al., 2016). Some parents reported that healthcare professionals were more qualified to make EOLC decisions for their child (Atout et al., 2017). One concern with parents as decision makers was guilt parents experienced in making EOLC decisions (Youngblut et al., 2017). Parents thought it was necessary to discuss EOLC options with healthcare professionals and appreciated honesty with their child's prognosis (Baughcum et al., 2017). Healthcare professionals empowered parents when they considered the parents' personal values in their child's healthcare plan (De Vos et al., 2015).

Communication between parents and healthcare professionals was identified as an important factor in caring for a child at EOL. Communication between parents and healthcare providers facilitated making EOLC decisions on behalf of the dying child (Baughcum et al., 2017). Parents thought it was important to communicate with healthcare professionals to understand their child's health conditions and EOLC options available (Ohs et al., 2015;

Popejoy, 2015; Zimmermann et al., 2016). Communication on a regular basis led to building healthy relationships between parents and healthcare professionals (Baughcum et al., 2017). Furthermore, communication was encouraged to provide the best EOLC to the dying child (Popejoy, 2015).

The studies in this systematic review discovered the importance of having a support system for parents caring for their child at EOL. The support system mentioned in the studies included partner support (parents themselves), family members, and healthcare professionals (Baughcum et al., 2017; De Vos et al., 2015; Haley & Walker, 2016; Katooa et al., 2015; Zimmermann et al., 2016). Parents experience grief, fear, despair and frustration when their child is at EOL (Arruda-Colli et al., 2016). The parents needed the support to express their emotions as a way to cope with their child being at EOL. Furthermore, parents felt that spirituality was another support system that helped them through tough times caring for their child at EOL (Arutyunyan et al., 2018; Haley & Walker, 2016). Support from family members and healthcare providers and through spirituality helped parents to make EOLC decisions for their dying child (De Vos et al., 2015). Because, parents felt the strength and comfort from the support that was surrounding them (Baughcum et al., 2017; De Vos et al., 2015; Haley & Walker, 2016; Katooa et al., 2015; Zimmermann et al., 2016).

Parents experienced grief before the death of their child, some even starting to grief as soon as their child's health worsened (Lou et al., 2015). Devastation and helplessness accompanied the grief, because parents were not able to help improve the health of their dying child (De Vos et al., 2015; Lou et al., 2015). Parents also feared the loss of their child and worried about what their life would be like after their child's death (De Vos et al., 2015; Lou et al., 2015). The parents felt hopeless because there was no cure for their child's condition, and it was painful to observe the deterioration (De Vos et al., 2015; Lou et al., 2015). Overall, it was very hard for the parents to let go and say goodbye to their child (Ohs et al., 2015).

Limitations/ Bias

Mothers and fathers were included in most studies chosen for this systematic review. Researchers indicated that most participants were mothers and the number of fathers was limited. Some researchers stated that there was no diversity between their participants. The participants included in all studies were limited to a single or a couple of healthcare facilities. A couple of studies mentioned the possibility of bias in their findings related to retrospective self-reports required from participants. Furthermore, there was a bias in selecting the studies for this systematic review, as the studies chosen were limited to specific inclusion criteria.

Gaps in the Literature/ Science

This systematic review identified the most recent studies conducted about EOL globally. However, there was a specific focus on the recent studies conducted in Saudi Arabia. Because, a future study is planned to be conducted in Saudi Arabia about the experiences of mothers caring for a child receiving EOLC. This systematic review revealed that studies about EOL have been conducted in Saudi Arabia. However, the studies conducted focused on healthcare providers' knowledge, beliefs, attitudes, and ability to discuss EOLC options with families (Aljohaney & Bawazir, 2015; Alkabba et al., 2012; Mobeireek et al., 1996). Other studies in Saudi Arabia showed that family members are involved in the EOLC decision making process (Alkabba et al., 2012). However, family members' involvement was not discussed in the Saudi Arabian quantitative or qualitative studies.

EOL and EOLC are considered taboo topics to discuss (Russell, 2015). Because, both topics are directly connected to Islam; and conflicts between people is common (Chamsi-Pasha

& Albar, 2016). Some individuals (including the dying person, family members and healthcare professionals) do not appreciate the importance of discussing EOLC options in advance (Alkabba et al., 2012). Other individuals are not fully aware of the EOLC options available in their healthcare facility (Alkabba et al., 2012). Lastly, some families are not aware of the care and support they could receive from the healthcare system during and after the death of their loved one (Alkabba et al., 2012).

Making EOLC decisions is a complex process for parents (Gothwal et al., 2015). Parents make EOLC decisions on behalf of their children (Gothwal et al., 2015). In the Saudi Arabian culture, mothers are the primary care givers and the gatekeepers for their children's health and illness (MOH, 2018). Mothers are known to be the closest person to their children, ill or healthy (MOH, 2018). The healthcare policies in Saudi Arabia do not give the mother the authority to make any EOLC decisions on behalf of her child (Alifta, n.d.). The mother's decision is taken into account if the father's decision does not align with the physician's decision (Alifta, n.d.). No studies were found that discuss the involvement of mothers, in Saudi Arabia, in the EOLC decision making process on behalf of their dying child.

Therefore, mothers' experiences with their children at EOL will provide insight into the EOLC process in Saudi Arabia. This study will present the EOLC experience from different perspectives. The mothers' experiences will be explained through the psychological, physical, social, and financial perspectives. Therefore, it is necessary to provide foundational knowledge about the understudied population, Saudi Arabian mothers caring for their dying children, for future research.

Conclusion

Based on this systematic review, more studies are needed related to children at EOL in Saudi Arabia. Studies have been conducted globally; but, the number of studies conducted in Saudi Arabia are limited. In Saudi Arabia the studies were mostly quantitative, focused on healthcare professionals, adult patients, and religious/ Islamic perspectives. There is limited information available about children and their family members' experiences at EOL/ EOLC in Saudi Arabia as it was presented in other countries. This systematic review aimed to support the importance of a future study that aims to explore mothers' experiences caring for a child receiving EOL care in Saudi Arabia. The research questions are (1) what are the factors that influence the experiences of mothers caring for a child receiving EOLC in Saudi Arabia? (2) How does caring for a child receiving EOLC impact the mothers' psychological, physical, social, and financial status?

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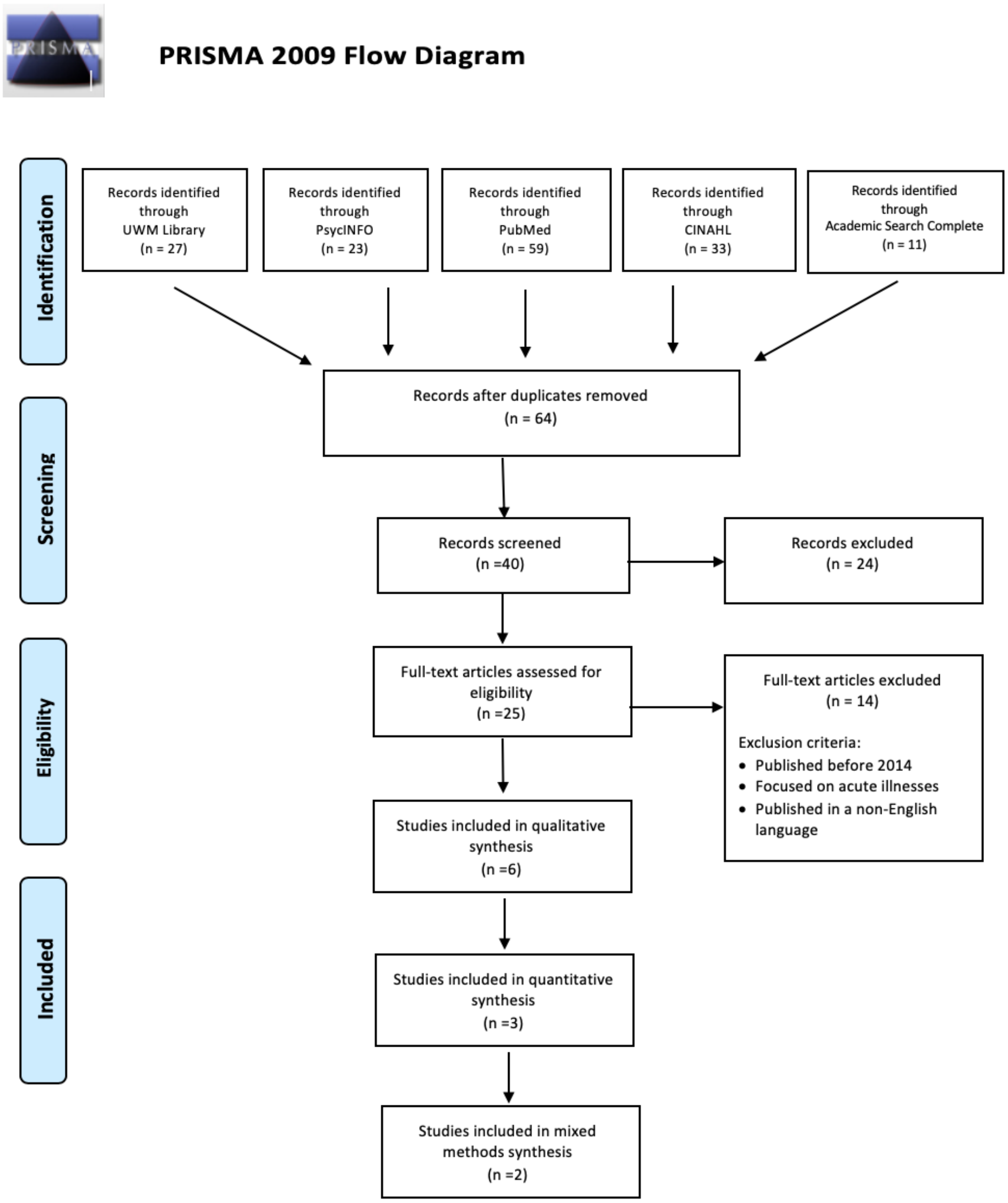
Appendix A

Figure 1.2

PRISMA Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal. pmed1000097

For more information, visit www.prisma-statement.org.

Appendix B

Table 1.2

Evidence Table

Author Year Country	**Purpose/ Question**	**Design Sample**	**Data Collection & Analysis**	**Findings**	**Strengths & Limitations**
1. Arruda-Colli, De Lima, Perina & Santos 2016 Brazil	Understand the maternal experience during an oncological disease recurrence phase of her child's treatment	• Descriptive exploratory qualitative design A 39-year old mother responsible for her child's treatment during a cancer relapse phase	Semi-structured interview Thematic content analysis	The themes identified: • Facing the imponderable and seeking to make sense of the experience • Facing losses on the relational sphere • Experiencing the relapse of the son with the perspective of death	Strengths: • Highlighted the importance of empathy and sympathy between HCPs and mother Limitations: • One participant
2.Arutyunyan, Odetola, Swieringa, & Niedner 2018 United States	• Understand whether parents of children admitted to PICU would want their physicians to ask about	• Observational cross-sectional study • 162 parents/ guardians of children admitted for more than 48 hours to the PICU	Modified survey about spiritual well-being Univariate and bivariate analyses were performed	• 48% of parents of wanted their physicians to ask about their religious or spiritual beliefs • 78% of parents had a	Strengths: • Highlighted the importance of spirituality • Encouraged physicians to be taught basic skills to approach

Author Year Country	**Purpose/ Question**	**Design Sample**	**Data Collection & Analysis**	**Findings**	**Strengths & Limitations**
	their religious or spiritual beliefs • Explore whether the child’s underlying illness or parental characteristics influence the responses to our primary objective			strong preference regarding prayer • 33% felt comfortable discussing their spiritual beliefs with various providers	spiritual history Limitations: • Small sample size • Limited diversity of participants • Single site Bias due to self-report measures
3. Atout, Hemingway & Seymour 2017 Jordan	Explore the experience of decision-making in the care of children with palliative care needs in Jordan, from the perspective of their mothers	• Collective qualitative case study approach • 24 mothers of children between the ages of 1-12 years old admitted in pediatric units diagnosed with a condition	• Participant observation • Semi-structured interviews with mothers, physicians, and nurses Constant comparison	• Jordanian mothers seek to transfer the role of decision-making to the physicians • Worry about future guilt • Mothers feared to make the wrong decisions (adverse	Strengths: • Large sample number • Participants included mothers, physicians, and nurses • Data was collected though observation and interviews

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
		eligible for PC • 12 physicians and 20 nurses who were involved in the care of the children		impact on the child) • Mothers requested details about their children's condition for second opinion, online search, or asking other parents in the same situation	• Culture was addressed Limitations: • The observation period varied significantly for each case study • No follow up with parents after the death of their children
4. Baughcum et al. 2017 United States	Examine parents' perspectives of their infants' EOL experience 3 months to 5 years after their infants' death in the NICU	• Mixed-method study design (cross-sectional) 29 mothers, 16 fathers representing 31 infants	• Demographic data from infants' medical records • Individual in-depth interviews or completing a survey Content analysis to develop themes (qualitative)	Themes identified: • Parents were partners in care • Communication with the healthcare team • Relationships with staff • Bereavement support	Strengths: • Provided perspectives of mother and fathers • Developed recommendations based on participants' experiences Limitations: • Limited number of fathers in the study compared to mothers

Author Year Country	**Purpose/ Question**	**Design Sample**	**Data Collection & Analysis**	**Findings**	**Strengths & Limitations**
			• Independent-sample t tests and X^2 analyses		• Retrospective reports could have been subject to bias • Limited sample diversity
5. De Vos et al. 2015 Netherlands	• How do physicians and parents communicate about decisions to withhold or withdraw LST? • To what extent do parents share in the decision-making process?	• Prospective exploratory study • Total of 27 physicians, 37 parents, and 19 children who have been involved in the decision to withhold or withdraw LST • Conducted in the PICUs of 2 Dutch University Medical Centers	Conversations between researchers and participants were audio recorded, ranging from 1 to 8 meetings per participant • Coding schemes were developed • Then the codes were qualitat-ively and quantitatively analyzed • Then the analyzed data/ results were discussed is several	Physicians and parents communicate about: • Information about the actual situation and treatment effects • Information about the prognosis • Information about remaining options, including pros and cons • Providing summary of the situation and any additional questions	Strengths: • Themes were clearly identified • Examples were provided Limitations: • Research was limited to 2 centers • Multiple researchers were involved in data collection • The data analysis was not clearly defined

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
			discussion rounds with all researchers	The extent of communication includes: • Asking about the preferred role in the decision-making process • Asking about the values and preferences regarding continuation or discontinuation • Expressing objections to treatment • Sharing emotions, grief, fear, despair, and frustration	
6. Haley & Walker 2016 United States	Explore the expanded use of the SG with a population of parents caring for their child in hospice/	• Descriptive study conducted using a qualitative grounded theory design • Quantitative component using PSRS before and	• Parents were recruited from Trinity Kids Care in California • One-on-one in-depth interviews	The attributes of strength were: • Handling emotions • Solving problems • Spirituality • Finding meaning	Strengths: • Participants were comfortably interviewed in their homes • The SG was found to be an effective intervention

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
	palliative care at home, to assess if new strengths emerge and if SG serves as an effective intervention	after the interview (constant comparative analysis) • Total of 8 participants (parents) who are caring for their children at home	• PSRS surveys before and after the interviews Constant comparative analysis	• Taking care of self • Taking care of family • Taking care of others in the community • Positive attitude • Resourcefulness • Sense of hardiness • Being with nature	• Themes were thoroughly discussed Limitations: • Small sample size • No variety between participants
7. Katooa, Shahwan-Akl, Reece & Jones 2015 Saudi Arabia	Describe and explore the coping patterns of Saudi Arabian parents and in particular the mothers as primary caregivers of chronically ill children	• Quantitative descriptive design • Total of 122 parents with chronically ill children	Survey question-nnaires • QOL scale • GSC scale • SSQ SPSS	Mothers coped by finding support from: • Family • Friends • Government association • The healthcare facility (hospital)	Strengths: • Both parents were included in the study • Participants were from different hospitals Limitations: • Small sample size • Number of fathers included in the study was minimal • Participants were from one city in Saudi Arabia (Jeddah)

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
8. Lou, Mu, Wong & Mao 2015 Taiwan	Explore the essence of the maternal experiences related to the anticipatory loss of families of a child with advanced cancer	• Retrospective study using Husserl's phenomenological approach • 10 mothers of children (ages 1-14 years) who died within the past 3 years due to a brain tumor • Mothers who are members of CBTA-Taiwan	In-depth face-to-face interviews Colaizzi's method for analyzing phenomenological data	Mothers discussed their experiences with • Losing hope of cure • Encountering death • Establishing a protective role toward the child • Intertwining the chaos and strengths of family life • Contending against death	Strengths: • Mothers with different years of struggle were included • Culture and religion were discussed Limitations: • Participants were limited to the members of CBTA-Taiwan • The data collected was retrospective and relied on participants' memories (within 3 years)
9. Ohs, Trees & Gibson 2015 United States	• What are the competing discourses about EOL decisions constructed by families making medical decisions for a family	• Qualitative study design • Total of 15 participants over the age of 18, who had been involved in an EOL medical decision of a close family member were	• In-depth interviews • Prior to the interview, a questionnaire was provided to gather background information • Contrapuntal analysis • The Relational	• All participants reported the struggle of letting go of a family member • Family interaction was important to manage the decision of letting go	Strengths: • Participants had different experiences • Valuable insight on families' decision-making process • HCPs roles were mentioned

Author Year Country	**Purpose/ Question**	**Design Sample**	**Data Collection & Analysis**	**Findings**	**Strengths & Limitations**
	member at the EOL? • How do families make sense of contradictory discourses?	included in the study	Dialectics Theory (RDT) was used to analyze the discourses around the struggle between holding on and letting go	• Struggle to decide who makes the decision and who should be involved in the decision • Contradictions between the patient and family's wishes • Contradictions between discourses of emotionality versus rationality	Limitations: • The majority of participants were females • Participants constructed accounts of good decisions, which limits the transferability of the findings

10. Popejoy
2015
England
	Understand the lived experience of parents throughout the process of making and revising EOLC decisions for their child	• Qualitative exploratory design
		• Three mothers who had been bereaved
			Semi-structured interview
			Interpretive phenomenological analysis
				Themes and sub-themes identified:
				• Making decisions
				  • Timing of discussions
				  • Decision makers
				  • Values
				• Revising and implementting EOLC plans
				  • Barriers and facilitators to
					Strengths:
					• Individual interviews were conducted
					• Consultants and child bereavement team were involved in the study for support and recruitment
					Limitations:
					• Small sample size

Author Year Country	**Purpose/ Question**	**Design Sample**	**Data Collection & Analysis**	**Findings**	**Strengths & Limitations**
				implementation - Revisiting plans	- Participants were from one hospital
11.Zimmermann et al. 2016 Switzerland	- Describe specific parental experiences in relation to the under-lying medical condition causing the child's death - Explore differences in parental perspectives between 4 common medical conditions responsible for childhood death (cardiology, neonatolo-gy, neurology oncology)	- Cross-sectional design - Total of 124 participants (parents) who had children died due to a cardiac, neurological, oncological condition, or during the neonatal period in the years 2011-2012	- Cross-sectional questionnaire survey was distributed to parents - Recruitment done between July 2013 and March 2014 at 8 children's hospitals in Switzerland Descriptive statistics	Parents' experiences included: - Support of the family - Communication with physicians - Shared decision making - Relief of pain and other symptoms - Continuity and coordination of care - Bereavement support Positive and negative experiences and quality of life	Strengths: - Positive and negative experiences were discussed - Several centers were used for recruitment Limitations: - Small sample - The data collected was retrospective and relied on participants' memories - Findings could be biased based on parents' favorable experiences

Table 2.2

Abbreviations

Abbreviation	Definition
CBTA-Taiwan	Childhood Brain Tumor Association-Taiwan
EOL	End of life
EOLC	End of life care
GSE	General self-efficacy scale
HCPs	Heath care professionals
ICU	Intensive care unit
LST	Life-sustaining treatment
NICU	Neonatal intensive care unit
PC	Palliative care
PICU	Pediatric intensive care unit
PSRS	Personal Strengths Rating Scale
QOL	Quality of life scale
SG	Strengths Guide
SPSS	Statistical package for the social sciences
SSQ	Social support questionnaire

Chapter 3

Methodology

Primary Care givers Caring for a Child at End of Life

Taking care of a child at end of life (EOL) is a challenging experience for mothers (Gothwal et al., 2015). In Saudi Arabia, mothers are the primary care providers for their children, especially when the children are ill (Saad, 2016). It is known that mothers face challenges while caring for their children at EOL (De Vos et al., 2015). Mothers go through psychological, physical, mental, and social challenges, just to ensure that their dying children are happy, comfortable, pain free, and at peace (Khraisat et al., 2017). Studies have been conducted in Saudi Arabia about end of life care (EOLC) and decision making (Al Dawood et al., 2012; Chamsi-Pasha & Albar, 2016; Katooa et al., 2015). Most studies focused on the religious (Islamic) perspectives, healthcare provider's beliefs and opinions, and family members' experiences (Al Ayed & Rahmo, 2014; Al Dawood et al., 2012; Hammami et al., 2015; Katooa et al., 2015; Miller et al., 2014;). Unfortunately, mothers caring for their children receiving EOLC is an understudied population.

Purpose and Research Questions

The purpose of this study is to explore the experiences of primary caregivers caring for a child at EOL in Saudi Arabia. The research questions are: (1) How does caring for a child receiving EOLC impact the primary caregivers' psychological, physical, social, and financial status? (2) What are the factors that influence the experiences of primary caregivers caring for a child receiving EOLC in Saudi Arabia?

Qualitative Perspective

The current study aimed to qualitatively explore the contextual factors associated with the EOL experiences of mothers/ primary care givers caring for a child receiving EOLC in Saudi Arabia. Qualitative research is known to explore the realities of individuals, grasp the ontological assumption of multiple truths, identify the contextual accounts of individuals' lives, and reflect the variation and diversity of lived experiences of individuals (Erlingsson & Brysiewicz, 2013). According to Sandelowski (2004) qualitative research has been conducted in healthcare, including nursing, exploring topics that are highly important for healthcare development. The topics in healthcare research include cultural and personal constructions on disease risk, prevention, and treatment. Other topics Sandelowski (2004) discussed include managing life with physical, psychological, and social effects of an illness and treatments (Sandelowski, 2004). Also, research focus on decision making about beginning and EOL, extending life, and technological interventions. Lastly, Sandelowski (2004) suggested that topics in healthcare research include cultural, historical, and discursive factors associated with good health, disease prevention, health disparities reduction, and healthcare access. Therefore, the findings of qualitative research are essential for healthcare research progression (Erlingsson & Brysiewicz, 2013; Sandelowski, 2004).

Furthermore, there are several studies about EOLC and EOL decision making that used qualitative research over the years (Balaban, 2000; Gallagher, 2015; Ohs et al., 2015; Singer et al., 1999). Nevertheless, there is a limited number of qualitative studies about EOL had been conducted in Saudi Arabia. Therefore, a qualitative study about mothers' experiences caring for a child receiving EOLC will fill a gap in the literature.

Philosophical Framework

Naturalistic inquiry is the philosophical lens chosen for this study. Naturalistic inquiry is a philosophy that focuses on individuals' behaviors during a genuine life experience (Frey et al., 1999). Naturalistic research indicates that the phenomena of interest should be studied in context, and the researchers themselves are considered the main instrument for data collection

(Frey et al., 1999). Collecting data using qualitative methods allows the researchers to describe, decode, translate, and interpret the meaning of the phenomena that occurs in its natural setting (Guba, 1981). The primary qualitative methods for data collection in naturalistic research are direct observation and in-depth individual interviews (Frey et al., 1999). The naturalistic philosophical lens will help in answering the research questions and understand the experiences of mothers caring for their children receiving EOLC, in Saudi Arabia.

Conceptual Model

Refering to the literature about parents' experiences caring for their child at EOL, a conceptual model was developed. The conceptual model will guide the research study. Concepts emerged from the literature regarding pediatric EOLC. However, four main concepts were used for this coceptual model. The concepts included in the model about EOL were decision making, communication, support system, and grief (see Figure 2.8). The decission making concept includes EOLC options parents and healthcare professionals discuss regarding the child care. EOLC communication ocurs at EOL between parents, healthcare professionals, and extended family. To power through the hard time at EOL, mothers need support from the husband, healthcare professionals, extended family members, and support group members. Lastly, all mothers grief the loss of the child, which could occur before or after the child's death.

Methods

Design

Descriptive phenomenology is the approach chosen to address the aim of this study. Phenomenology exposes the feelings, behaviors, understandings, and thoughts from the perspectives of another (Schneider et al., 2014). According to Streubert and Carpenter (2011) phenomenology is a suitable approach to explore a phenomenon within a cultural context.

Furthermore, descriptive phenomenology describes the essence of the phenomenon as it was experienced by a person (Willis et al., 2016). The lived experiences were described using Giorgi's approach. Referring to Giorgi's (1997) approach, the researcher identified what is meaningful to all participants and made sense of the web of relationships between the meanings that emerged. Therefore, the findings of the research were presented in themes and subthemes (Giorgi, 1997; Giorgi & Giorgi, 2003).

The EOL phenomena is clearly described within the religion followed in Saudi Arabia (Islam). However, the EOL phenomena has not been clearly described through the Saudi Arabian culture, traditions, and mothers' experiences. Therefore, descriptive phenomenology will clarify the meaning of the EOL phenomena. The aim was to conduct interviews with Saudi Arabian mothers/ mother figures caring for a child receiving EOLC.

Sample and Setting

Sample and Setting

Sample. Mothers and female care givers were chosen because, they are the primary care givers for the children in the family, in Saudi Arabia. Thus, their experiences with the dying child shed a light on EOL and EOLC in Saudi Arabia. The sample size included 30 participants, referring to Adler and Adler (2012) and Ragin (2012), a sufficient sample size for a qualitative study ranges between 12 and 60 participants (Ritchie et al., 2014). Data saturation was reached, in-depth individual interviews were conducted with the 24 participants.

The inclusion criteria included Saudi Arabian mothers and female care givers (grandmother, aunt, sister, or stepmother etc.) caring for a child at EOL. The mother/ female care givers were 18 years of age or older. The children mothers/ female care givers were caring for had to be diagnosed with a terminal illness or in a critical condition from an acute health problem. The children at EOL were between the ages of one day and 14 years. According to the Ministry of Health in Saudi Arabia (MOH), individuals over the age of 14 years old is an adult and should be admitted in an adult ward. The exclusion criteria included non-Saudi Arabian mothers/ female care givers, fathers/ male care givers, primary care givers younger than 18 years of age, and whose children are over the age of 14 years.

Recruitment. A purposive sample was selected for this study. The required sample was based on who met the inclusion criteria and available at the hospital pediatric or neonatal care units and agreed to participate. In addition, snowball sampling was used to further expand the purposive sample and identify potential participants in the community. After the interview, mothers/ female care givers were given a 50 Riyals (13 US Dollars) gift card for their time that they provided to participate in the study.

Setting. Participants were recruited from the Maternity and Children's Hospital, King Abdulaziz University Hospital, King Faisal Specialist Hospital, and the National Guard Hospital in Jeddah, Saudi Arabia. The Maternity and Children's Hospital is one of the largest government hospitals in Jeddah that specializes in maternity and child care. All hospitals have pediatric and neonatal intensive care units, pediatric and neonatal special care for less serious cases, and pediatric oncology units which included children at their EOL.

Data Collection

Instrument

An interview guide/ questions was used as an instrument for data collection. The interview guide was developed based on what has been previously presented in the literature on EOL. Furthermore, the interview questions included open-ended prompts; because, they help faciltating a richer discussion about the topic (Connelly & Peltzer, 2016). Additionally, probing questions were used to elicit more information (Connelly & Peltzer, 2016). So, the interview started by asking about the demographic data, followed by less sensitive to more sensitive questions (see Table 3.8, Table 4.8 and Table 5.8).

In-depth individual interviews were conducted with 24 participants in Arabic. It was estimated that the interview would last around 60 minutes per interview depending on how much the participant wanted to share. In-depth individual interviews are conversations with purpose (Ritchie et al., 2014); and they are flexible, interactive and generative (Yeo et al., 2014). The researcher can also observe the participant during an individual interview (Blandford, 2013). Moreover, the interview questions included open-ended prompts; because, they help faciltating a richer discussion about the topic (Connelly & Peltzer, 2016). Additionally, probing questions were used to elicit more depth of information (Connelly & Peltzer, 2016). So, the interview started by asking about the demographic data, followed by less sensitive to more sensitive questions. Furthermore, the interviews were conducted in a meeting room at the hospital.

Data Analysis

The data was analyzed using a thematic analysis consistent with Giorgi’s approach. Thematic analysis is one of the strategies that is compatible with descriptive phenomenology research (Schneider et al., 2014). A thematic analysis is a method that allows for identification, analyzing, and reporting themes that emerge from the data (Braun & Clarke, 2006). Interviews were conducted in Arabic; because, it is the mother language and preferred language used in Saudi Arabia. The interviews were audio taped and then transcribed into English by the investigator, then back translated to Arabic by a graduate level research assistant for accuracy. Once transcribed, the investigator reviewed the audio recordings and transcripts for accuracy and consistency.

The thematic analysis was conducted using the English version of the data. The transcribed data was read thoroughly by the investigator and major professor multiple times to understand the data and identify the emerging themes. To identify the themes in the data, a thematic map was a helpful strategy. A thematic map is a visual presentation of themes, codes, relationships between the themes and codes, detailed description of the themes and their criteria, examples, and other similar details presented in the data (Vaismoradi et al., 2013). Development of the thematic map included codes and labels, followed by the themes, and then the examples (participants' narratives) were added. A matrix of the codes and themes was also developed for the data of this study as it helped to identify the codes and themes across participants.

Scientific Rigor

Scientific rigor is maintained through trustworthiness (Sandelowski, 1993). Sandelowski (1993) stated that trustworthiness is a "matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore, auditable; it is less a matter of claiming to be right about a phenomenon than of having practiced good science." Trustworthiness is categorized into credibility (internal validity), dependability (reliability), transferability (generalizability), and confirmability (objectivity) (Sandelowski, 1993).

Credibility is achieved by observing the participants persistently, engaging with the participants, providing a deep description of the participants' experiences and the contexts where the experiences occur, and reflexivity (Morrow, 2005). In this study, the researcher was present at the research site to observe and socialize with the participants to build rapport. The researcher was able to describe their perception of the participants' experiences accurately and realistically within the actual context of the experience. Furthermore, reflexivity is the researcher's recognition of their own biases (Davies & Dodd, 2002). There are two strategies to maintain reflexivity (Morrow, 2005). First, a self-reflective journal which the researcher will maintain as an ongoing record of the research (experiences, reactions, assumptions, decisions, and biases) (Morrow, 2005). Second, a researcher/ peer/ consultant will be assigned to write fieldnotes for the researcher's responses and actions during the research process (Hill et al., 2005). For this study, reflexivity was ensured with consistent implementation of both strategies.

Dependability indicates that the findings are consistent and repeatable in future research studies (Gasson, 2004). Dependability will be achieved by preserving an audit trail, a detailed record of the research processes, activities, data collection and analysis methods, data categories and themes, and analytic memos (e.g. field notes) (Morrow, 2005). The audit trail will be tested by other fellow researchers or colleagues in the field to assure dependability (Morrow, 2005). In this study, the dependability was assured through the assistance of the graduate level colleague.

Transferability is the ability to generalize and apply the findings of the study to other similar studies (Gasson, 2004). Researchers will attain transferability by providing adequate information about themselves, research context, participants, processes, and researcher-participant relationships (Morrow, 2005). Confirmability is the acknowledgement that the study is not objective (Morrow, 2005). The findings will represent the experiences of the participants as clearly as possible, with great effort to insure the data is not influenced by the researcher's beliefs or biases (Morrow, 2005). The researcher will describe the connections between the data, analytic process, and findings to ensure the reader as able to verify the adequacy of the research findings (Morrow, 2005).

Adequacy of data is an essential concept of trustworthiness. Erickson (1986) identified multiple ways to ensure the adequacy of qualitative data. Three ways of ensuring adequacy, developed by Erickson, was used in this study. The three ways include adequate amounts of evidence, adequate variety in kinds of evidence, interpretive status of evidence. Adequate amounts of evidence do not refer to the sample size, but refers to the quality, length, and depth of the data collected (Morrow, 2005). Therefore, qualitative researchers use purposive sampling method to ensure the richness of the data (Patton, 2002).

Ethical Issues

The participants were informed verbally and through written consent that participating in the study was voluntarily. Their male guardians were informed verbally and through a written informed consent to obtain their approval. Participants were assured that their children's medical care will not be affected, regardless of their participation decision. The interviews were digitally recorded, and the recordings were transcribed in English by the investigator and back translated to Arabic by the graduate level research assistant. The recordings and transcribed documents were stored electronically in a de-identified form on the investigator and major professor's encrypted hard drives. The English transcription of the interviews were shared with the researcher's major professor, graduate level research assistant who was back translating the data. Findings will be anonymously presented in aggregate form in publications and conferences using the de-identified data. Upon completion of the study, the recordings were permanently destroyed. However, the transcribed documents were saved for future analysis and dissemination, until the process in completed, at which point they will be destroyed. Finally, mothers with children who are at EOL are considered a vulnerable population; therefore, their rights will be guaranteed and respected.

Limitations

The findings of the study provided insight into the experiences of Saudi Arabian mothers/ primary care givers caring for their children receiving EOLC. Even though generalizability was not the aim, it is important to note that the participants pool is limited to four hospitals in Jeddah, Saudi Arabia. Also, the study focused on mothers/ female care givers instead of fathers/ male care givers.

It was expected that there will be difficulties in recruiting the participants. Talking about the EOL of a child is personal, sensitive, and an emotional topic for mothers/ female care givers to discuss. The child's condition may worsen, or the child could die during the time of the study, which could lead the participants to refuse or hesitate to participate. In addition, women in Saudi Arabia are required to have a male guardian's permission to participate in any formal or legal activity. The male guardian would refuse to allow the mother to participate in the study. There is a possibility that hospitals may reject my proposal due to the sensitivity of the topic. Lastly, the community data collection will be more challenging, because it is difficult to find an appropriate place for conducting interviews.

To overcome the expected challenges, rapport was developed with the participants by being available at the unit instead of asking for their participation upon my arrival. The participants and their male guardians were assured that the interview recordings will be destroyed after completing the study, and the data will be anonymous while obtaining their consent. It was important to mention that participation or withdrawal from the study will not affect the child's care. If the child's condition worsened or died, the participants will be reminded that participating in the study is voluntary. If the hospitals chosen rejected the request for data collection in the proposal, there are other hospitals in Jeddah that fit the study criteria, and it is possible to recruit participants from the community. Lastly, interviews with participants in the community would be appropriate to be conducted in a mosque.

Conclusion

The purpose of this study is to explore the experiences of primary caregivers caring for a child at EOL in Saudi Arabia. The research questions are: (1) How does caring for a child receiving EOLC impact the primary caregivers' psychological, physical, social, and financial status? (2) What are the factors that influence the experiences of primary caregivers caring for a child receiving EOLC in Saudi Arabia? Therefore, a phenomenological descriptive study was conducted, and 30 mothers/ mother figures will be interviewed individually. The data will be analyzed using thematic analysis. Furthermore, the current study will have implications for nursing practice, policy, and research. The care provided at EOL have to include the dying child and family members. In this case, mothers have to be a priority in nursing care. Furthermore, policies regarding EOLC need to include family members in the child's plan of care and the EOLC decision making process. Further research is recommended to explore the experiences of fathers/ male care givers caring for a child receiving EOLC in Saudi Arabia.

Chapter 4

Primary Caregivers Caring for a Child at End of Life

Manuscript 2

Abstract

Caring for children at end of life can be devastating for primary caregivers who are providing for the physical, social, and emotional needs of their dying child. Limited information was found on resources in Saudi Arabia to manage the impact on female primary caregivers from caring for their child at end of life. The purpose of this study was to explore the experiences of primary caregivers caring for a child receiving end of life care within the Saudi Arabian healthcare system. Therefore, a phenomenological descriptive study was conducted, and 24 female primary caregivers were interviewed individually. The data was analyzed using thematic analysis, and the analysis was conducted within and across all interviews. The findings suggest that primary caregivers caring for a child receiving end of life care experienced biopsychosocial and financial alterations. This study has implications for nursing education, practice, policy, and research regarding end of life care.

Keywords: end of life, end of life care, children at end of life, primary caregivers, Saudi Arabia

Taking care of a child at end of life (EOL) is a challenging experience for primary caregivers (Gothwal et al., 2015). In Saudi Arabia, mothers/females are the primary care givers for their children regardless of the type or severity of the child's illness (Saad, 2016). The primary care giver intimately experiences their child's life limiting illness (Khraisat et al., 2017). Facing the death of a child can be traumatic, impacting the primary caregivers psychologically, physically, and socially (Khraisat et al., 2017). The goal of EOLC is to provide comfort to the dying individual by managing their pain and other undesired symptoms (NCI, 2018).

Aim of the study

The aim of this study was to explore the experiences of primary caregivers caring for a child at EOL in Saudi Arabia.

Conceptual Model

Four main concepts emerged from the literature regarding pediatric EOLC, which were used to develop an initial conceptual model for this study. Upon completion of the study, the conceptual model was adapted to reflect the initial concepts and the current findings. The model that emerged is an integration of the concepts from the literature and parental experiences caring for their child at EOL (see Figure 1.4).

Method

Design

This investigation was part of a larger phenomenological study, addressing the following research question: How does caring for a child receiving EOLC impact the primary caregivers' psychological, physical, social, and financial status? IRB approval was obtained at all appropriate institutions prior to conducting the investigation, including the investigators University, the Saudi Ministry of Health, and healthcare organizations.

Participants and Setting

Participants. A purposive sample of participants were recruited for this investigation. The inclusion criteria were: (a) Saudi Arabian female primary caregivers (mother, grandmother, aunt, sister, or stepmother etc.) caring for a child at EOL, (b) 18 years of age or older, (c) caring for child(ren) diagnosed with a terminal illness or critical condition from an acute health problem, (d) child(ren) between one day and 14 years of age.

Setting. Participants were recruited at three large government hospitals and the surrounding community. The interviews were conducted while assuring that the child was observed and cared for during that time.

Measures

Demographic data was collected in addition to an 11-item investigator developed interview guide. The interview guide was a template of open-ended questions derived from the EOL literature.

Data collection

A purposive sample was used to recruit the participants, and snowball sampling was used to further expand the participants who were recruited from the community. Following the completion of the investigator administered demographic data sheet, individual in-depth interviews were conducted with 24 participants. The interviews were conducted in Arabic by the investigator whose first language was Arabic. The interviews lasted between 15 minutes to an hour, dependent on how much the participant wanted to share. The investigator started the interviews by asking about less sensitive topics, followed by topics that were potentially more sensitive. Following the interview, female caregivers were offered a 50 Riyals (13 US Dollars) gift card as appreciation for the time they provided to participate in the study. The data was collected over a period of seven weeks.

Data analysis

The interviews were transcribed in Arabic and translated into English, and then back translated into Arabic. The investigator reviewed all audio recordings and transcripts for accuracy and consistency in both Arabic and English. A thematic analysis process was followed to analyze the data, using the English version of the transcripts. The transcribed data was read thoroughly by the investigators multiple times to understand the data and identify the codes. Each interview was coded individually by the investigators, and then compared for consistency, with subsequent discussions to ensure consensus was reached. From the coded data, the emerging themes and subthemes were identified and organized into tables. A matrix table was established to assist in identifying the patterns that emerged from the data.

Findings

Participants

Participants were recruited from government hospitals and communities in Jeddah in Saudi Arabia. Caregivers included in this study were mothers (n = 22), a sister (n = 1), and a nanny (n = 1), ranging in from 18-47 years of age. A majority of the participants (n = 20) were housewives. Some participants were comfortable to share their education level (see Table 1.4). The participants were caring for 25 children, 13 females and 12 males, ranging in age from 11 days to 13 years old, with varying durations of EOLC (see Table 2.4). A majority of the children (n = 18) were hospitalized, with the remaining (n = 7) being cared for at home. The children's life limiting conditions included: congenital anomalies, neurodegenerative disease, and cancer. All the hospitalized children had DNR orders on their charts.

The questions from the interviews focused on four different areas of exploration, psychological, physical, social, and financial. From the psychological interview questions, there emerged three themes: *life flipped upside down, my heart was breaking,* and *how could I let go of a piece of my heart?* which will be discussed here.

Life Flipped Upside Down

Participants expressed a range of emotions to describe the overwhelming changes that occurred in their lives with the realization that their child's health had dramatically altered. Mothers and caregivers expressed similar responses of "shock" when informed about their child's diagnosis and prognosis. The mothers and caregivers were in shock and realized that their lives and that of their children had changed and will never be the same. A mother expressed her shock by saying *"I was in shock at first, cancer!? Not a flu? I have never been to hospitals before!... I was surprised he has the disease [cancer]... it was a shock! My life flipped upside down" (012).*

Some participants verbally described the intensity of their "disbelief" and cried and sobbed inside the private rooms where the interviews were conducted. While other respondents demonstrated the shock and disbelief in their tone of voice and facial expressions. A mother expressed her disbelief by saying "*at the beginning when they told me I couldn't believe the doctors. The doctors at [hospital in Jeddah] did the blood works again and I couldn't believe it! I couldn't believe that she has this disease [leukemia]" (022).*

My heart was breaking

Mothers and caregivers expressed how *"heartbroken"* they were watching their child suffering. Participants repeatedly placed their hand on their chest when talking about their heartbreak during the interview. Some mothers even pounded on their chest and cried as they expressed how deeply heartbroken they were seeing their child's health deteriorating. The participant's heartbreak was evident, and she pounded her chest and shared the following: *"I told my husband that I feel my heart my heart my heart my heart my heart was coming out of my chest!... my heart wasn't in its place" (007),* while another mother just placed a hand over her heart and stated: *"I cried all the time and my heart was breaking seeing my son getting worse every day! Not moving!" (024).*

Mothers shared that at some point, during their child's illness, they reached a point in their child's illness that they felt they could not go on. The mothers had "suicidal ideations" as they could not handle the fact that they were healthy, and their child is dying. None of the mothers had thought that they would outlive their children. The thought of their child suffering more if they were not there to care for them, stopped the mothers. The concerns were reflected by the following: *"I wasn't doing well, psychologically! I thought of ending my life! But then I thought who is going to take care of my son if I'm not there?!" (021).*

How Could I Let Go of a Piece of My Heart?

A majority of participants described being very "attached" to their children, a special bond had formed between them and caregivers. The children were not able to verbally express attachment to their mothers and caregivers. However, their facial expressions visibly changed when the mother was not close. The strong attachment to each other was discussed by one caregiver as:

> *Even when I go home for a break I can't stay long… I can't wait for the day to end so I can come back to hospital…. when I come back she gets better.... I don't feel obligated… it's just my heart is so attached to her. No*

> *matter how long I spend time away from her, she is always on my mind (013)*

Respondents found it hard to accept being separated from their child. Mothers went to extreme measures just to be with their dying child. "Desperation" was expressed, as the need to see the child was overwhelmingly powerful. Participants needed to confirm that the child was still alive. The mothers were determined to be with the child, believing they are the only ones who could feel the child's suffering even from far away. The intensity of their feelings resonates in their words:

> *I told the doctors just let me stay by the door, by the door! I just wanted to see him, I just wanted to see him! The doctors said no!... my husband was dragging me around! I was on the floor and couldn't move! I couldn't imagine losing [child]…. when he was in the intensive care unit I wanted to kneel and kiss the doctors' feet to let me stay with him [child] (007)*

Being with their dying child was a source of "strength" for participants, which kept them surviving all this time. Mothers and caregivers believed that being strong, and caring for their child, was essential to nursing their child back to health. Strength was the participants' way of showing their love for the child. A mother shared her experience by stating:

> *I remember when I used to cry my son was young, he used to say why mama cry? Why mama cry? I used to tell him I have a headache, then he says ok mama no cry… so I made myself stronger… I will never show my weakness! I don't want my child to see it and get sick…. I have to make myself strong.. even if I'm shattered from the inside, the outside has to be strength (012)*

The physical was another area explored. From the physical interview questions, there emerged two themes: *when you are sad you don't eat well*, and *I sleep but not sleep* which will be discussed in the following section.

When You are Sad You Don't Eat Well

Caring for a child at EOL not only affected the participants emotionally but took a toll on them physically. A majority of the caregivers shared their experiences with alterations in their appetite, and lack of appetite. Overwhelmingly, the alteration in appetite led the participants to "lose their appetite" and reported a great deal of "weight loss." Loss of appetite and weight was not a major concern for the women, as the enveloping sadness they were experiencing was focused on their child's devastating health condition. Eating well was not a priority for the respondents, as they expressed their sadness over the child, as evidenced by the following: *"when you are sad you don't eat wellI, I mean I don't want to eat" (010*).

Exhaustion was one of the factors that caregivers experienced, and visually the participants appeared to be very weary. Weight loss was even attributed to their exhaustion as well as decreased intake, which resulted in subsequent weight loss, as evidenced by the following:

> *Yeees I lost weight, I mean I used to be 86 kilos [189 pounds] and now I am 74 [163 pounds]. I wasn't eating! I mean I wasn't eating, and my body is not the type that lose weight fast! (007)*

I Sleep, but not Sleep

Sleep alterations was described by participants as they shared their experiences caring for their dying children. Distraction was also pervasive amongst the women, as the sleep deprivation was ongoing, and they discussed being overwhelmed worrying about the welfare of their child.

Some were not able to sleep because they were up all night next to the child. The caregivers wanted to confirm that the child's needs were met to so the child could sleep well. The respondents were not complaining that they were not sleeping, they were explaining the reason for not being able to sleep at night, stating:

> *No sleep… I stay awake two days like this. Sometimes three days. And if I sleep, I sleep half an hour, not an hour.. because I have to take care of my son, his milk, change his diapers, suction his sputum. Next to him like this I could sleep [mother laying in bed with the child] (002)*

Another area discussed in the interview questions was social. Two themes were identified from the social questions: *isolated themselves from the entire world* and *can't go out and leave the child alone*, which will be discussed here.

Isolated Themselves from the Entire World

The social life of the participants changed once they learned about their child's diagnosis. The respondents focused their attention towards caring for their child at EOL. The caregivers shared that they "isolated themselves" from everyone around them, because socializing with others was not their priority. Participants even shared that they did not want to talk to people, as evidenced by the following: *"I didn't feel like going out or meeting anyone… I was kind of isolated during that time, I didn't even talk to my family! isolated" (018).*

Even when participants were surrounded by people, the participants expressed that they could not feel their presence. The respondents shared that they were constantly distracted thinking of their child, which made socialization insignificant. A caregiver shared her challenges socializing by stating: *"honestly, I was sitting with people but I don't feel them. All the time, I was thinking of her [child]" (003).*

Can't Go Out and Leave the Child Alone

A majority of the participants remained at their child's side the entire time the child was in the hospital. When the child was admitted to the pediatric or neonatal intensive care units, respondents reported not being allowed to stay with their child. Nevertheless, caregivers agonized about "leaving the child alone" at the hospital. The participants worried that the child's health might deteriorate while they were away, as a mother reported: *"I can't go out, I can't leave my son alone… I worry my son gets sick and I'm not around… I can't go anywhere" (015)*.

A couple of children who were stable enough, accompanied the participants while socializing with friends. A care giver shared: *"Currently I don't go out, I don't meet anyone… and even if I go out we go out together [participant and child" (017).* Conversely, there were participants who spoke about how limited circumstances in which they were able to go out with the child. Due to the child's health status, the caregivers sought to protect them from any harm. Therefore, the participants frequently cancelled going out with the child to protect them, as evidenced by the following: "*you can't go everywhere, I had to cancel for her… uuum there are some places you can't go because of her" (005).*

Finally, the financial area was explored, and two themes emerged from the data: *without financial support we could not care for our child* and *we were struggling financially* which will be explained here.

Without Financial Support We Could Not Care for Our Child

The majority of the participants (n = 17) were recruited from government hospitals in Jeddah, Saudi Arabia. The participants recruited from the government hospitals discussed at great care their child received. Not only did the participants appreciate receiving the best care, but the financial support they were receiving from the Saudi Arabian government. A respondent shared:

> *It is a government hospital… but in general there are no expenses, because it is a government hospital they don't ask you for anything… the government is paying all the hospital expenses… the government is providing the best care in the hospital (001)*

The remaining participants (n = 7) were recruited from the community. The respondents shared that they were receiving financial support from a nonprofit organization. The nonprofit organization provided financial support for the child and the family. Not only were the healthcare expenses covered, but housing, transportation, and daily expenses for individuals living in towns or cities other than Jeddah, Saudi Arabia. The caregivers highly appreciated the support they received from the nonprofit organization, as evidenced by the following: *"also the [nonprofit organization] are very supportive. Without them we could not be able to care for our daughter" (018).*

We Were Struggling Financially

Participants shared about their financial struggles while caring for their child at EOL. Families were receiving financial support from the government or nonprofit organization for the child's healthcare. However, the ongoing nature of the child's health needs led to inevitable financial challenges. Some respondents shared that their child was admitted to a private hospital before the cost or care required them to be transferred to a government hospital. Unfortunately, there were participants who did not realize that there were resources available to them via the nonprofit organization. Hence, the families were struggling paying for their child's healthcare. A caregiver stated:

> *I mean we spent over 70 thousand [Saudi Riyals = 18,666 Dollars] paying hospitals for appointments and MRIs I mean a loooot… EEG, follow up appointments and other things… can you believe this! We spent one night at [private hospital] we had to pay around 15 thousand [Saudi Arabia = 4,000 Dollars]! (007)*

Daily expenses at home needed to be maintained, even though the child was sick in the hospital, as a mother stated:

> *His father's salary is not much, we can barely afford transportation, school necessities and the kitchen, you know we have to buy food every other day, my son gets hungry (012)*

Discussion

Mothers in Saudi Arabia are the primary caregivers for their children during illness (Saad, 2016). In this study, the primary caregivers were overwhelmingly mothers, who reported being in *shock* and *disbelief* as their *life flipped upside down* when told about the child diagnosis and prognosis. The *shock and disbelief* were obvious in the respondents' tone and facial expressions while sharing their experience in the interviews. Similarly, Young (2018) reported that in the U.S. therapeutic strategies need to be addressed when providing counseling for parents of children with cancer. Common stressors reportedly affected parents of children diagnosed with cancer, including being in shock upon diagnosis. Counselors who were provided with information on parents' feelings while caring for a child with cancer, ensured the parents received the counseling care they needed.

Arabiat et al. (2013) explored the beliefs of Jordanian mothers (N = 51) regarding the cause of their children's cancer. It was painful and heartbreaking for the participants to see their child physically suffering. In this study, respondents felt *their heart was breaking,* as they were not being able to relieve their child's suffering. The mothers' hearts broke as they observed the child's health deteriorate; as they realized that the child was slipping away sooner than expected.

Zetumer et al. (2015) conducted a study on the behaviors and thoughts of parents (mothers = 273, fathers = 72) grieving their children who died. Parents reported that as they grieved: 36 percent frequently thought about suicide; 13 percent considered engaging in suicidal behaviors; three percent contemplated attempting suicide. *Suicide ideation* was brought up by a few mothers in this study who expressed a desire to end their life. However, the mothers shared their *worry* about their child being left alone, therefore they could not act on their suicidal ideation. All of the mothers in the study were Muslim, and in Islam suicide is forbidden. Though not mentioned by the mothers, their religion could have been an influence on any decisions that were made.

Previous studies focused on the negative psychological impact on mothers of caring for a terminally ill child (Arruda-Colli et al., 2016; Atout et al, 2017). However, limited studies discussed the positive feelings that mothers acquired during their devastating EOL experience with their child. A descriptive study conducted by Haley and Walker (2016) studied caregivers' strength while caring for their child at EOL. The participants [mothers (n =7), grandmother (n = 1)] were interviewed to explore their experience with the child's EOLC. The investigators found that the caregivers expressed deeper and stronger unconditional love for the child. Additionally, mothers/grandmother reported wanting to spend as much time as they could with the child who was dying. Participants in this study, whether mothers or caregivers, also expressed their great *love* for the child, especially as the child's health deteriorated. There were respondents that reported loving and favoring the child who was dying over their other children. Also, the mothers in the current study demonstrated their love to the child at EOL by being *strong*. Physical and psychological *strength* were perceived as needed by the primary caregivers, to nurture the child back to health.

Lou et al. (2015) conducted a qualitative retrospective study of mothers' experiences of anticipatory loss of a child from cancer. The investigators interviewed mothers (N = 10) who lost a child within the past three years. Mothers expressed their desperation and fear of the cancer recurrence. Also, the mothers felt desperate because of the anticipated child's loss. However, in this study the respondents' *desperation* was related to being with the child, to provide the care required. Mothers were so *desperate* to be with the child at the hospital. The participants begged HCPs to let them help the nurses provide the child's EOLC. Participants wanted to be with them all the time, with mothers sharing that their day was not complete until they visited the child at the hospital. As the respondents shared, the attachment to the child was mutual. Because, even though the child was not speaking, the child's vital signs improved when the primary caregivers were present. Therefore, the mothers expressed that leaving the child at the hospital, felt like letting go a piece of their hearts.

Participants in this study did not have time to care for themselves physically; as their child needed the physical care more than the caregiver at EOL. Mothers in this study shared that they were physically affected when caring for their child at EOL. Consistent with this study, Baughcum et al. (2017) explored parents' perspectives on their infants' EOLC experience in the NICU. The participants in the study (mothers = 29, fathers = 16) were interviewed three months to five years after their infant's death. The parents reflected on how tired they were from watching their infant suffering and spending such long hours at the hospital. The physical fatigue of parents whose children were seriously ill was also found in the study by Tutelman et al. (2020). Tutelman et al. conducted an investigation to identify the concerns of parents of a child receiving Pediatric Palliative Care (PPC) at home. The parents (mothers = 25, fathers = 10) were interviewed soon after the child was settled at home for PPC. One of the concerns shared by the parents was their overwhelming tiredness. Their child's PPC at home was just initiated, yet parents already feeling tired, and worried would impact their child's care.

De Andrade et al. (2017) studied the experiences of a small group of grieving mothers when they cared for their children at EOL. Mothers (N = 3) were interviewed after the child's loss to a chronic illness. The participants shared that they had a feeling of being fatigued throughout their caregiving experience. In another study, Leske et al. (2012) studied the effects on a small group of family members being present while a loved one was being resuscitated. Participants (N =3) shared they also experienced exhaustion when caring for their loved one at EOL. The researchers in both studies identified exhaustion as one of the experiences of family members caring for a loved one. However, studies did not provide details on how primary caregivers were impacted physically beyond being fatigued and exhausted. In the current study, the participants shared details about their fatigue and exhaustion.

Eating was not a priority for the participants in the current study, since they were the primary caregivers. The participants in this study discussed how caring for the child at EOL took a toll on them physically; they were tired and exhausted. One of the factors, that primary caregivers believed contributed to their physical exhaustion, was their *lack of appetite*. The sadness and devastation at the realization that the child who was dying, made eating less of a priority for the respondents. While the importance of eating decreased, the primary caregivers experienced a significant amount of *weight loss* over time. As eating less was not intentional, participants were surprised when they became aware of their *weight loss*. The primary caregivers appeared to focus on maintaining the child's appetite and weight, but not their own. The impact of their child's health status on a parent's appetite was also discussed in a study by Church et al. (2019). In the study, investigators explored the impact of prolonged hospitalization of a child on the parents' dietary habits. Mothers (n = 13) and fathers (n = 2) reported that the stress and worry about their child's neurological condition impacted their appetite. Parents shared that irregular eating patterns and snacking affected their dietary habits. Some parents lost their appetite and subsequently lost weight, while other parents overate and felt frustrated for their weight gain.

Sleep disturbance was another issue that contributed to the primary caregiver's physical fatigue and exhaustion. There were two main causes for *lack of sleep* that the respondents identified: Care for the child; Thinking about the child; Monitors. Frequently, primary caregivers stayed awake for two or three nights to provide care for the child. When not caring for the child, participants found that they were constantly thinking about the child's condition. Therefore, it was difficult for the participants to get into deep sleep, which left them feeling tired. The multiple monitors the child was attached to had alarms that went off periodically, making it difficult to sleep soundly at night. Sleep deficits due to having a child who is chronically ill was shared in a study by Kish et al. (2020). The investigators conducted a qualitative study to explore the experiences of working mothers (N = 15) whose child lived with a chronic illness. According to Kish et al. mothers found taking care of their child led to constant exhaustion. After experiencing an incident with their child, such as an asthma attack, the mothers had little time to sleep.

Previous studies have shown that mothers isolated themselves to provide child with EOLC (Arruda-Colli et al., 2016; Atout et al., 2017). Broady (2017) conducted a literature review on the experiences of carers providing EOLC. Twenty-three studies between 2005 and 2016 were included in the review. The researcher identified that the carers isolated themselves to care for the dying patient (Broady, 2017). The caregivers dedicated their time to the patient and neglected themselves. Like the current study, the respondents spent all their time with the child, whether at home or the hospital. Therefore, the participants became *isolated from the entire world*, including families and friends. Even when family members offered to help, the primary caregivers could not bring themselves to go out and leave the child at the hospital. The participants felt that being *isolated from the entire world* with the child made them comfortable during this devastating time.

Collins et al. (2016) explored parents' experiences when caring for a child with a life-limiting illness. The researchers discovered that the parents (mothers = 12, fathers = 2) and children were inseparable. The parents were committed to be the primary caregivers for their child and could not leave the child alone (Collins et al., 2016). In this study, the respondents had the same feeling that *leaving the child alone*, at home or hospital, was concerning. The participants were concerned that the child's condition might deteriorate while they were not around. It seemed that the primary caregivers would not forgive themselves if the child died while they were away.

Selman et al. (2018) investigated the impact of stigma on parents of children with autism. Some participants (mothers = 12, fathers = 3) shared that despite the negativity and rejection from the community; the child accompanied the parents in public. However, the parents took their child to places where there is a low chance for an autistic meltdown. C*hildren accompanied the primary caregivers* while socializing with family and friends, according to the participants in the current study. The respondents were not comfortable socializing unless their child was with them; as they were stable enough to leave home or the hospital for short periods of time. The primary caregivers made sure that it was safe for the child to meet other people. Socializing was not as important to the respondents, as staying with the child. The primary caregivers did not mind feeling lonely as long as the child was not left alone.

In Saudi Arabia, the public healthcare service includes primary, secondary, and tertiary levels of care, and free provision to citizens (Al-Hanawi et al., 2018). Al-Hanawi aimed to explore the views of Saudi Arabians (males = 31, females = 5) on the public healthcare sector. It was reported that Saudi citizens appreciated the free public healthcare services provided to patients (Al-Hanawi et al., 2018). Participants consistently expressed their appreciation for the Saudi Arabian government. The primary caregivers personally would not have been able to pay for the child’s EOLC. Also, the respondents shared that the *Saudi Arabian government provided several financial resources* to ensure health promotion and maintenance. The financial resources included the Rehabilitation Initiative of Saudi Arabia; the Ministry of Labor and Social Development Support; and decrees. Depending on the child’s health condition, the resources were chosen by the government. For instance, if the child was disabled, they would receive financial support from the Ministry of Labor and Social Development Support (MLSD, 2020).

A group of participants in this study (n = 7) talked about the *financial support they received from a nonprofit organization*. The organization provides financial support to families who have a child diagnosed with cancer. The primary caregivers spoke highly of the services they received through the nonprofit organization. The organization fully paid for expensive private hospital care and medications for some children. Additionally, the *financial support they received from a nonprofit organization* included housing for families who were not local residents. Similarly, the HealthWell Foundation (2020) is a nonprofit that financially supports underinsured patients with prescription copays, out of pocket expenses, and pediatric treatment costs. Both the nonprofit organization in Saudi Arabia and the HealthWell Foundation aim to ensure that all patients can afford healthcare.

Globally, it is known that EOLC cost is considered a burden to families and healthcare systems (Aldridge & Kelley, 2015; Gardiner et al., 2016; Hageman et al., 2018). Rowland et al. (2017) used a national census survey to explore the expenditure of families providing cancer EOLC at home. Participants (N = 1504) reported their most frequent expenditure were increased expenses on transportation, meals, medical care supplies, and household bills. In the current study, the primary caregivers also mentioned *struggling financially* due to increased expenditures since their child started receiving EOLC. The participants and their families were *struggling financially*. The financial struggles were not limited to the child's healthcare, but on daily expenses, transportation and rent. It appeared the participants were overwhelmed by struggling financially and appreciated receiving financial support.

Limitations

The findings of the study provided insight into the experiences of Saudi Arabian primary caregivers caring for their children receiving EOLC. Generalizability was not the aim. However, it is important to note that the participants pool was limited to three hospitals and a nonprofit organization in Jeddah, Saudi Arabia. Also, the study focused on female caregivers instead of male care givers.

Implications

There are ethical dilemmas related to EOLC decision-making for neonates and pediatrics. Therefore, EOLC policies need to be clearly explained to patients and their families. Clear detailed policies guide healthcare professionals in assisting family members in the decision-making process. Historically, research has clearly found that limiting visitation of infants and children who are hospitalized has a seriously negative impact on both the infants and children, and their parents (Saria et al., 2019; In et al., 2019, Smith, 2018). Family centered care focuses on the needs of the child and family, and not on the comfort or needs of the healthcare providers or agency (Barnard-Brak et al., 2017). Therefore, it is recommended that 24-hour visitation policies be developed for healthcare facilities in which infants and children receive care. Familial presence is especially important when the infant or child are at EOL, as those are precious moments that need to be spent together as a family.

It is not common for a male to be a primary caregiver for a child in Saudi Arabia. Mothers are the primary parent when a child is sick, though male family members (father, grandfather, brother, etc.) are involved in the decision-making process related to the child's EOLC (MOH, 2018). Therefore, further research is recommended to explore the fathers' experiences caring for their child at EOL.

Future studies also need to focus on the experiences of siblings when their brother or sister is at EOL. It is known that siblings of children who are hospitalized are affected psychologically (Niinomi & Fukui, 2018) by the pending loss. However, limited studies were found regarding assisting ill children's siblings through the EOL process. It is important to consider the well-being of the whole family, including the siblings.

Children who survived a life threating illness appreciated being listened to when they shared their preferences while they were ill (Jalmsell et al., 2016). Understanding the child at EOLs feelings and behaviors is essential to provide high quality nursing care (Darcy et al., 2019). Yet, there remains limited information in the literature on children at EOL, their thoughts, and feelings. Therefore, the journey that children at EOL go through needs to be further explored. Gaining a greater understanding of the needs of the child at EOL and their families can assist care providers to ensure they receive the highest quality of care.

Conclusion

This descriptive phenomenological study shed a light on the experiences of primary caregivers caring for a child at EOL, in Saudi Arabia. Through individual interviews, the investigator identified the holistic impact on primary care givers caring for a child at EOL. Thematic analysis was used to analyze the data, and the themes and subthemes were organized based on the research question. Similar to what has been reported in the literature, primary caregivers were affected psychologically, physically, socially, and financially while caring for a child at EOL. The findings of this study can be used to provide for improving the education, practice, and policies of nurses, as well as contribute to the body of knowledge on EOLC in Saudi Arabia and worldwide.

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Declaration of conflicting interests

The investigators declare no conflict of interest.

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Appendix A

Table 1.4

Participants Education Level

Education Level	Number of Participants
Elementary school	2
Middle school	7
Highschool	2
Some college degree or diploma	5
Graduate degree	1

* Not all participants responded to the Education Level question

Table 2.4

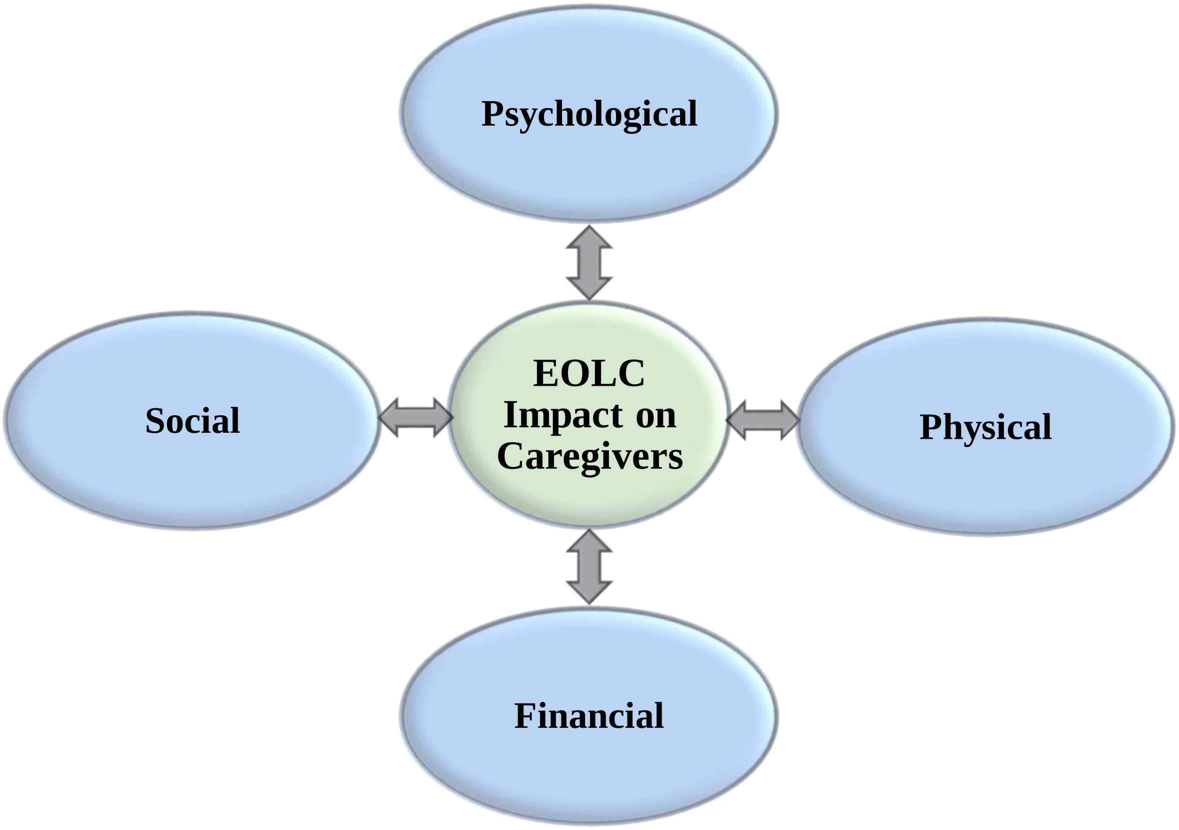
Child Age, Gender, and Duration of Receiving EOLC

Range (<1 mo.-13 yrs.)	Children (n = 25)	Males (n =12)	Females (n = 13)	Duration of EOLC (n = 25)
< 1 month	1	1	0	1
1-4 months	1	0	1	2
4-8 months	3	0	3	6
8-12 months	0	0	0	3
1-4 years	7	4	3	8
4-8 years	5	3	2	1
8-12 years	6	3	3	2
12-13 years	2	1	1	1

Appendix B

Figure 1.4

Conceptual Model



Chapter 5

Impact of Islamic Faith on End of Life Care

Manuscript 3

Abstract

Taking care of a child at end of life is a challenging experience for primary caregivers. In Saudi Arabia, mothers are the primary caregivers for their children. Studies conducted on end of life care in Saudi Arabia are limited; however, Islam was found to have an impact on end of life care and primary caregivers. The purpose of this study was to explore the perceptions of mothers and faithful Muslims, caring for their child at end of life, in Saudi Arabia. A descriptive phenomenological approach guided the research and interviews were conducted with 24 female primary caregivers caring for a child at end of life. The researchers found that Islam had an influence on primary caregivers. The findings have implications on the healthcare education, research, and practice regarding end of life care. Furthermore, it will guide future research on end of life in Saudi Arabia other Muslim countries.

Keywords: end of life, end of life care, children at end of life, primary caregivers, Saudi Arabia, Islam

Muslims find comfort and peace in spirituality, especially at EOL (Hammami et al., 2015), though, in Saudi Arabia, EOL and EOLC are considered taboo topics (Russell, 2015). The focus of EOL studies in Saudi Arabia is on the religious (Islamic) perspectives, healthcare professionals' beliefs, and family members' experiences (Al Ayed & Rahmo, 2014; Hammami et al., 2015; Katooa et al., 2015; Miller et al., 2014). No investigations were found exploring female primary caregiver's religious perspectives when caring for a child receiving EOLC in Saudi Arabia. The purpose of this study was to explore how primary caregiver's Islamic faith impacted their care of a child at EOL.

Statement of the Problem

Parental decision-making has been viewed through the lens of information received from the healthcare providers (Saeed et al., 2015). However, in Saudi Arabia, the parental role, and their Islamic faith are integral to the decision-making process when their child is receiving EOLC. De Vos et al. (2015) indicated that parents experience distress, fear, despair, helplessness, and grief when their child is dying. Mothers expressed that their spiritual beliefs, culture and traditions, family and friends, and healthcare system influenced their experience (Haley & Walker, 2016; Atout et al., 2017; Khraisat et al., 2017). Yet, little is known about Saudi Arabian mother's experiences with their child at EOL.

Islam is the religious foundation of Saudi Arabia, and mothers are the primary caregivers within the familial unit. The studies conducted in Saudi Arabia were overwhelmingly quantitative, focused on healthcare providers, and adult patients. Islam was found to have an impact on primary caregivers and EOLC. No studies were found regarding the experiences of Muslim mothers caring for a child receiving EOLC. The focus of this study will be on exploring the perceptions of mothers and faithful Muslim primary caregivers, caring for the child at EOL.

Islam is a monotheistic religion that provides a foundation for human conduct, laws and regulations, behaviors, and lifestyle (Bamousa et al., 2016). Saudi Arabia is an Islamic country where Islam shapes the culture. Thus, understanding Islam's rules, laws, and values regarding illness, death, and EOL are fundamental to understanding the Saudi Arabian culture, laws and Muslims' perspectives towards EOLC.

Muslims believe that suffering from an illness as an atonement for one's sins (Chamsi-Pasha & Albar, 2016). According to Chamsi-Pasha and Albar (2016), Muslims believe that suffering patients and their families who care for them will be rewarded by *Allah* in the hereafter. Therefore, in Islam, taking care of the ill is a high obligation. Muslims trust that *Allah* is merciful, has the ultimate wisdom, and is the healer for all physical and psychological illnesses. Islam encourages using advances in healthcare for treating curable illnesses; however, using passive or active medical procedures to end someone's life is forbidden. Muslims believe that incurable illnesses are *Allah's* will and he will end the person's life at the right time (Chamsi-Pasha & Albar, 2016). *Allah* said *"Wa asbiroo inna Allah ma'a alsabireen*" (Holy Quran: Al Anfal verse 46, Chapter 10), meaning that God is with those who patiently persevere (Almaany, 2017). So, patience is highly appreciated and fortified in Islam, especially when suffering from an illness (Chamsi-Pasha & Albar, 2016).

In Islam, an individual's life is "sacred but finite in duration" (Steinberg, 2011, p. 155). According to Tayeb et al. (2010) Muslims believe that death is an inevitable destiny and predetermined only by *Allah*. Therefore, people in Saudi Arabia avoid talking about EOL decisions or death. As humans we cannot interfere with fate as it is beyond our control. Muslims in general are accepting of death; which influences how the patient, family, and healthcare providers view death (Silbermann et al., 2012).

Based on the Islamic laws, there are limited EOLC options allowed for Muslims. Saeed et al. (2015) explained that full support requires providing the patient with all required medical care including cardiopulmonary resuscitation (CPR). Do not resuscitate (DNR) orders requires providing the essential ICU management excluding CPR. Palliative care is an approach that improves the patient's quality of life related to a life-threatening illness (WHO, 2016); for example, providing pain management for a cancer patient. Lastly, withdrawal from life support, if the patient has a poor quality of life (Saeed et al., 2015). There has been concerns related to futile medical therapy where the patient's life is prolonged with no benefits for their quality of life (Chamsi-Pasha & Albar, 2016). Islamic scholars (*Ulamá)* agree that delaying death with hopeless therapy is unacceptable. In situations where the patient is receiving futile treatment, withdrawal from life support is encouraged (Chamsi-Pasha & Albar, 2016).

The Ministry of Health (MOH) in Saudi Arabia (2015) have developed a policy regarding withholding or withdrawing life support from patients in the pediatric intensive care unit (PICU). The policy indicates that it is allowed to withhold or withdraw life support if the pediatric patient has suffered brain death (MOH, 2015). There are other criteria that need to be met to apply the policy (MOH, 2015). The criteria identified by MOH (2015) include: the brain death diagnosis must be supported by two physicians, and one of them should be a neurologist or a neurosurgeon. The assigned physician would document in the patient's record the causes of brain death. A patient must be pronounced brain dead before disconnecting the ventilator. The brain death law has to be explained to the family and other interested people before the procedure is applied. After that, the agreement of two physicians (neurologist or neurosurgeon and a pediatrician) must be obtained if life support machines are being withheld or withdrawn. The second neurologist or neurosurgeon should not be a practice associate of the pediatrician. In addition, the patient's medical record must indicate that there has been no expressed intention from the patient that life support machines be initiated or maintained in such circumstances. The patient's medical record needs to reflect that the patient's family, guardian or conservator (male), agrees in the decision to withhold or withdraw life support. Finally, the dignity and comfort of the patient should be maintained if death does not occur after withholding or withdrawing life support machines.

Conceptual Model

Refering to the literature about parents' experiences caring for their child at EOL, a conceptual model was developed. The conceptual model guided the research study. Concepts emerged from the literature regarding pediatric EOLC and religion (see Figure 1.5).

Purpose and Research Question

The purpose of this study was to explore the perceptions of mothers and faithful Muslims, caring for their child at EOL, in Saudi Arabia. The research question: How does Islam impact primary caregivers' experience caring for a child receiving EOLC?

Methods

Design

The current study is a part of a larger qualitative phenomenological study. The qualitative study focused on the experiences of primary caregivers caring for a child at EOL in Saudi Arabia.

Participants

In this study, the inclusion criteria were Muslim Saudi Arabian women caring for a child receiving EOLC; such as, mother, grandmother, aunt, sister, or stepmother etc. The primary caregivers must be 18 years of age or older. The participants must be caring for a child who is terminally ill or in a critical condition, and not older that 14 years of age. According to the Saudi Arabian Ministry of Health, individuals over the age of 14 years are considered adults and must be admitted in adult wards.

Recruitment

Participants for this investigation was a purposive sample (N = 24) to ensure they met the inclusion criteria for the study. The participants (n = 17) were recruited from three government healthcare centers in Jeddah, Saudi Arabia. In addition, participants from the community were recruited through a nonprofit organization (n=7) using snowball sampling. After the interview, female caregivers were given a 50 Riyals (13 US Dollars) gift card as appreciation for the time they provided to participate in the study.

Data Collection

In-depth individual interviews were conducted with 24 participants in Arabic. The interviews lasted between 15 minutes to an hour, depending on how much the participant wanted and was able to share. At the hospital, the interviews were conducted at the patient single room or a meeting room at the same unit. It was insured that the child was observed and cared for during the time of the interview. In the community, the interviews were conducted at the child’s family home. All the interviews conducted at home; the child was present in the room to ensure their safety. The data collection was completed over a period of seven weeks in Jeddah, Saudi Arabia.

Instrument

An interview guide with questions and probing follow up statements was the measure used for data collection. The interview guide was developed based on what has been previously presented in the literature on EOL. In-depth individual interviews were conducted with 24 participants in Arabic. The interviews lasted between 15 minutes to an hour. The interviews started by asking about the demographic data, followed by exploring in greater depth the respondents' views of caring for a child at end of life.

Data Analysis

The thematic analysis was conducted using the English version of the data. Each interview was coded individually, and the emerging themes and subthemes were organized into tables. In addition, a matrix of the codes and themes was established for the data of this study as it assisted in identifying the patterns that emerged from the data.

Findings

Participants

Primary care givers included in the study were mothers (n = 22), a sister (n = 1), and a nanny (n = 1), ages between 18-47 years old (see Table 1.5). A majority of the primary caregivers (n = 20) were housewives (see Table 2.5). The participants were caring for children (n = 25) with life limiting conditions; such as, cancer, congenital anomalies, and neurodegenerative disease. The majority of children were hospitalized (n = 18) and had DNR orders on their charts. The remaining children (n = 7) were receiving EOLC at home.

Results

Thanks to Allah

All the participants included in this study were Muslims. The Islamic beliefs of the caregivers emerged from the data as they shared their experiences with the dying child. It was clear that the respondents had strong religious beliefs when it came to their child's illness and prognosis. All participants were "thankful to *Allah*" at some point in their interview, regardless of how their child's condition was progressing. Respondents expressed thanks to *Allah* by stating: *"thanks to Allah now.. she was on a ventilator and the doctors removed it today, I hope she doesn't need it anymore… thanks to Allah" (009).* Another participant noticed the improvement of her child's health over time and was thankful to *Allah*, sharing: "*she was on oxygen for a month… I started decreasing the amount [oxygen liters] until she didn't need it at all, never thanks to Allah" (005).*

Participants got emotional while expressing their "thanks to Allah", especially when the child overcame a dangerous phase during their treatment. The tears of gratitude the caregivers conveyed during the interview showed how thankful they are to *Allah*. While crying, a responded shared:

> *Thanks to Allah we were very happy after the surgery… we were relieved that the tumor was removed, and the doctors said we passed the dangerous phase thanks to Allah… I will never forget what the doctor said to my mom, your daughter is a miracle. Thanks to Allah (019).*

Pray to Allah

The majority of the respondents expressed that "praying to *Allah*" was a source of patience and strength. The caregivers shared that praying gave them the patience and strength they needed to care for their child at EOL, stating: *"I prayed to Allah to give me strength and patience" (024).* A caregiver expressed that being strong and patient the entire time depended on her prayers to *Allah*, she said: *"praying to Allah is what makes me patient and strong in the first place" (001).* Another mother stated that she, also, prayed to seek help from *Allah* to accept her child's health condition: *"I pray to Allah to give me strength and help me accept this situation I am in now" (023).*

Everything is from Allah's

The Majority of the participants expressed their "acceptance" of the child's terminal condition. Acceptance was derived from different religious perspectives. Some respondents accepted their child's illness because they "believed in fate", and fate is set by *Allah.* A mother shared that it is not possible to escape her fate or her child's, stating *"this is my daughter, this is my future, and this is my fate, that's it. There is no runaway, and I have to accept her and love her" (003).*

A caregiver strongly believed in fate, and *Allah* is the one who writes fate. The participant expressed that the fate of her child could not be changed, even with the best healthcare. However, *Allah* is the one that has the power to heal her child, as evidenced by the following:

> *You know I have strong faith and believe in fate, and I know everything is from Allah, and it is written for him to become like this… and if death is what Allah wants, it will happen even if 1000 machines were connected… I have hope and believe that Allah brings back life to the bones. If Allah wrote healing to him, he would heal him" (002)*.

Respondents did not give up on finding a cure for the child's illness. Unfortunately, all the children were diagnosed with a terminal illness that they could not recover from. As a result, some participants expressed that they had to accept the fate of the child's prognosis. A caregiver shared: *"I told the doctors do whatever you have to do to help him… but there were no donors! So we said thanks to Allah and we accepted the fate of our son" (016).*

Other participants accepted the child's illness and believed that it is "*Allah's* will." Caregivers shared that caring for their child at EOL is a way of accepting *Allah's* will. However, it is hard to accept the fact the child is dying. A participant stated:

> *I mean it was really hard but I accept that it is Allah's will… after a while you accept the fact and you feel like.. its Allah's will… Eventually people adjust to the situation and learn what to do. Because we are all Muslims we believe that it is Allah's will [kada'a Allah wa kadaroh] and we have to accept it (005).*

A couple of respondents shared that they accepted the child's prognosis, because all "lives come to an end." The caregivers believed that the journey of life includes good and bad, sickness and health. Nevertheless, death is inevitable, as a caregiver shared:

> *This is life! We're going to live life during the good and bad, sickness and health.. in the end you will loose your life in a second.. we are not immortal! Prophet Mohammed peace be upon him said.. the ages of my people is between 60s and 70s, isn't that right?... you see? How long we'll live? Over 70? I'm 33 years old, how many more years will I live? How much more do I have left? (001).*

Entrust in Allah

Few caregivers expressed how they "trusted and entrusted in *Allah"* to protect the child. The respondents believed that if they were not with the child, *Allah* will be caring for the child until they reunite. A mother shared her entrust in *Allah* when she left her sick twins in the intensive care unit:

> *I am leaving them [children] with the nurses… I entrust that they are in the care of Allah… when I see a lot of patients I think to myself how can I leave my children here? But then I just pray to Allah and entrust they are with him (004).*

A couple of participants believed that the child survived because they trusted *Allah* to do the best for the child. Caregivers trusted that not objecting to *Allah's* will, will keep the child alive, as evidenced by the following: *"we trusted Allah and he did what is best for her [child]… we never objected… that is why everything worked out [successful surgery]" (019).*

A few caregivers shared that they trusted that "*Allah* does what is best" for themselves and the child. The participants truly believed that the child's illness is what is best, even if the child's condition appeared bad, as was shared by a respondent: *"I truly believe whatever Allah gives me it is for the best, regardless if it seems good or bad" (024).*

Test from Allah

A majority of the participants described their belief that the child's illness is a "test from *Allah*." Being patient while caring for the dying child was the respondents' way of coping with *Allah's* test, as a respondent expressed: *"they [mothers] have to be patient because this is a test from Allah the most merciful, and in sha'a Allah [Allah willing] they will go to heaven… and this is life!" (014).* Other participants mused that they hoped to be able to handle *Allah's* test: *"we thank Allah for what he gave us [child], I hope we can handle the test Allah gave us [sick child]" (007).*

Other caregivers expressed that staying strong while caring for the dying child was the way to handle *Allah's* test. Also, the participants believed that accepting the child's illness could be rewarded with the child's survival, as shared by a caregiver:

> *There are a lot of mothers that I talk to here, I tell them to stay strong, accept what has happened… maybe it is a test from Allah… you could stay with your child and they wake up in 18 or 8 years healthy! you don't know! (013).*

Rewarded from Allah

Some caregivers mentioned they believed that they will be "rewarded from *Allah*" for caring for the child during the illness journey. The participants stated that the reward will be going to heaven in the afterlife. A mother said: *"I mean when I get bored my husband tells me its ok you are rewarded from Allah and you will get a house in heaven… he makes me feel better" (014).*

Other participants expressed that having a terminally ill child was a blessing, and not bad. Because, mothers believed that they will join their children in the afterlife. With *Allah's* permission, the child would lead the mother into heaven, as evidenced by the following:

> *It is like she is something bad!? She is not something bad.. she could get me into heaven, she could hold my hand and take me to heaven.. she would go in through any door, with Allah's permission, she would take me with her… She could take me to heaven (001).*

Quranic Recitation and Evil Eye

A couple of participants revealed their views on the "evil eye" curse, and that it could be the cause of the child's illness. Muslims believe that a person will be protected from an "evil eye" by reciting the Quran on the person. A participant mimicked this view, when she talked about her belief in the Quranic recitation, saying: *"I will recite Quran on my son and I truly believe that Allah will protect him from everything" (012).*

The mother further shared the story of a woman who gave her son the “evil eye” that caused his illness, stating:

> *A Sheikh came to see my son in the hospital, and he said that it is an evil eye! I felt that it was an evil eye from the beginning! There was this lady who talked about my son, and soon as she was done my son’s nose started to bleed! I swear to Allah she is a kind woman, maybe she didn’t mean to, but she did not say ma sha’a Allah [Allah bless]… hasbi Allah w nima alwakeel [Allah suffices me, for he is the best disposer of affairs] (012).*

Discussion

Muslims pray in different ways, as recognized in the interviews of the current study. It was not a surprise to identify Religion/Islam as a factor that affects the primary caregivers’ experiences with the dying child. The desire to be at peace with *Allah* was reported by Hammami et al. (2015). In the study by, the investigators explored the opinions of Saudi Arabian men (N = 120) on their EOL priorities. The researchers discovered that the participants’ priorities were based on Islamic beliefs. Men in the study wanted to practice Islamic rituals to be at peace with *Allah* at EOL, for instance, praying.

In this study, the participants repeatedly said “*Al Hamdu li Allah*” [Thanks to *Allah*] throughout their interviews. In Islam, being thankful to *Allah* is one of the essential prayers that Muslims are encouraged to say. Muslims need to be thankful to *Allah* regardless of the situation they are going through, pleasant or unpleasant. “*Al Hamdu li Allah*” is one of the favorite prayers to *Allah*, gets the individual closer to *Allah*, and increases livelihood of individuals (Abdul Salam, 2019). Therefore, Muslims feel a sense of comfort and strength when they thank

Allah, especially during devastating experiences; such as, caring for a child at EOL (Ahmed, 2019).

Oakley et al. (2019) report that individuals nearing EOL or caring for someone at EOL seek strength and peace through spirituality. In this study, Islam was the source of spirituality for the primary caregivers. In the Holy Quran, *Allah* stated: "*When My worshipers ask you [prophet Mohammad] about Me, tell them that Allah says, "I am near; I answer the prayers of those who pray*" (Al Baqarah, verse 186, Chapter 1). Therefore, the participants prayed to *Allah* in different ways, until they found strength, patience, and comfort. Prophet Mohammad, peace be upon him (PBUH), encouraged individuals to pray to get closer to *Allah,* and seek support, help, and strength (Abu Ramees, 2020). It was clear in this study that the primary caregivers were praying constantly, hoping for the best for the child.

In Islam, it is important to recognize that all that happens is from *Allah* and he knows best (Hawajri, 2017). The participants truly believed that the child's illness was "*Iradat Allah*" [*Allah's* will], and it the best for themselves and the child. As mentioned in the Holy Quran: "*Surely his [Allah's] command, if he wills a thing, is only to say to it, "Be!" and it is"* (Ya Seen, verse 82, Chapter 23). Therefore, Muslims accept what *Allah* gave them knowing that it is out of their control. However, it does not mean that Muslims have to give up on finding treatment for their illnesses (Chamsi-Pasha & Albar, 2016). Accepting the situation, means that individuals should do whatever they can to seek treatment, and not rebel on *Allah's* will (Chamsi-Pasha & Albar, 2016). In this study, the primary caregivers were accepting and embracing the child's illness, as the participants believed in *Allah's* will. *Allah* said in the holy Quran: *"But it may be that you hate something while it is good for you"* (Al Baqarah, verse 216, Chapter 1).

The participants "*Astawda'at Allah"* [entrusted in *Allah*] knowing that the child is in his protection. Prophet Mohammad, PBUH, said: "*If you entrust something to Allah, he will protect it*" (Ibn Omar, Sahih Ibn Habban). Additionally, in the Holy Quran, *Allah* stated: "*Allah is the best protector and he is the most merciful of those who show mercy*" (Yusuf, verse 64, Chapter 13). Muslims trust others to protect their children; however, the ultimate protection is from *Allah*. The primary caregivers of this study highlighted that they entrust in *Allah* when they left the child at the hospital.

Muslims understand that the illness is a test from *Allah*, and they will be rewarded for their acceptance, patience, and providing care (Abu Bakr, 2017). Terminal illnesses are considered as a test, and the individual will be rewarded in the afterlife. Prophet Mohammad, PBUH, said: "*A Muslim, male or female, continues to remain under trial in respect of his life, property and offspring until he faces Allah, the exalted, with no sin record*" (Abu Huraira, Al Tirmithi). However, parents who lose their child would be rewarded differently. Prophet Mohammad, PBUH, said: *"If the worshiper's son died, Allah says to his angels: did you take my worshiper's son? Then they say yes: then he [Allah] says: did you take the apple of his eye? Then they would say: yes, so he [Allah] would say: what did my worshiper say? Then they [the angels] say: he praised you and said we belong to Allah and to him we shall return, then Allah says: build a house for my worshiper in paradise and call it the House of Praise*" (Abu Mousa, Al Tirmithi). There are many other versus in the Holly Quran and prophet Mohammad's sayings about the parents' rewards. In the current study, some mothers talked about other examples of *Allah's* rewards. For instance, the child would hold the mother's hand and lead her into heaven in the afterlife.

"The effect of an evil eye is a fact" said prophet Mohammad, PBUH (Abdullah Bin Abbas, Sahih Al Albani). In Islam, it is believed that the evil eye can cause different types of illnesses, and in extreme cases death (Ziyad, 2019). Some Muslims believe that sudden illnesses with no cure are a result of an evil eye (Ziyad, 2019). A couple of participants in this study shared that the child's terminal illness is caused by an evil eye. Stories were shared that their child unexpectedly got sick after being around people that gave the child compliments on her/his health. Islam supports the existence of the evil eye curse, and in Saudi Arabia many people relate bad situations to an evil eye curse. However, being obsessive about the evil eye and continuously talking about it is a cultural norm. Culturally, it is normal that families and friends help to find the person who gave the evil eye to the sick individual. Some try to find a cure to release or remove the curse of the evil eye.

Since the evil eye curse exists, Muslims are encouraged to recite Quran for protection or a cure. There are combinations of verses in the Holy Quran that Muslims recite for protection from the evil eye. For example, one of the verses, from the Holy Quran, is: "*I seek refuge in the Lord of daybreak (1) From the evil of that which He created (2) And from the evil of darkness when it settles (3) And from the evil of the blowers in knots (4) And from the evil of an envier when he envies (5)"* (Al Falaq, verse 1-5, Chapter 30). Additionally, prophet Mohammad, PBUH, prayed for protection from the evil eye or any harm by saying: *"I seek refuge in the perfect words of Allah from every devil and poisonous reptile, and from every envious evil eye"* (Ibn Abbas, Sahih Ibn Jubayr). When prophet Mohammad, PBUH, visited a sick person, he put his right hand on their forehead and pray: *"O Allah! the Allah of mankind. Remove this disease and cure (him or her). You are the great curer. There is no cure but through you, which leaves behind no disease"* (Aisha, Sahih Bukhari and Muslim).

Implications

Inclusion of EOLC in the nursing curriculum is foundational for students to develop confidence and provide compassionate care to children at EOL and their family. Dimoula et al. (2019) purported that it is essential for nursing students to understand that holistic care includes the patient and their primary caregivers. Future nurses need to respect the religious and spiritual beliefs of patients and their families. It is essential to understand the influence of religion and spirituality at EOL and EOLC, as it shapes patients' lives and perspectives.

Spiritual practices for patients and their families provided comfort, peace, hope, and helped with coping at EOL. Even though HCPs did not participate in spiritual practices; the participants had the freedom to practice their spirituality with no judgement from HCPs. Future nurses should be encouraged to ask patients or their families about their cultural preferences to ensure they receive a high standard of care. Family members should be involved in their child's healthcare plan at EOL, as parents are the guardians who were making decisions on behalf of their child. The investigators findings suggest that including parents in their child's care plan was beneficial for all individuals involved in the care plan.

Support is a critical element that family members need while caring for a child who is dying. Families could be supported by offering group meetings with other families going through similar experiences. Primary caregivers in this study expressed their exhaustion from constantly caring for their child at the hospital. Some participants shared that they needed time to spend with their families without worrying about their child being alone.

Ethical Considerations

Prior to the conducting the research, IRB approval was obtained from all appropriate institutions in the U.S and Saudi Arabia. The institutions included the researchers University, the Ministry of Health of Saudi Arabia, and healthcare organizations.

Limitations

This qualitative study shed a light on the experience of primary caregivers caring for a child at EOL, in Saudi Arabia. However, this investigation was limited to three government hospitals and a small community in Jeddah, Saudi Arabia. Also, the participants in this study were female primary caregivers only.

Conclusion

This study shed a light on the experiences of primary caregivers caring for a child at EOL, in Saudi Arabia. Similar to what has been reported in the literature, previous studies demonstrated that religion has an impact on EOL and EOLC. This study also presented the impact of Islam on primary caregivers' experiences with a child who is dying. Islam had a positive impact on the primary caregivers' experiences with their children who were in a terminal condition. The findings of this study can be used to provide for improving the education, practice, and policies of nurses, as well as contribute to the body of knowledge on EOLC in Saudi Arabia and other Muslim Countries.

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Declaration of conflicting interests

Researchers declare no conflict of interest.

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Appendix A

Table 1.5

Participants Age

Range	Number of Participants
18-30 years	5
30-40 years	12
40-50 years	7

Table 2.5

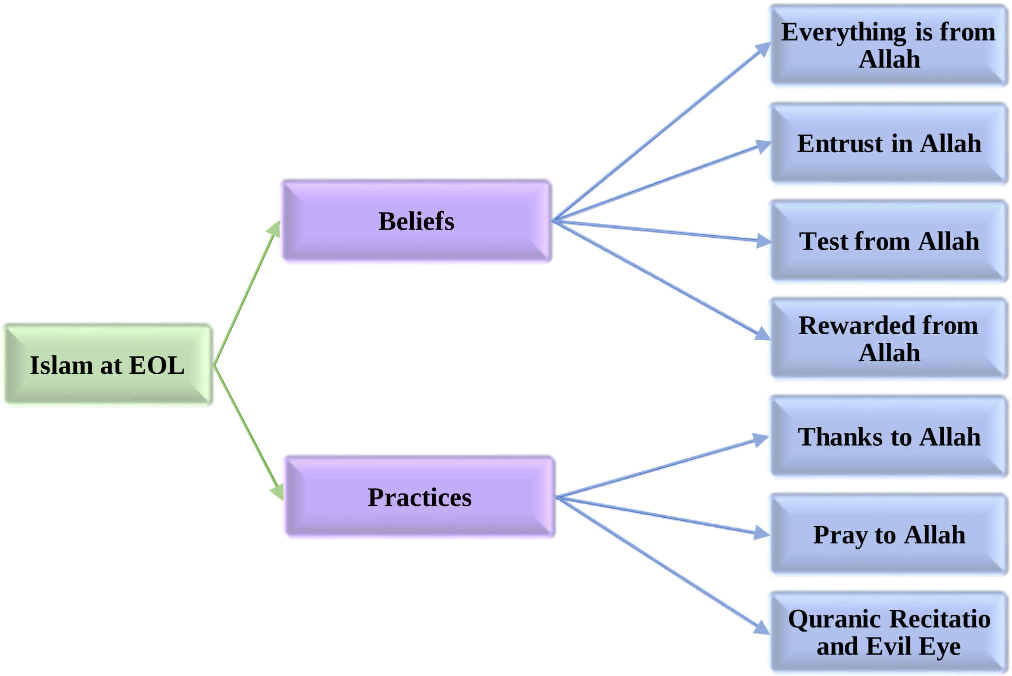
Participants Occupation

Occupation	Number of Participants
Housewife	20
Nurse	1
Nanny	1
Teacher	1
Student (older sister)	1

Appendix B

Figure 1.5

Conceptual Model



Chapter 6

Findings

Primary Caregivers Caring for a Child at End of Life

In this study, thematic analysis was used to analyze the data. The themes identified were guided by the main research questions. The participants shared the impact of caring for their child at EOL on their psychological, physical, social, and financial status. Also, the respondents' experience was influenced by three major factors including religion/ Islam, support system, and the Saudi Arabian Culture. Furthermore, the demographic data of the participants and the children are presented in this chapter.

Purpose and Research Questions

The purpose of this study is to explore the experiences of primary caregivers caring for a child at EOL in Saudi Arabia. The research questions are: (1) How does caring for a child receiving EOLC impact the primary caregivers' psychological, physical, social, and financial status? (2) What are the factors that influence the experiences of primary caregivers caring for a child receiving EOLC in Saudi Arabia?

Methods

Participants and Setting

Participants. In the current study, the participants (N = 24) included mothers (n=22), sister (n=1), and a nanny (n=1). The age of primary caregivers ranged from 18-47 years of age. The majority of the respondents (n = 19) were married (see Table 6.8 and Table 7.8). The participants cared for female (n = 13) and male (n = 12) children in this study. The children's ages ranged between 11 days and 13 years old, as well as their duration of receiving EOLC, (see Table 8.8). The children admitted into the hospital (n = 17) were identified as DNR (do not resuscitate) patients. Whereas the children receiving care at home (n = 7), the investigator had no access to their medical records. The children had a mixture of multiple illnesses; such as, cancer, neurodegenerative disease, congenital anomalies, end stage renal failure, down syndrome, cerebral palsy, encephalomyelitis, seizure disorder, pneumonia, sepsis, and hypoxic-ischemic encephalopathy.

Setting. Participants were recruited from King Abdulaziz University Hospital, National Guard Hospital, and East Jeddah General Hospital in Jeddah, Saudi Arabia. The hospitals included are large government hospitals, that patients from different regions of Saudi Arabia travel to for healthcare. All hospitals have pediatric and neonatal intensive care units, pediatric medical and surgical units which included children at their EOL (n=17). In addition, participants from the community were recruited through a nonprofit organization (n=7).

At the hospitals, the interviews were conducted at the patient's single room or a meeting room at the same unit. It was insured that the child was observed and cared for during the time of the interview. In the community, the interviews were conducted at the child's family home. The child was present in the room to ensure their safety during the interviews.

Data Collection

A purposive sample was used to recruit the participants. The required sample was based on who meets the inclusion criteria and available at the hospital's pediatric or neonatal care units and agree to participate. In addition, snowball sampling was used to further expand the purposive sample, and participants were recruited from the community. After the interview, female caregivers were given a 50 Riyals (13 US Dollars) gift card as appreciation to the time they provided to participate in the study.

Gatekeepers were assisting in the recruitment process. The gatekeepers included nurses, social workers, and physicians. The researcher visited the hospitals and a nonprofit organization frequently to establish rapport with workers and potential participants. After identifying potential participants, the gatekeeper introduced the researcher to the primary caregivers. When the caregiver agreed to participate, the researcher explained the process and obtained a signature on the consent form. Also, the participant received a copy of the signed consent form. After that, the time and date of the interview was set conveniently to the participant.

In-depth individual interviews were conducted with 24 participants in Arabic. The interviews lasted between 15 minutes to an hour, which depended on how much the participant wanted and was able to share. So, the interviews started by asking about the demographic data, followed by less sensitive to more sensitive questions. The data collection was completed over a period of seven weeks in Jeddah, Saudi Arabia.

Data Analysis

The thematic analysis was conducted using the English version of the data. The transcribed data was read thoroughly by the investigator and major professor multiple times to understand the data and identify the emerging themes. Each interview was coded individually, and the emerging themes and subthemes were organized in table. A separate table was developed to include the narratives as a reference for every theme and subtheme. In addition, a matrix of the codes and themes was established for the data of this study as it assisted in identifying the patterns that emerged from the data.

Question 1 Findings

The first research question was guided by four major themes identified in the question. The four themes included the psychological, physical, social, and financial impact on the primary caregivers' experiences. For every major theme, subthemes were identified from the data.

Themes

Psychological

Life Flipped Upside Down

Participants expressed a range of emotions to describe the overwhelming changes that occurred in their lives with the realization that their child's health had dramatically altered. Mothers and caregivers expressed similar responses of *shock* when informed about their child's diagnosis and prognosis. The mothers and caregivers were in shock and realized that their lives and that of their children had changed and will never be the same. A mother expressed her shock by saying *"I was in shock at first, cancer!? Not a flu? I have never been to hospitals before!... I was surprised he has the disease [cancer]… it was a shock! My life flipped upside down" (012).*

Some participants verbally described the intensity of their *disbelief* and cried and sobbed inside the private rooms where the interviews were conducted. While other respondents demonstrated the shock and disbelief in their tone of voice and facial expressions. A mother expressed her disbelief by saying "*at the beginning when they told me I couldn't believe the doctors. The doctors at [hospital in Jeddah] did the blood works again and I couldn't believe it! I couldn't believe that she has this disease [leukemia]" (022).*

Individuals reported that they *broke down* as soon as they learned about the child's diagnosis. The caregivers shared that they were not able to vocalize their feelings when learning the news about the child's terminal illness. Breaking down was the only emotion the participants were able to express, as one mother stated:

> *The doctor's honesty [about the diagnosis] made me breakdown in front of him….. aaah! I broke down… I broke down, I can't explain to you how I*

> *felt…. now I'm talking to you [interviewer] I feel fine, but if you tell me go home I will breakdown, I can't! (007)*

Participants also shared that since they were told about their child's illness, they became *distracted* thinking about the child. During the interview, it was obvious that the participants were taking a glance at the child every couple of minutes throughout the interviews. It was hard for the mothers and primary caregivers to concentrate while they appeared visually to be continuously thinking about their child's suffering. Verbally, the participants more clearly described their sense of distraction, as evidenced by the following statement: *"I feel I was distracted and worried… until now….. my time is messed up.. my life got messed up since then…. I'm just far away… I keep seeing her image and how she is suffering" (009).*

A majority of mothers and caregivers expressed *empathy* when they shared that the child will never outgrow the health condition they were suffering from. Participants discussed that the child will not enjoy an independent childhood similar to what other children experienced. The mothers' empathy was demonstrated by the following: *"I mean now she has renal failure, poor thing she can't see, she can't walk, she can't depend on herself, ever" (006).*

Shattered from the Inside

Participants indicated that they hid their actual emotions toward the child's terminal condition from people. Mothers and caregivers did not want to express to anyone how shattered they were inside. However, at the same time, caregivers described that the *pain* they were carrying around every day was so intense since the child was diagnosed, that they could literally explode. Respondents described the need to hide the pain and show everyone how capable they were to support the dying child. A participant described her aching pain as:

> *At home I feel bitter because I am far from her… when I come to the hospital I feel that my pain gets worse when I see her like this… when I leave I don't feel comfortable… when I have to leave after visiting hours, I feel deep pain that I am leaving her… to be honest I am in a constant state of pain all day. When I arrive at the hospital entrance my heart hurts (009)*

Mothers and caregivers expressed how *heartbroken* they were watching their child suffering. Participants repeatedly placed their hand on their chest when talking about their heartbreak during the interview. Some mothers even pounded on their chest and cried as they expressed how deeply heartbroken they were seeing their child's health deteriorating. The participant's heartbreak was evident, and she pounded her chest and shared the following: *"I told my husband that I feel my heart my heart my heart my heart my heart was coming out of my chest!... my heart wasn't in its place" (007),* while another mother just placed a hand over her heart and stated: *"I cried all the time and my heart was breaking seeing my son getting worse every day! Not moving!" (024).*

Only a few mothers discussed their sense that *this is my fault* for their child's health problem, blaming themselves. Participants reported their concerns that they had contributed in some way to their child's health problem. The perspective shared was that if they had taken different actions, the mother could have prevented their child from getting ill or dying. A respondent even described the unbearable heavy weight on their chest over their child's condition and caring for their child made them feel a little of that weight lifted. Still the participants couldn't shake the feeling that it was their fault the child was dying. This was reflected in statements:

> *I wasn't taking any contraceptives, I wasn't taking folic acid pills either! And this is my fault… so it would have been better if I was taking it [folic acid]… it's just a small pill if we [mothers] didn't take it, it will affect us psychologically and affect the "baby" physically!" (009),*
>
> and *"maybe because psychologically I wasn't feeling ok.... maybe because I took medications? Maybe, I don't know?... I keep saying to myself, I am a bad mother! I am careless!" (001)*

Participants shared their *worries* about their child's deteriorating health. Mothers and caregivers were worried about the impact of losing their child. The participants were not able to imagine what their lives would be like if they lost their child. Even mothers who were optimistically focused on having their child get better expressed that the worries remained in the back of their minds. A mother articulated her worry by saying: *"I am worried that someday the doctors tell me that she is gone… I don't know what I would do? My mother tells me that she is sick and she could die, I can't! I'm a mother!... it is very difficult" (008).*

Mothers shared that at some point, during their child's illness, they reached a point in their child's illness that they felt they could not go on. The mothers had *suicidal ideations* as they could not handle the fact that they were healthy, and their child is dying. None of the mothers had thought that they would outlive their children. The thought of their child suffering more if they were not there to care for them, stopped the mothers. The concerns were reflected by the following: *"I wasn't doing well, psychologically! I thought of ending my life! But then I thought who is going to take care of my son if I'm not there?!" (021).*

How Could I Let Go of a Piece of My Heart?

All the mothers and caregivers described the strong emotions they felt for their dying children. Though the mothers had other children, the dying child became very special to them. The participants eyes sparkled, and face lit up when they conveyed their unconditional *love* for their dying child. The love was expressed as evidenced by the following:

> *Even though I have to visit her every day. I don't feel like my day is complete until I see her… I want her, I want to see her!... she is my life, she is my world.. .all my children are in one hand, and she is in the other (001)*

Other mothers described their intense love emerging from their total acceptance of the child who was so ill, sharing:

> *After I started thinking like this [acceptance] I began to love her… love her. I now understand when she cries what she wants…. She is my world now…. I wanted to take her and hug her, although she was sick, I never felt like she was abnormal (003)*

A majority of participants described being very *attached* to their children, a special bond had formed between them and caregivers. The children were not able to verbally express attachment to their mothers and caregivers. However, their facial expressions visibly changed when the mother was not close. The strong attachment to each other was discussed by one caregiver as:

> *Even when I go home for a break I can't stay long… I can't wait for the day to end so I can come back to hospital…. when I come back she gets better.... I don't feel obligated… it's just my heart is so attached to her. No*

> *matter how long I spend time away from her, she is always on my mind (013)*

Respondents found it hard to accept being separated from their child. Mothers went to extreme measures just to be with their dying child. *Desperation* was expressed, as the need to see the child was overwhelmingly powerful. Participants needed to confirm that the child was still alive. The mothers were determined to be with the child, believing they are the only ones who could feel the child's suffering even from far away. The intensity of their feelings resonates in their words:

> *I told the doctors just let me stay by the door, by the door! I just wanted to see him, I just wanted to see him! The doctors said no!... my husband was dragging me around! I was on the floor and couldn't move! I couldn't imagine losing [child]…. when he was in the intensive care unit I wanted to kneel and kiss the doctors' feet to let me stay with him [child] (007)*

Being with their dying child was a source of *strength* for participants, which kept them surviving all this time. Mothers and caregivers believed that being strong, and caring for their child, was essential to nursing their child back to health. Strength was the participants' way of showing their love for the child. A mother shared her experience by stating:

> *I remember when I used to cry my son was young, he used to say why mama cry? Why mama cry? I used to tell him I have a headache, then he says ok mama no cry… so I made myself stronger… I will never show my weakness! I don't want my child to see it and get sick…. I have to make myself strong.. even if I'm shattered from the inside, the outside has to be strength (012)*

Physical

When You are Sad You Don't Eat Well

Caring for a child at EOL not only affected the participants emotionally but took a toll on them physically. A majority of the caregivers shared their experiences with alterations in their appetite, and lack of appetite. Overwhelmingly, the alteration in appetite led the participants to *lose their appetite* and reported a great deal of *weight loss*. Loss of appetite and weight was not a major concern for the women, as the enveloping sadness they were experiencing was focused on their child's devastating health condition. Eating well was not a priority for the respondents, as they expressed their sadness over the child, as evidenced by the following: *"when you are sad you don't eat well, I mean I don't want to eat" (010*). Even when the participants would sit down to the table to eat, they could not bring themselves to eat, stating: *"when I sit at the table for food I don't feel like eating….as soon as I sit at the table I don't feel like eating" (001).*

Exhaustion was one of the factors that caregivers experienced, and visually the participants appeared to be very weary. Weight loss was even attributed to their exhaustion as well as decreased intake, which resulted in subsequent weight loss, as evidenced by the following: *"I lost 11 kilos… I feel exhausted" (001).* Some were surprised by their weight loss, since their bodies did not lose weight easily or rapidly, stating:

> *Yeees I lost weight, I mean I used to be 86 kilos [189 pounds] and now I am 74 [163 pounds]. I wasn't eating! I mean I wasn't eating, and my body is not the type that lose weight fast! (007)*

I Sleep, but not Sleep

Sleep alterations was described by participants as they shared their experiences caring for their dying children. Distraction was also pervasive amongst the women, as the sleep deprivation was ongoing, and they discussed being overwhelmed worrying about the welfare of their child. Thinking about the child's condition and prognosis became exhausting, preventing the respondent's ability to sleep to the point of commenting *"As soon as I put my head on the pillow something wakes me up, how is my daughter? This is what was exhausting me" (003).*

Some were not able to sleep because they were up all night next to the child. The caregivers wanted to confirm that the child's needs were met to so the child could sleep well. The respondents were not complaining that they were not sleeping, they were explaining the reason for not being able to sleep at night, stating:

> *No sleep… I stay awake two days like this. Sometimes three days. And if I sleep, I sleep half an hour, not an hour.. because I have to take care of my son, his milk, change his diapers, suction his sputum. Next to him like this I could sleep [mother laying in bed with the child] (002)*

Social

Isolated Themselves from the Entire World

The social life of the participants changed once they learned about their child's diagnosis. The respondents focused their attention towards caring for their child at EOL. The caregivers shared that they *isolated themselves* from everyone around them, because socializing with others was not their priority. Participants even shared that they did not want to talk to people, as evidenced by the following: *"I didn't feel like going out or meeting anyone… I was kind of isolated during that time, I didn't even talk to my family! isolated" (018).* Other caregivers did not visit anyone and isolated themselves by staying home. The respondents expressed that they would only leave their homes if it was for the child's hospital appointments, as one participant stated: *"I mean my son has been sick for 7 months, I didn't visit anyone, I stayed at home.. if I left home it would be because I'm going to the hospital, and back home again" (007).*

It was shared by the caregivers that they *could not bring themselves to go out* and leave the child alone at the hospital. Even when the participants were tempted to go out and meet people, they were distracted thinking about the child. Therefore, the respondents felt it was impossible to enjoy their time with family or friends while their child is dying, as evidenced by the following:

> *I stopped going out with him [husband] and my children. It is difficult for me to go out.. I can't, just can't enjoy myself with our family or relatives… because her [child] image is always in my head… I'm not going out like I used to (009)*

Even when participants were surrounded by people, the participants expressed that they could not feel their presence. The respondents shared that they were constantly distracted thinking of their child, which made socialization insignificant. A caregiver shared her challenges socializing by stating: *"honestly, I was sitting with people but I don't feel them. All the time, I was thinking of her [child]" (003).* Other participants expressed that they excused themselves from talking to visitors, as evidenced by the following: "even gatherings at home… if someone is sitting next to me just to talk, I would excuse myself and leave within like…3 minutes" (009).

Can't Go Out and Leave the Child Alone

A majority of the participants remained at their child's side the entire time the child was in the hospital. When the child was admitted to the pediatric or neonatal intensive care units, respondents reported not being allowed to stay with their child. Nevertheless, caregivers agonized about *leaving the child alone* at the hospital. The participants worried that the child's health might deteriorate while they were away, as a mother reported: *"I can't go out, I can't leave my son alone… I worry my son gets sick and I'm not around… I can't go anywhere" (015)*. Participants were attached to the child and could not bring themselves to stay away for long periods of time. A caregiver stated:

> *Sometimes I meet my friends over the "weekend", a Thursday or a Friday… even my family, I don't stay with them for too long. Instead of 2 days off at home, I would stay one day only then I go back to [child] (013)*

A couple of children who were stable enough, accompanied the participants while socializing with friends. A care giver shared: *"Currently I don't go out, I don't meet anyone… and even if I go out we go out together [participant and child" (017).* Conversely, there were participants who spoke about how limited circumstances in which they were able to go out with the child. Due to the child's health status, the caregivers sought to protect them from any harm. Therefore, the participants frequently cancelled going out with the child to protect them, as evidenced by the following: "*you can't go everywhere, I had to cancel for her… uuum there are some places you can't go because of her" (005).*

Financial

Without Financial Support We Could Not Care for Our Child

The majority of the participants (n = 17) were recruited from government hospitals in Jeddah, Saudi Arabia. The participants recruited from the government hospitals discussed at great care their child received. Not only did the participants appreciate receiving the best care, but the financial support they were receiving from the Saudi Arabian government. A respondent shared:

> *It is a government hospital… but in general there are no expenses, because it is a government hospital they don't ask you for anything… the government is paying all the hospital expenses… the government is providing the best care in the hospital (001)*

Some children were receiving EOLC at nongovernmental hospitals. However, even outside the governmental hospitals the caregivers shared that the Saudi Arabian government provided financial support through other resources. Multiple governmental resources were shared by the respondents, whose statements were reflected by the following:

A mother stated that both her children, who are receiving EOLC, were admitted into the hospital by a decree:

> *No, health insurance. But they [two children at EOL] were admitted by a decree (004)*

Other participants shared that they received financial support monthly from the *Rehabilitation Initiative of Saudi Arabia. A*s one respondent shared:

> *She is an individual with disability… she gets paid from the Ta'aheel Initiative [Rehabilitation Initiative of Saudi Arabia] (005)*

Another source of support that was discussed was the *Ministry of Labor & Social Development Support.* Participants discussed the financial benefits from the government, including ongoing support:

> *There is a monthly salary from the Ministry of Labor and Social Development [for disabled individuals in Saudi Arabia] (016)*

The remaining participants (n = 7) were recruited from the community. The respondents shared that they were receiving financial support from a nonprofit organization. The nonprofit organization provided financial support for the child and the family. Not only were the healthcare expenses covered, but housing, transportation, and daily expenses for individuals living in towns or cities other than Jeddah, Saudi Arabia. The caregivers highly appreciated the support they received from the nonprofit organization, as evidenced by the following: *"also the [nonprofit organization] are very supportive. Without them we could not be able to care for our daughter" (018).*

We Were Struggling Financially

Participants shared about their financial struggles while caring for their child at EOL. Families were receiving financial support from the government or nonprofit organization for the child's healthcare. However, the ongoing nature of the child's health needs led to inevitable financial challenges. Some respondents shared that their child was admitted to a private hospital before the cost or care required them to be transferred to a government hospital. Unfortunately, there were participants who did not realize that there were resources available to them via the nonprofit organization. Hence, the families were struggling paying for their child's healthcare. A caregiver stated:

> *I mean we spent over 70 thousand [Saudi Riyals = 18,666 Dollars] paying hospitals for appointments and MRIs I mean a loooot… EEG, follow up appointments and other things… can you believe this! We spent one night at [private hospital] we had to pay around 15 thousand [Saudi Arabia = 4,000 Dollars]! (007)*

Other respondents expressed their overwhelming financial challenges paying for transportation, rent, and daily expenses. A variety of financial issues were shared, and even transportation to and from the hospital was a struggle:

> *I was struggling.. sometimes my son would drive us around and sometimes we would take an "Uber"… then we had to bring him [son] a car, I called one of his father's relatives to bring him a car, you know "Uber" is very costly!" (005)*

Renting a place to live while their child was hospitalized was a challenge some of the participants experienced, best described as:

> *She was in the hospital for a month. We had to rent an apartment. The hospital is half an hour away, and we pay for gas! (019)*

Daily expenses at home needed to be maintained, even though the child was sick in the hospital, as a mother stated:

> *His father's salary is not much, we can barely afford transportation, school necessities and the kitchen, you know we have to buy food every other day, my son gets hungry (012)*

Question 2 Findings

The second research question highlighted the factors that affected the experiences of the primary caregivers. Religion/ Islam, support system, and culture were the factors identified through the thematic analysis.

Religion

Thanks to Allah

All the participants included in this study were Muslims. The Islamic beliefs of the caregivers emerged from the data as they shared their experiences with the dying child. It was clear that the respondents had strong religious beliefs when it came to their child's illness and prognosis. All participants were *thankful to Allah* at some point in their interview, regardless of how their child’s condition was progressing. Respondents expressed thanks to *Allah* by stating: *“thanks to Allah now.. she was on a ventilator and the doctors removed it today, I hope she doesn’t need it anymore… thanks to Allah” (009).* Another participant noticed the improvement of her child’s health over time and was thankful to *Allah*, sharing: “*she was on oxygen for a month… I started decreasing the amount [oxygen liters] until she didn’t need it at all, never thanks to Allah” (005).*

Participants got emotional while expressing their *thanks to Allah*, especially when the child overcame a dangerous phase during their treatment. The tears of gratitude the caregivers conveyed during the interview showed how thankful they are to *Allah*. While crying, a responded shared:

> *Thanks to Allah we were very happy after the surgery… we were relieved that the tumor was removed, and the doctors said we passed the dangerous phase thanks to Allah… I will never forget what the doctor said to my mom, your daughter is a miracle. Thanks to Allah (019)*

Pray to Allah

The majority of the respondents expressed that *praying to Allah* was a source of patience and strength. The caregivers shared that praying gave them the patience and strength they needed to care for their child at EOL, stating: *“I prayed to Allah to give me strength and patience” (024).* A caregiver expressed that being strong and patient the entire time depended on her prayers to *Allah*, she said: *“praying to Allah is what makes me patient and strong in the first place” (001).* Another mother stated that she, also, prayed to seek help from *Allah* to accept her child’s health condition: *“I pray to Allah to give me strength and help me accept this situation I am in now” (023).*

Everything is from Allah's

The Majority of the participants expressed their *acceptance* of the child's terminal condition. Acceptance was derived from different religious perspectives. Some respondents accepted their child's illness because they *believed in fate*, and fate is set by *Allah.* A mother shared that it is not possible to escape her fate or her child's, stating *"this is my daughter, this is my future, and this is my fate, that's it. There is no runaway, and I have to accept her and love her" (003).*

A caregiver strongly believed in fate, and *Allah* is the one who writes fate. The participant expressed that the fate of her child could not be changed, even with the best healthcare. However, *Allah* is the one that has the power to heal her child, as evidenced by the following:

> *You know I have strong faith and believe in fate, and I know everything is from Allah, and it is written for him to become like this… and if death is what Allah wants, it will happen even if 1000 machines were connected… I have hope and believe that Allah brings back life to the bones. If Allah wrote healing to him, he would heal him" (002)*

Respondents did not give up on finding a cure for the child's illness. Unfortunately, all the children were diagnosed with a terminal illness that they could not recover from. As a result, some participants expressed that they had to accept the fate of the child's prognosis. A caregiver shared: *"I told the doctors do whatever you have to do to help him… but there were no donors! So we said thanks to Allah and we accepted the fate of our son" (016).*

Other participants accepted the child's illness and believed that it is *Allah's will*. Caregivers shared that caring for their child at EOL is a way of accepting *Allah's will*. However, it is hard to accept the fact the child is dying. A participant stated:

> *I mean it was really hard but I accept that it is Allah's will… after a while you accept the fact and you feel like.. its Allah's will… Eventually people adjust to the situation and learn what to do. Because we are all Muslims we believe that it is Allah's will [kada'a Allah wa kadaroh] and we have to accept it (005)*

A couple of respondents shared that they accepted the child's prognosis, because all *lives come to an end*. The caregivers believed that the journey of life includes good and bad, sickness and health. Nevertheless, death is inevitable, as a caregiver shared:

> *This is life! We're going to live life during the good and bad, sickness and health.. in the end you will loose your life in a second.. we are not immortal! Prophet Mohammed peace be upon him said.. the ages of my people is between 60s and 70s, isn't that right?... you see? How long we'll live? Over 70? I'm 33 years old, how many more years will I live? How much more do I have left? (001)*

Entrust in Allah

Few caregivers expressed how they *trusted and entrusted in Allah* to protect the child. The respondents believed that if they were not with the child, *Allah* will be caring for the child until they reunite. A mother shared her entrust in *Allah* when she left her sick twins in the intensive care unit:

> *I am leaving them [children] with the nurses… I entrust that they are in the care of Allah… when I see a lot of patients I think to myself how can I leave my children here? But then I just pray to Allah and entrust they are with him (004)*

A couple of participants believed that the child survived because they trusted *Allah* to do the best for the child. Caregivers trusted that not objecting to *Allah's* will, will keep the child alive, as evidenced by the following: *"we trusted Allah and he did what is best for her [child]… we never objected… that is why everything worked out [successful surgery]" (019).*

A few caregivers shared that they trusted that *Allah does what is best* for themselves and the child. The participants truly believed that the child's illness is what is best, even if the child's condition appeared bad, as was shared by a respondent: *"I truly believe whatever Allah gives me it is for the best, regardless if it seems good or bad" (024).*

Test from Allah

A majority of the participants described their belief that the child's illness is a *test from Allah*. Being patient while caring for the dying child was the respondents' way of coping with *Allah's* test, as a respondent expressed: *"they [mothers] have to be patient because this is a test from Allah the most merciful, and in sha'a Allah [Allah willing] they will go to heaven… and this is life!" (014).* Other participants mused that they hoped to be able to handle *Allah's* test: *"we thank Allah for what he gave us [child], I hope we can handle the test Allah gave us [sick child]" (007).*

Other caregivers expressed that staying strong while caring for the dying child was the way to handle *Allah's test*. Also, the participants believed that accepting the child's illness could be rewarded with the child's survival, as shared by a caregiver:

> *There are a lot of mothers that I talk to here, I tell them to stay strong, accept what has happened… maybe it is a test from Allah… you could stay with your child and they wake up in 18 or 8 years healthy! you don't know! (013)*

Rewarded from Allah

Some caregivers mentioned they believed that they will be *rewarded from Allah* for caring for the child during the illness journey. The participants stated that the reward will be going to heaven in the afterlife. A mother said: *"I mean when I get bored my husband tells me its ok you are rewarded from Allah and you will get a house in heaven… he makes me feel better" (014).*

Other participants expressed that having a terminally ill child was a blessing, and not bad. Because, mothers believed that they will join their children in the afterlife. With *Allah's* permission, the child would lead the mother into heaven, as evidenced by the following:

> *It is like she is something bad!? She is not something bad.. she could get me into heaven, she could hold my hand and take me to heaven.. she would go in through any door, with Allah's permission, she would take me with her… She could take me to heaven (001)*

Support System

Husband

Their Source of Support

Mothers expressed how grateful they were for their husbands *supporting* them during the journey of their child's terminal illness. The participants esteem for their husbands was described in multiple ways, such as: *"her [child's] father is always with me and ma sha'a Allah*

[Allah bless] he is the best, may Allah give him joy" (006). Other husbands were a source of strength and positivity to their wives, a participant shared:

> *Her [child] father [husband] is the first source of support for me honestly. I mean if it wasn't for Allah then him, I would not be with this strength… the most person who encourages me to be positive is her father (003)*

Few respondents shared how *compassionate* their husbands were, and considerate to their feelings about their child's health condition. Mothers talked about their husbands calming them down when they learned about their child's diagnosis and prognosis, as evidenced by the following:

> *My husband, he didn't tell me [the child has cancer] because he didn't want me to be scared… but I hugged my husband and cried and cried, and I kept hugging him and he said we will take him to [government hospital] to get treatment… my husband used to tell me that everything is fine with our son and it is just a small thing no need to worry (024)*

He Does Not Want to be Responsible

Some participants mentioned that their husbands were *not supportive* while the child was receiving EOLC. There were husbands/ fathers who did not want to be responsible for their sick child regarding their treatment plan. One mother said: *"her [child] father does not want to be responsible for her. He says you are responsible for her, you take her everywhere, you make all the decisions at the hospital, you take her" (005).*

A few mothers were in *disbelief* over their husband's behavior toward their child's illness. Husbands who did not spend time visiting their dying children, though the mothers were consistently with the child. A participant expressed her view of the fathers absence by saying:

> *Oh, her father told me he wants to travel! I only have a short period of time until I go back to work, so I want to travel, I want to enjoy myself! Your daughter's illness is taking too long! What can I say about a man like him?! (001)*

Respondents shared their *hurt and disappointment* when their child's father opted not to be there for the child. Some fathers were not present while their child was in a critical condition and needed their support, as stated by a participant:

> *What hurt me the most was that his father was not there for the transplant! He stopped responding to our calls! After he [child] was out of the intensive care and was feeling better, his father showed up! He was supposed to be there for him! (023)*

Changes in their Relationship

Participants noticed the *change in their relationship* with their spouses after the child was diagnosed with a terminal illness. Changes were positive for some mothers, who shared that their relationships with their husbands improved when their child was diagnosed. The parents became "stronger together", as evidenced by the following: *"my husband and I are always together so we can make each other stronger" (018).* Another respondent described the closeness that emerged in her relationship:

> *I mean my relationship with my husband today is much, much, better than before I delivered my daughters. Praise Allah they brought us closer to each other. I don't know if all the people are like this, or me and my husband are a different case. I mean our daughters made us close in an impossible way, thanks to Allah (003)*

On the other hand, there were *relationships that deteriorated* between the respondents and their husbands after the child's illness. Mothers disclosed that they stopped spoiling and began to ignore their husbands to focus on caring for their dying child, as evidenced by this statement:

> *I don't see him anymore! He keeps telling me this is not a life… So I ignored him! I didn't check on him, didn't check on his clothes… I used to spoil him and sit with him… honestly, now I don't (007)*

Mothers divulged that they had a *tense relationship* with husbands during their pregnancy, after the child was diagnosed. Relationships between spouses became more strained after the child was born with congenital defects which were terminal. A respondent expressed her misery by saying:

> *At first it was exhausting for me and my husband. he didn't accept the fact our daughter is sick and neither did I, he blamed me, and I blamed him! Because he is struggling financially, and he blamed me for everything… I told him you are the one who is making me miserable! When I was pregnant with [child], I told him if she was born with defects it is your fault! And of course, what I expected happened (008)*

Family

Familial Encouragement

A majority of the participants recounted how *supportive* families were of them while they were caring for their dying children. Different family members demonstrated their support *emotionally* to help the caregivers cope with the child's condition. A participant was thanking *Allah* for having her mother at her side: *"when my mom calls me she says calm down* *[participant name] that is not right, you need to take care of yourself, so she talks to me… thanks to Allah" (013).*

Few families provided *financial support* to the caregivers for the child's healthcare. In addition, the family members encouraged the participants to seek the best healthcare for the terminally ill child. A respondent expressed her gratitude for the familial support:

> *Our families said they will support our decision no matter what we chose to do.. they will help us if we decide to travel. My brother was the best support for us, he encouraged us to come here [Jeddah] and helped us a lot! May Allah give him happiness (018)*

Don't take care of that child

A couple of family members were *not supportive* of the caregiver nor the child who was at EOL. Some respondents expressed how their families were against their belief that the child will overcome the life-threatening condition. A respondent said:

> *I feel bad because I am one person against… an army! Her father's family say let her die… You know when our relatives call him and his cellphone is loud enough for me to hear what they are saying? She [child] is better off dead than alive and disabled (001)*

Respondents were emotionally hurt when family members talked in unpleasant ways about their terminally ill child. There were family members who tried to convince the participants to care for their healthy children instead of the sick child, as evidenced by the following:

> *When I leave the room, they [husband's family] say what is this child? This child is paralyzed?! You know? So, I was acting like I didn't hear*

> *them say that, I mean aaah… I have an older son, and I had this one 10 years later. So, my older son goes to school, so they [husband's family] say don't take care for that [child] take care of the one that goes to school! This one is paralyzed and just in bed at home! Take care of the healthy child! (014)*

My Children Feel Like They are Orphans

A couple of participants realized that they *neglected their healthy children* at home. Because the mothers' attention was towards caring for the child receiving EOLC. A caregiver admitted her neglect to her other children, stating: *"my children were like aaaah… its like they didn't have a mother, they were like orphans… I didn't cook good food or anything else, I could barely just wash clothes, pray and leave to the hospital" (007).*

Mothers rarely mentioned that their children were *accepting*. However, the healthy children helped the respondents physically and psychologically to provide care for their dying sibling. The healthy children were accepting of the fact that the child's illness is from *Allah.* A participant shared how her children supported them at home:

> *Her [child] siblings accept her, I mean they help carry her around thanks to Allah since they were young they learned that this is their sister from Allah… I mean psychologically they are always there [mother started to cry] I feel they are always with me… I mean they are the ones who feel what you are going through the most because they are at home with me (005)*

Some caregivers mentioned the *attachment* the siblings had for their terminally ill sister/brother. The mothers shared that many of their children were young and not aware of the seriousness of their sibling's health condition. Therefore, the children were excited to be with their sick sibling. A mother expressed her feelings when she realized during her pregnancy, that her baby had a terminal congenital defect. The younger daughter was unable to comprehend that her baby sister was dying, and was so excited to have a new sibling:

> *My daughter was very happy and attached [to the baby], even the clothes she outgrew she saved them for the baby… My heart broke every time I saw her happy and excited, she is a child, she doesn't understand… One time I told her that what is inside me is not a "baby", it's a pouch full of water, she said no! I saw the baby on the screen! I took her once with me when I went to get an ultrasound, so she heard the doctor saying look this is the head, this is a leg… she was soooo happy, when is the baby girl coming? How many days left? (009)*

Neighbors

All respondents were asked about friends' support. Most participants considered mothers in the same pediatric unit as their *supportive friends*. The caregivers appreciated other mothers because they were going through similar experiences with their children. However, some children were terminally ill, and others were in a critical condition. A couple of participants named other mothers as "neighbors" since their children's rooms were next to each other. A participant appreciated the relationships with her neighbors by stating:

> *The neighbors, the ones who are staying here for a long time like me… for example [pediatric patient next door] he has the same problem like [child]. They [neighbors] come over and ask what is wrong with her? What happened? So they sit with me and calm me down (013)*

A few caregivers thanked *Allah* for having other mothers supporting them at the hospital. The participants shared how the mothers sustained them at their time of need while caring for the dying child. A mother expressed her gratitude to other mothers, saying:

> *When my son was first admitted we were in a shared room with 4 other children and their mothers. I used to close the curtain and just cry… so the mothers came to me and talked to me and said that we are all in the same boat and we need to support each other. We would sit together and talk and drink coffee! If I needed a break to go out to the hospital garden, they would take care of my son until I got back… I really needed that kind of support at that time. Thanks to Allah they were there for me (024)*

A couple of participants shared that their relationships with other mothers, at the hospital, remained after the child's discharge or loss. The mothers stayed in touch through social media, as evidenced by the following:

> *I swear to Allah that period of 9 months passed by so fast.. and mothers started saying our children got better and they were discharged. We are still in touch. We have this group on What's app so we can check on each other every once in a while.. ma sha'a Allah we became like sisters (012)*

Healthcare Providers (HCPs)

Healthcare Providers Work from their Heart

The respondents mentioned the support they received from HCPs. The participants shared how the HCPs were *kind* to them and their children while providing EOLC, as stated: *"ma sha'a Allah [Allah bless] the doctors and nurses are very kind… the nurses work from their heart when caring for my son. They are very kind ma sha'a Allah" (015).* Some participants talked about HCPs supporting them emotionally during intense times they had to go through with their dying child. A child was coded at the hospital, and the mother talked about social workers supporting her during the code:

> *At that time [child was coded] I broke down and all the sisters here from social services came and spend time with me to calm me down, and I think they brought me here [waiting area], they were calming me down and telling me she will be fine inshallah [Allah willing] (003)*

Some respondents talked about HCPs helping them to the best of their ability. The HCPs were kind to the participants and understood the difficulty of learning that their child is dying. As shared by one of the caregivers:

> *They [HCPs] were treating us very well. Especially at first, because of our daughter's condition we didn't have much time to waste. They helped us with scheduling appointments and tests in a short period of time. They were very kind and tried to help us as much as they can even though there were a lot of things that were out of their control! For example, sending her [child] reports to hospitals out of the country (018)*

Healthcare Providers Can be Harsh

Few participants expressed that HCPs did their job providing EOLC to the child. However, some HCPs were insensitive when informing the mothers about their child's terminal condition. One of the mothers stated: *"when the doctor came to me, he told me may Allah compensate you. [Child] is dead" (002).* Another respondent shared her experience saying: *"I met the doctor who delivered her [child] and he said when we opened your belly, she looked so ugly! She looked so ugly in your belly! he said the girl looked ugly in your belly!" (001).*

A couple of mothers were dissatisfied with the care their children were receiving at the hospital. However, the participants were hesitant to complain, because the parents worried the HCPs would hold a grudge towards the child. A respondent stated:

> *The nurses are doing their jobs, changing diapers and stuff, but they [nurses] don't play with the children… I swear to Allah, every time we complain I feel the nurses hold a grudge towards us… for example I told the nurses don't feed the boys like this, they don't bottle feed, they hang the bag of milk at the edge of the crib and drips on the bed sheets and they don't clean up! Sometimes I find milk on the pillow, clothes, the bed, more than once! My husband talked to them [nurses] here… aaah he talked to the head nurse and the nurses treated the boys well, just for a while, and then they went back (004)*

Culture

Father's Role

Elements of the Saudi Arabian culture emerged from the data. The cultural perspectives did not, necessarily, affect the experiences of the participants. However, the culture has an influence on the way individuals reported sharing parental responsibilities. A participant discussed their Saudi Arabian cultural views on the responsibilities of the "father role" on caring for the child at EOL, stating: *"he is the father, he believes that he should only pay for everything. He just pays for the house expenses" (001).* Conversely, another participant expressed a unique view within the Saudi Arabian culture of her husband's *father role*, as evidenced by the following:

> *My other daughter is with him [husband] now at home, everyone is surprised how he cares for a disabled child, she doesn't move, she doesn't talk, and he is a man! It is known here that men generally do not look after or care for the children. The normal is that they do not tolerate children, but it is not a rule, even the hospital here knows that (husband) no, the other girl, where is she? With her father at home (003)*

Don't Like to Tell my Friends about my Child

Anecdotally, it is common knowledge in Saudi Arabia that individuals do not share personal information with people. Participants expressed their dislike of sharing information about their child's condition with friends or family members. A care giver reported discomfort with disclosing information to her friends: *"I don't like to tell my friends about everything that is happening to my son" (015).* Another respondent shared her dislike of sharing information about her child to family and friends, as evidenced by: *"I do have friends, but I don't like to talk to people about my personal life, I don't even like to give too much details about my daughter's illness to my family" (018).*

Quranic Recitation and Evil Eye

A couple of participants revealed their views on the *evil eye* curse, and that it could be the cause of the child's illness. Muslims believe that a person will be protected from an *evil eye* by reciting the Quran on the person. A participant mimicked this view, when she talked about her belief in the Quranic recitation, saying: *"I will recite Quran on my son and I truly believe that Allah will protect him from everything" (012).*

The mother further shared the story of a woman who gave her son the *evil eye* that caused his illness, stating:

> *A Sheikh came to see my son in the hospital, and he said that it is an evil eye! I felt that it was an evil eye from the beginning! There was this lady who talked about my son, and soon as she was done my son's nose started to bleed! I swear to Allah she is a kind woman, maybe she didn't mean to, but she did not say ma sha'a Allah [Allah bless]… hasbi Allah w nima alwakeel [Allah suffices me, for he is the best disposer of affairs] (012)*

Conclusion

The data in this study was analyzed using thematic analysis. The themes identified, revealed how the primary caregivers were affected psychologically, physically, socially, and financially. Psychologically, participants felt their lives flipped upside down, they were shattered from the inside, and could not imagine leaving a piece of their heart behind. Physically, the respondents shared that providing EOLC to the child affected their eating habits and sleeping patterns. Socially, the caregivers isolated themselves, and could not bring themselves to go out and leave the child alone. Financially, the participants shared that they struggled financially, from different aspects, and needed financial support to care for the child.

Three main factors that had in impact on the caregivers emerged from the data. The factors included religion/ Islam, support system, and culture. The respondents believed that everything happening to their child is from *Allah* as a test, and they will be rewarded from *Allah.* The caregivers entrusted in *Allah*, prayed to *Allah,* and were thankful to *Allah* as the child's condition progressed. Moreover, some participants appreciated the support they received from their husband, family, neighbors/ friends, children, and HCPs. Where other caregivers shared the lack of support from the people surrounding them while providing EOLC to the child. Lastly, the participants shared how the Saudi Arabian cultural norms affected their experience caring for the child at EOL.

Chapter 7

Discussion

Primary Caregivers Caring for a Child at End of Life

The purpose of this study was to explore the experiences of primary caregivers caring for a child at EOL in Saudi Arabia. The findings of the study were organized separately based on the research objectives. The first objective for this investigation was to understand the impact of caring for a child at EOL on primary caregivers. Similar to research reported in the literature, caring for a child at EOL impacted the primary care givers psychologically, physically, socially, and financially (Arruda-Colli et al., 2016; Atout et al., 2017; Haley & Walker, 2016; Lou et al., 2015).

The second objective was to identify factors that influenced the primary caregivers' experiences of caring for the child at EOL. Multiple factors were reported in the literature as influencing the primary caregivers' experiences including finance, spirituality, communication, etc. (Hageman et al., 2018; Hammami et al., 2015; Saeed et al., 2015). Three domains emerged during this study that influenced the primary caregivers' experiences: Religion/Islam, support system, and culture. Though conducted with different populations than the current study, investigators in Saudi Arabia have found similar domains of religion and culture reported regarding EOLC (Al Mutair et al., 2019; Al Mutair et al., 2018; Katooa et al., 2015).

Conceptual Model

After conducting the research study, the conceptual model had to be modified. Some of main concepts in the conceptual model emerged fom the data, while other concepts did not. The intitial conceptual model included: decission making, communication, grief, and support system at EOL. The modified conceptual model includes the following: holestic health, support system, and religion (see <u>Figure 5.8</u>). The holistic health includes the primary caregivers' psychological, physical, social, and financial status. Primary caregivers appreciated the support they received from their husband/ child's father, family members, neighbors/ friends, and HCPs. Religiosly, primary caregivers indicated the impact of religion/ Islamic beliefs and practices on their experience caring for a child at EOL.

Question 1 Discussion

Psychological

Life Flipped Upside Down

Mothers in Saudi Arabia are the primary caregivers for their children during illness (Saad, 2016). In this study, the primary caregivers were overwhelmingly mothers, who reported being in *shock* and *disbelief* as their *life flipped upside down* when told about the child diagnosis and prognosis. The *shock and disbelief* were obvious in the respondents' tone and facial expressions while sharing their experience in the interviews. Similarly, Young (2018) reported that in the U.S. therapeutic strategies need to be addressed when providing counseling for parents of children with cancer. Common stressors reportedly affected parents of children diagnosed with cancer, including being in shock upon diagnosis. Counselors who were provided with information on parents' feelings while caring for a child with cancer, ensured the parents received the counseling care they needed.

Primary caregivers in this investigation shared that they became so *distracted* by the needs of their child who was ill, that they failed to care for their own needs. Kourkoutas et al. (2015) reported similar findings when exploring a long-lasting counseling of a parent dyad with a child at risk for dying. Participants' feelings and their dynamics changed after the child's diagnosis of a potentially life limiting health condition. The parents became focused on caring for the child instead of pursuing their own needs or resuming their normal routine.

Arruda-Colli et al. (2016) conducted a case study to explore the in-depth experiences of a mother caring for their child with recurrent cancer. During the qualitative interviews, the mother shared her weakness and sadness for the child when HCPs discovered her child’s cancer recurring. Participants in the current study expressed feeling weak and *broke down* at the news of their child’s diagnosis. Not only were the mothers sad and *empathetic* regarding their child’s terminal condition, but the mothers understood that with the illness, their child’s and their *lives had flipped upside down*. The primary caregivers expressed their understanding that they were starting an EOL journey with the child.

Shattered from the Inside

Arabiat et al. (2013) explored the beliefs of Jordanian mothers (N = 51) regarding the cause of their children’s cancer. During the interviews, the mothers shared the guilt they felt about their child getting cancer. It was painful for the participants to see their child physically suffering. Mothers described their guilt and negligence in not providing their child with healthy food, which caused the cancer. Primary caregivers in this study shared similar feelings of being *shattered from the inside*, as they lived with the guilt that *it was my fault*. Participants believed that their actions or lack of actions contributed to the child being diagnosed with a terminal illness. One mother believed her child was born with a congenital anomaly because she did not take folic acid during her pregnancy. Mothers shared their pain at seeing their child suffering. Respondents felt *shattered from the inside,* as they were not being able to relieve their child’s suffering. The mothers’ hearts broke as they observed the child’s health deteriorate. The primary caregivers were *heartbroken* as they realized that the child was slipping away sooner than expected.

Zetumer et al. (2015) conducted a study on the behaviors and thoughts of parents (mothers = 273, fathers = 72) grieving their children who died. Parents reported that as they grieved: 36 percent frequently thought about suicide; 13 percent considered engaging in suicidal behaviors; three percent contemplated attempting suicide. *Suicide ideation* was brought up by a few mothers in this study who expressed a desire to end their life. However, the mothers shared their *worry* about their child being left alone, therefore they could not act on their suicidal ideation. All of the mothers in the study were Muslim, and in Islam suicide is forbidden. Though not mentioned by the mothers, their religion could have been an influence on any decisions that were made.

Leaving the child to suicide was not the only *worry* expressed by mothers, they also *worried* about their own lives after losing the child. *Worry* consumed the respondents' thoughts as they constantly thought about their child's death, which was the worst-case scenario. The primary caregivers of this study felt *shattered from the inside* yet continued to hide their guilt, pain, heartbreak, worry, and suicidal ideations. The participants shared the desire to remain strong enough to accompany the child at the hospital. The respondents must be strong for their child since they were their primary caregivers.

How Could I Let Go of a Piece of My Heart?

Previous studies focused on the negative psychological impact on mothers of caring for a terminally ill child (Arruda-Colli et al., 2016; Hemingway & Seymour, 2017). However, limited studies discussed the positive feelings that mothers acquired during their devastating EOL experience with their child. A descriptive study conducted by Haley and Walker (2016) studied caregivers' strength while caring for their child at EOL. The participants [mothers (n =7), grandmother (n = 1)] were interviewed to explore their experience with the child's EOLC. The investigators found that the caregivers expressed deeper and stronger unconditional love for the child. Additionally, mothers/grandmother reported wanting to spend as much time as they could with the child who was dying. Participants in this study, whether mothers or caregivers, also expressed their great *love* for the child, especially as the child's health deteriorated. There were respondents that reported loving and favoring the child who was dying over their other children. Also, the mothers in the current study demonstrated their love to the child at EOL by being *strong*. Physical and psychological *strength* were perceived as needed by the primary caregivers, to nurture the child back to health.

Lou et al. (2015) conducted a qualitative retrospective study of mothers' experiences of anticipatory loss of a child from cancer. The investigators interviewed mothers (N = 10) who lost a child within the past three years. Mothers expressed their desperation and fear of the cancer recurrence. Also, the mothers felt desperate because of the anticipated child's loss. However, in this study the respondents' *desperation* was related to being with the child, to provide the care required. Mothers were so *desperate* to be with the child at the hospital. The participants begged HCPs to let them help the nurses provide the child's EOLC. Participants wanted to be with them all the time, with mothers sharing that their day was not complete until they visited the child at the hospital. As the respondents shared, the attachment to the child was mutual. Because, even though the child was not speaking, the child's vital signs improved when the primary caregivers were present. Therefore, the mothers expressed that leaving the child at the hospital, felt like letting go a piece of their hearts.

Physical

Participants in this study did not have time to care for themselves physically; as their child needed the physical care more than the caregiver at EOL. Mothers in this study shared that they were physically affected when caring for their child at EOL. Consistent with this study, Baughcum et al. (2017) explored parents' perspectives on their infants' EOLC experience in the NICU. The participants in the study (mothers = 29, fathers = 16) were interviewed three months to five years after their infant's death. The parents reflected on how tired they were from watching their infant suffering and spending such long hours at the hospital. The physical fatigue of parents whose children were seriously ill was also found in the study by Tutelman et al. (2020). Tutelman et al. conducted an investigation to identify the concerns of parents of a child receiving Pediatric Palliative Care (PPC) at home. The parents (mothers = 25, fathers = 10) were interviewed soon after the child was settled at home for PPC. One of the concerns shared by the parents was their overwhelming tiredness. Their child's PPC at home was just initiated, yet parents already feeling tired, and worried would impact their child's care.

De Andrade et al. (2017) studied the experiences of a small group of grieving mothers when they cared for their children at EOL. Mothers (N = 3) were interviewed after the child's loss to a chronic illness. The participants shared that they had a feeling of being fatigued throughout their caregiving experience. In another study, Leske et al. (2012) studied the effects on a small group of family members being present while a loved one was being resuscitated. Participants (N =3) shared they also experienced exhaustion when caring for their loved one at EOL. The researchers in both studies identified exhaustion as one of the experiences of family members caring for a loved one. However, studies did not provide details on how primary caregivers were impacted physically beyond being fatigued and exhausted. In the current study, the participants shared details about their fatigue and exhaustion.

When You are Sad You Don't Eat Well

Eating was not a priority for the participants in the current study, since they were the primary caregivers. The participants in this study discussed how caring for the child at EOL took a toll on them physically; they were tired and exhausted. One of the factors, that primary caregivers believed contributed to their physical exhaustion, was their *lack of appetite*. The sadness and devastation at the realization that the child who was dying, made eating less of a priority for the respondents. While the importance of eating decreased, the primary caregivers experienced a significant amount of *weight loss* over time. As eating less was not intentional, participants were surprised when they became aware of their *weight loss*. The primary caregivers appeared to focus on maintaining the child's appetite and weight, but not their own. The impact of their child's health status on a parent's appetite was also discussed in a study by Church et al. (2019). In the study, investigators explored the impact of prolonged hospitalization of a child on the parents' dietary habits. Mothers (n = 13) and fathers (n = 2) reported that the stress and worry about their child's neurological condition impacted their appetite. Parents shared that irregular eating patterns and snacking affected their dietary habits. Some parents lost their appetite and subsequently lost weight, while other parents overate and felt frustrated for their weight gain.

I Sleep, but not Sleep

Sleep disturbance was another issue that contributed to the primary caregiver's physical fatigue and exhaustion. There were two main causes for *lack of sleep* that the respondents identified: Care for the child; Thinking about the child; Monitors. Frequently, primary caregivers stayed awake for two or three nights to provide care for the child. When not caring for the child, participants found that they were constantly thinking about the child's condition. Therefore, it was difficult for the participants to get into deep sleep, which left them feeling tired. The multiple monitors the child was attached to had alarms that went off periodically, making it difficult to sleep soundly at night. Sleep deficits due to have an child chronically ill was shared in a study by Kish et al. (2020). The investigators conducted a qualitative study to explore the experiences of working mothers (N = 15) whose child lived with a chronic illness. According to Kish et al. mothers found taking care of their child led to constant exhaustion. After experiencing an incident with their child, such as an asthma attack, the mothers had little time to sleep.

Social

Isolated Themselves from the Entire World

Previous studies have shown that mothers isolated themselves to provide child with EOLC (Arruda-Colli et al., 2016; Atout, Hemingway & Seymour, 2017). Broady (2017) conducted a literature review on the experiences of carers providing EOLC. Twenty-three studies between 2005 and 2016 were included in the review. The researcher identified that the carers isolated themselves to care for the dying patient (Broady, 2017). The caregivers dedicated their time to the patient and neglected themselves. Like the current study, the respondents spent all their time with the child, whether at home or the hospital. Therefore, the participants became *isolated from the entire world*, including families and friends. Even when family members offered to help, the primary caregivers could not bring themselves to go out and leave the child at the hospital. The participants felt that being *isolated from the entire world* with the child made them comfortable during this devastating time.

Can't Go Out and Leave the Child Alone

Collins et al. (2016) explored parents' experiences when caring for a child with a life-limiting illness. The researchers discovered that the parents (mothers = 12, fathers = 2) and children were inseparable. The parents were committed to be the primary caregivers for their child and could not leave the child alone (Collins et al., 2016). In this study, the respondents had the same feeling that *leaving the child alone*, at home or hospital, was concerning. The participants were concerned that the child's condition might deteriorate while they were not around. It seemed that the primary caregivers would not forgive themselves if the child died while they were away.

Selman et al. (2018) investigated the impact of stigma on parents of children with autism. Some participants (mothers = 12, fathers = 3) shared that despite the negativity and rejection from the community; the child accompanied the parents in public. However, the parents took their child to places where there is a low chance for an autistic meltdown. C*hildren accompanied the primary caregivers* while socializing with family and friends, according to the participants in the current study. The respondents were not comfortable socializing unless their child was with them; as they were stable enough to leave home or the hospital for short periods of time. The primary caregivers made sure that it was safe for the child to meet other people. Socializing was not as important to the respondents, as staying with the child. The primary caregivers did not mind feeling lonely as long as the child was not left alone.

Financial

Without Financial Support We Could Not Care for Our Child

Saudi Arabian Government

In Saudi Arabia, the public healthcare service includes primary, secondary, and tertiary levels of care, and free provision to citizens (Al-Hanawi et al., 2018). Al-Hanawi aimed to explore the views of Saudi Arabians (males = 31, females = 5) on the public healthcare sector. It was reported that Saudi citizens appreciated the free public healthcare services provided to patients (Al-Hanawi et al., 2018). Participants consistently expressed their appreciation for the Saudi Arabian government. The primary caregivers personally would not have been able to pay for the child's EOLC. Also, the respondents shared that the *Saudi Arabian government provided several financial resources* to ensure health promotion and maintenance. The financial resources included the Rehabilitation Initiative of Saudi Arabia; the Ministry of Labor and Social Development Support; and decrees. Depending on the child's health condition, the resources were chosen by the government. For instance, if the child was disabled, they would receive financial support from the Ministry of Labor and Social Development Support (MLSD, 2020).

Nonprofit Organization

A group of participants in this study (n = 7) talked about the *financial support they received from a nonprofit organization*. The organization provides financial support to families who have a child diagnosed with cancer. The primary caregivers spoke highly of the services they received through the nonprofit organization. The organization fully paid for expensive private hospital care and medications for some children. Additionally, the *financial support they received from a nonprofit organization* included housing for families who were not local residents. Similarly, the HealthWell Foundation (2020) is a nonprofit that financially supports underinsured patients with prescription copays, out of pocket expenses, and pediatric treatment costs. Both the nonprofit organization in Saudi Arabia and the HealthWell Foundation aim to ensure that all patients can afford healthcare.

We Were Struggling Financially

Globally, it is known that EOLC cost is considered a burden to families and healthcare systems (Aldridge & Kelley, 2015; Gardiner et al., 2016; Hageman et al., 2018). Rowland et al. (2017) used a national census survey to explore the expenditure of families providing cancer EOLC at home. Participants (N = 1504) reported their most frequent expenditure were increased expenses on transportation, meals, medical care supplies, and household bills. In the current study, the primary caregivers also mentioned *struggling financially* due to increased expenditures since their child started receiving EOLC. The participants and their families were *struggling financially*. The financial struggles were not limited to the child's healthcare, but on daily expenses, transportation and rent. It appeared the participants were overwhelmed by struggling financially and appreciated receiving financial support.

Question 2 Discussion

Religion

Muslims pray in different ways, as recognized in the interviews of the current study. It was not a surprise to identify Religion/Islam as a factor that affects the primary caregivers' experiences with the dying child. The desire to be at peace with *Allah* was reported by Hammami et al. (2015). In the study by, the investigators explored the opinions of Saudi Arabian men (N = 120) on their EOL priorities. The researchers discovered that the participants' priorities were based on Islamic beliefs. Men in the study wanted to practice Islamic rituals to be at peace with *Allah* at EOL, for instance, praying.

Thanks to Allah

In this study, the participants repeatedly said "*Al Hamdu li Allah*" [Thanks to *Allah*] throughout their interviews. In Islam, being thankful to *Allah* is one of the essential prayers that Muslims are encouraged to say. Muslims need to be thankful to *Allah* regardless of the situation they are going through, pleasant or unpleasant. "*Al Hamdu li Allah*" is one of the favorite prayers to *Allah*, gets the individual closer to *Allah*, and increases livelihood of individuals (Abdul Salam, 2019). Therefore, Muslims feel a sense of comfort and strength when they thank *Allah*, especially during devastating experiences; such as, caring for a child at EOL (Ahmed, 2019).

Pray to Allah

Oakley et al. (2019) report that individuals nearing EOL or caring for someone at EOL seek strength and peace through spirituality. In this study, Islam was the source of spirituality for the primary caregivers. In the Holy Quran, *Allah* stated: "*When My worshipers ask you [prophet Mohammad] about Me, tell them that Allah says, "I am near; I answer the prayers of those who pray*" (Al Baqarah, verse 186, Chapter 1). Therefore, the participants prayed to *Allah* in different ways, until they found strength, patience, and comfort. Prophet Mohammad, peace be upon him (PBUH), encouraged individuals to pray to get closer to *Allah,* and seek support, help, and strength (Abu Ramees, 2020). It was clear in this study that the primary caregivers were praying constantly, hoping for the best for the child.

Everything is from Allah

In Islam, it is important to recognize that all that happens is from *Allah* and he knows best (Hawajri, 2017). The participants truly believed that the child's illness was "*Iradat Allah*" [*Allah's* will], and it the best for themselves and the child. As mentioned in the Holy Quran:

"*Surely his [Allah's] command, if he wills a thing, is only to say to it, "Be!" and it is"* (Ya Seen, verse 82, Chapter 23). Therefore, Muslims accept what *Allah* gave them knowing that it is out of their control. However, it does not mean that Muslims have to give up on finding treatment for their illnesses (Chamsi-Pasha & Albar, 2016). Accepting the situation, means that individuals should do whatever they can to seek treatment, and not rebel on *Allah's* will (Chamsi-Pasha & Albar, 2016). In this study, the primary caregivers were accepting and embracing the child's illness, as the participants believed in *Allah's* will. *Allah* said in the holy Quran: *"But it may be that you hate something while it is good for you"* (Al Baqarah, verse 216, Chapter 1).

Entrust in Allah

The participants "*Astawda'at Allah"* [entrusted in *Allah*] knowing that the child is in his protection. Prophet Mohammad, PBUH, said: "*If you entrust something to Allah, he will protect it*" (Ibn Omar, Sahih Ibn Habban). Additionally, in the Holy Quran, *Allah* stated: "*Allah is the best protector and he is the most merciful of those who show mercy*" (Yusuf, verse 64, Chapter 13). Muslims trust others to protect their children; however, the ultimate protection is from *Allah*. The primary caregivers of this study highlighted that they entrust in *Allah* when they left the child at the hospital.

Test and Reward from Allah

Muslims understand that the illness is a test from *Allah,* and they will be rewarded for their acceptance, patience, and providing care (Abu Bakr, 2017). Terminal illnesses are considered as a test, and the individual will be rewarded in the afterlife. Prophet Mohammad, PBUH, said: "*A Muslim, male or female, continues to remain under trial in respect of his life, property and offspring until he faces Allah, the exalted, with no sin record*" (Abu Huraira, Al Tirmithi). However, parents who lose their child would be rewarded differently. Prophet

Mohammad, PBUH, said: *"If the worshiper's son died, Allah says to his angels: did you take my worshiper's son? Then they say yes: then he [Allah] says: did you take the apple of his eye? Then they would say: yes, so he [Allah] would say: what did my worshiper say? Then they [the angels] say: he praised you and said we belong to Allah and to him we shall return, then Allah says: build a house for my worshiper in paradise and call it the House of Praise*" (Abu Mousa, Al Tirmithi). There are many other versus in the Holly Quran and prophet Mohammad's sayings about the parents' rewards. In the current study, some mothers talked about other examples of *Allah's* rewards. For instance, the child would hold the mother's hand and lead her into heaven in the afterlife.

Support system

Husband

Their Source of Support

Mothers participating in the current study expressed how grateful they were for their husbands' *support* throughout their child's illness journey. Some husbands were the main source of strength and positivity to the mothers. Few participants shared stories about their husbands being *compassionate.* However, husbands were viewed as being considerate of the mothers' feelings, calming them down when informed about the child's terminal condition. Similarly, Wang et al. (2019) conducted a study on the experiences of parents caring for a child with cancer at EOL. The investigators discovered that parents (mothers = 6, fathers = 4) supported each other while the child received EOLC. According to Wang, parents reported making shared EOLC decisions on behalf of their child. Additionally, both parents stayed with their child at the hospital, and jointly provided care for the child at home.

He Does Not Want to be Responsible

Currie et al. (2016) qualitatively explored the experiences of parents with EOLC and palliative care in the NICU. The participants (mothers = 7, fathers = 3) discussed the support they needed from each other when their child was admitted to the NICU. The investigators found that mothers complained about the fathers not being supportive of them or their child. Mothers in the Currie study felt the fathers were available physically at the hospital, but not emotionally. The fathers were focused on going to work and maintaining financial support, with one father leaving the relationship due to an inability to handle the stress of the child's illness (Currie et al., 2016). Similarly, in this study, some mothers complained about their *unsupportive husband* who *does not want to be responsible* for the child. A couple of husbands made it official by signing a waiver that indicated the mother was the legal guardian responsible for the child. All husbands believed that the mother should be the primary caregiver, and most indicated they would only support the child financially. Therefore, the mothers in this study were in *disbelief* from their husbands' unsupportive demeanor of not wanting to be involved in their child's EOLC. In addition, mothers expressed their *hurt* and *disappointment* that the father was not there for the child. It seemed that the mothers knew the child would feel more loved if the father was present.

Changes in their Relationship

The mothers in this study shared how their relationship with their husbands changed since the child's EOL journey started. The relationship between some parents became *stronger.* The parents became *stronger* and committed to care for their child who is receiving EOLC as a team. Similar findings were reported in a study by Welch (2018). Welch conducted a grounded theory study on experiences of parents expecting the death of their infant from a life-limiting congenital anomaly. Some parents (mothers = 11, fathers = 1) discussed how the infant's condition impacted their relationship. The parents kept reminding themselves that they had to lean on each other to overcome this devastating experience. So, the parents became stronger together to care for their infant who was dying.

Silva-Rodrigues et al. (2016) explored the impact of having a child with cancer on parents' marital relationships. Interviews were conducted with nine married couples (N = 18) about the changes in their relationships, since their child's diagnosis. Some parents shared that during their child's illness, they became detached and their relationship deteriorated. The parents felt detached because they were only talking about the child's terminal condition. The couples focused on caring for the child and neglected their own relationship. In the current study, some mothers shared that their relationships with their husbands *deteriorated* over time. Because, the mothers focused on the child's EOLC and neglected their husbands. The mothers stopped spoiling their husbands and spent less time talking about their life together.

An investigation conducted by Pelentsov et al. (2016) aimed to understand the experiences of parents caring for a child living with a rare disease. Focus group interviews were conducted with mothers (n = 17) and fathers (n = 6) exploring a variety of events, including their marital relationship. Parents shared that their relationship became tense when the child became sick, with tension developing between parents over the daily caregiving demands. Also, some parents assumed the role of the expert on the child's disease which lead to tense conversations. In this study, a few mothers shared that their relationships with their husbands became so *tense* and unstable. A couple of mothers mentioned that the *tension* in their marital relationship became unbearable and might lead to a divorce. Furthermore, the separated/ divorced mothers, shared that the relationship with their ex-husbands became more distant when the child got ill.

Family

Familial Encouragement

Kelada et al. (2019) investigated the experiences of parents of cancer survivors and their familial support during the child's cancer treatment. Interviews were conducted with the parents (mothers = 32, fathers = 3) of cancer survivors discussing their families' support since the child's diagnosis. The parents considered their family as an important source of support during the child's treatment journey and appreciated their emotional support. The families were supportive by being available to listen to parents and being empathetic towards the child and parents experience. In this study, the primary caregivers received support from different family members, including their parents, siblings, children, and their in-laws. Similar to Kelada's study, the participants of the current study appreciated the *emotional* support from their families since the child's terminal diagnosis. In addition, the primary caregivers shared that their family members offered to support them *financially*. The families encouraged the respondents to seek the best healthcare for the child who was terminally ill.

Don't take care of that child

In the current study, some family members were discouraging and hurtful to the participants for caring for a child who was terminally ill. Consequently, the relationship between the primary caregivers and their families significantly changed for being *unsupportive*. Because, the participants expected more from their families, and unfortunately, they were not available for them or the child. Katooa et al. (2015) reported similar findings in their study on the coping patterns of Saudi Arabian mothers whose children were chronically ill. The mothers (N = 122) completed surveys, including the Social Support Questionnaire (SSQ). Eighteen percent of the mothers indicated that their families were not supportive. Some family members were supportive at the beginning of the child's journey; however, when the child's condition became terminal, families stopped supporting the mothers.

My Children Feel Like They are Orphans

In a study conducted by Stevenson et al. (2017) investigators explored how parents cope with their grief in the first year after the loss of their child. In the interviews, mothers (n = 15) and fathers (n = 6) discussed their relationships with their surviving children. Some children were a source of support to their parents and the family became closer after the child's death. Whereas other parents did not know how to talk to their children about the loss of their sibling. Additionally, parents were so devastated, that they focused on their own grief, requesting help from external resources to support the surviving children. Similarly, in the current study, mothers discussed how supportive and understanding their older children were. The older children listened to their mother, drove her and the child to appointments, and took care of younger siblings at home. However, in the case of younger children, they were unintentionally neglected by the mother for caring for the dying child. So, the participants asked their parents and siblings to help them by caring for the children at home.

Neighbors

Brooten et al. (2019) explored how parents coped after the death of their infant or child in the ICU. The investigators asked the parents (mothers = 81, fathers = 23) about their support system before the child's death. Sharing their experiences with other parents in a similar situation, helped the participants cope with their child's terminal illness. It was also helpful for the parents to be in support groups while caring for their child at EOL. Some parents expressed their appreciation to their friends for listening to them during this rough period. Primary caregivers in this investigation talked about their friends as a part of their support system. The participants considered other primary caregivers at the same hospital unit as their friends. However, the participants called their friends at the hospital *neighbors*. The respondents believed that no one understood their devastation over the child's condition as much as their *neighbors*. Some primary caregivers felt that their *neighbors* were the main source of support for them. It seemed that the *neighbors* were the support group the primary caregivers needed while caring for the child at EOL. Some HCPs connected the mothers caring for a dying child with mothers in similar situations. However, the hospitals included in this study did not have a support group services. But the primary caregivers had access to the social work department if they needed support.

Healthcare Providers (HCPs)

Healthcare Providers Work from their Heart

A qualitative study conducted by Dos Santos et al. (2020) studied families' relationships with HCPs while their child was receiving EOLC. Family members (N = 24) shared that HCPs were empathetic, compassionate, and trustworthy. In addition, family members appreciated that HCPs were transparent and honest about the child's cancer prognosis. Participants in the current study reported cherishing the support they received from nurses, doctors, and social workers. The HCPs were sympathetic, kind, and supportive when caring for the child who was dying. Also, HCPs explained the child's condition clearly to the primary caregivers and answered all their questions. The participants' requests and privacy were respected by the HCPs. It seemed that the primary caregivers trusted the HCPs decisions and depended on them for the child's EOLC.

Healthcare Providers Can be Harsh

The primary caregivers of this study expressed their frustration and disappointment at the care they received from some of the HCPs. Some HCPs were insensitive and harsh when they informed the participants about the child's diagnosis and prognosis. A few primary caregivers expressed their dissatisfaction with the care provided for the child at the hospital. Respondents sensed that HCPs were just doing their jobs without considering the child or the primary caregivers' feelings. However, the respondents were not dissatisfied to the point that they took the child out of the hospital against medical advice. In a study by Henricks et al. (2017), parents' attitudes towards the decision-making process regarding their preterm infants was explored. The parents (mothers = 12, fathers = 8) shared that they were dissatisfied with the HCPs poor communication and lack of support. Unfortunately, some HCPs withheld information from parents regarding their infant's treatment plan and were not always transparent about the infant's condition. Most parents felt they were not actively involved in the infant's EOLC decisions. The concern was that HCPs have already decided on the treatment plan before discussing it with the parents.

Culture

Culturally, in Saudi Arabia, EOLC decisions are a shared decision-making process. Abu-Ghori et al. (2016) investigated the experiences of nurses caring for Saudi Arabian patients at EOL. Registered nurses (N = 26) were present when patients and their families were making their do not resuscitate decision. The nurses noticed how culture influenced the families and patients', as they worked together to during the decision-making process.

Another study conducted by Khraisat et al. (2019) investigated oncology nurses' (N = 250) perceptions of pediatric EOLC in Saudi Arabia. The nurses believed that culture was influencing the experiences of children and their families at EOL, as it impacted family member's relationships, and they became closer. In this study, limited cultural beliefs were shared by the respondents, and appeared to have had minimal impact on the respondents' experiences. Nevertheless, cultural behaviors and comments which reflected Islamic beliefs were found to be imbedded in the way participants shared their experiences (e.g. the role of the husband). It is impossible to overlook the impact of Islamic beliefs on the culture in Saudi Arabia, they are intertwined (Osra & Jones, 2018).

Father's Role

It is commonly known that Saudi Arabian men are the breadwinners for their families (Bursztyn et al., 2018). So, it is a cultural norm that fathers are responsible for healthcare expenses for their child. In the Holy Quran, *Allah* said: *"let the man of means expend according to his means"* (Al Talaq, verse 7, Chapter 28). The previous *ayah* [verse] is referring to the husband/ father and his financial responsibility towards his wife and children. Also, prophet Mohammad, PBUH, said: *"a man is a shepherd within his family and is responsible for them"* (Ibn Omar, Sahih Al Albani). In some cases, a husband would support his wife by providing care for their children. A respondent shared that her *husband was unique* compared to other Saudi Arabian husbands. Because, her husband cared for their disabled child at home while she was accompanying their dying child at the hospital.

Muslims believe that *Allah* created kindness, mercy and tenderness in the heart of every women (Mohammad, 2014). Therefore, women are able to provide care, comfort and safety to their children (Mohammad, 2014). Prophet Mohammad, PBUH, said: *"a woman is a shepherdess in charge of her husband's house and children, and she is responsible for them"* (Ibn Omar, Sahih Al Albani). Consequently, the Saudi Arabian culture expects women to care for children, in health and illness. This study supports the view that women, especially *mothers, are the primary caregivers* for their children. In addition, studies have shown that children are more attached to their mothers (Meins et al., 2018; Posada & Waters, 2018; Karakaş et al., 2020). The children included in this study were highly attached to their female caregivers (mothers, sister, and nanny).

In past decades, movement towards gender equality have had an impact on the Saudi Arabian culture and traditions (Al-Bakr et al., 2017). Therefore, men and women have different expectations of their roles (Al-Bakr et al., 2017). The cultural view that the father is only responsible for supporting his child financially was not acceptable to the respondents of this study. The primary caregivers expected their child's father to be involved in the provision of care. Some mothers wanted the child's father to participate in EOLC decision making, and the physical care for the child. However, other participants had no expectations for the fathers to provide care for their child, because it is not a cultural norm in Saudi Arabia.

Don't Like to Tell my Friends about my Child

It is culturally acceptable that individuals, in Saudi Arabia, do not share personal information with others. Because, prophet Mohammad, PBUH, said: *"take help in fulfilling your needs by concealing them"* (Muath Bin Jabal, Sahih, Al Albani). Muslims always try their best to follow prophet Mohammad's, PBUH, sayings and behaviors. So, the primary caregivers were uncomfortable disclosing information about the child's condition. Details about the child's EOLC experience was considered personal information the participants *did not want to share with friends*. Regardless of how close the friends were, primary caregivers preferred their privacy.

Furthermore, some participants thought that talking to their friends about the child's devastating situation would seem like complaining. The primary caregivers did not want to bother their friends. It is stated in the Holy Quran: *"I only complain of my grief and sorrow to Allah"* (Yusuf, verse 86, Chapter 13). The previous verse, from the Holy Quran, referred to a story of a father who lost both his sons. Therefore, it is culturally acceptable that individuals do not share sad experiences with friends or strangers. However, the participants were comfortable to share their experience with the researcher. The respondents shared that they trusted the researcher to be nonjudgmental and understanding. Also, confidentiality was assured by the researcher.

Evil Eye and Quranic Recitation

"The effect of an evil eye is a fact" said prophet Mohammad, PBUH (Abdullah Bin Abbas, Sahih Al Albani). In Islam, it is believed that the evil eye can cause different types of illnesses, and in extreme cases death (Ziyad, 2019). Some Muslims believe that sudden illnesses with no cure are a result of an evil eye (Ziyad, 2019). A couple of participants in this study shared that the child's terminal illness is caused by an evil eye. Stories were shared that their child unexpectedly got sick after being around people that gave the child compliments on her/his health. Islam supports the existence of the evil eye curse, and in Saudi Arabia many people relate bad situations to an evil eye curse. However, being obsessive about the evil eye and continuously talking about it is a cultural norm. Culturally, it is normal that families and friends help to find the person who gave the evil eye to the sick individual. Some try to find a cure to release or remove the curse of the evil eye.

Since the evil eye curse exists, Muslims are encouraged to recite Quran for protection or a cure. There are combinations of verses in the Holy Quran that Muslims recite for protection from the evil eye. For example, one of the verses, from the Holy Quran, is: "*I seek refuge in the Lord of daybreak (1) From the evil of that which He created (2) And from the evil of darkness when it settles (3) And from the evil of the blowers in knots (4) And from the evil of an envier when he envies (5)"* (Al Falaq, verse 1-5, Chapter 30). Additionally, prophet Mohammad, PBUH, prayed for protection from the evil eye or any harm by saying: *"I seek refuge in the perfect words of Allah from every devil and poisonous reptile, and from every envious evil eye"* (Ibn Abbas, Sahih Ibn Jubayr). When prophet Mohammad, PBUH, visited a sick person, he put his right hand on their forehead and pray: *"O Allah! the Allah of mankind. Remove this disease and cure (him or her). You are the great curer. There is no cure but through you, which leaves behind no disease"* (Aisha, Sahih Bukhari and Muslim).

Implications

Education

Inclusion of EOLC in the nursing curriculum is foundational for students to develop confidence and provide compassionate care to children at EOL and their family. Dimoula et al. (2019) purported that it is essential for nursing students to understand that holistic care includes the patient and their primary caregivers. Therefore, the researchers conducted a study on 2nd, 3rd, and 4th year nursing students (N = 529) from two universities in the U.S. The investigators found that nursing students were uncomfortable, uncertain, and lacked knowledge on caring for dying patients and their families. According to the investigators, the findings suggest that structured courses on caring for the dying should be included in the nursing curriculum. According to the researchers, future nurses would benefit from learning about the emotional support family need while caring for children at EOL.

Future nurses need to respect the religious and spiritual beliefs of patients and their families. It is essential to understand the influence of religion and spirituality at EOL and EOLC, as it shapes patients' lives and perspectives. Kisorio and Langley (2016) conducted an exploratory study on family members' experiences with their loved ones at EOL, in South Africa. Family members (N = 17) of patients admitted in the ICU, from three different hospitals, were interviewed. The participants discussed the value of spiritual support at EOL. Spiritual practices for patients and their families provided comfort, peace, hope, and helped with coping at EOL. Even though HCPs did not participate in spiritual practices; the participants had the freedom to practice their spirituality with no judgement from HCPs.

Wong et al. (2020) explored HCPs perceptions of the factors that impact palliative and EOLC in China. Focus groups and individual interviews were conducted with HCPs (N = 72) to identify their perceptions of their patients and families' needs at EOL. The HCPs shared that their awareness and understanding of the Chinese culture helped them shape the patient's treatment plan. Respecting patient's cultural beliefs made the EOL experience bearable for patients and their families. The HCPs in the Wong et al. study promoted the importance of culture education for new HCPs. The investigators recommended that nursing students receive education regarding diverse cultural beliefs to help them provide the best nursing care. Also, future nurses should be encouraged to ask patients or their families about their cultural preferences to ensure they receive a high standard of care.

Practice

Family members should be involved in their child's healthcare plan at EOL, as parents are the guardians who were making decisions on behalf of their child. Simeone et al. (2018) conducted a study in Brazil to examine parents' experiences with their children who were admitted in the pediatric cardiac ICU. The parents (mothers = 9, fathers = 7) shared a desire to be involved in their child's healthcare plan. Some parents expressed their frustration at not being consulted by HCPs regarding their child's treatment. Other parents shared their appreciation for the HCPs who respected their wishes for being involved in their child's treatment plan. The investigators findings suggest that including parents in their child's care plan was beneficial for all individuals involved in the care plan.

Educating the family about the child's diagnosis and prognosis can help them make EOLC decisions. Knowledge of the illness can decrease the uncertainty and self-doubt that family members experience. Multidisciplinary healthcare professionals need to be available to answer patient and family's questions related to EOLC. A study conducted by Price et al. (2017) explored nurses' perceived competency on providing EOLC to patients who were hospitalized. Nurses (N = 583) included in the study were chosen from 25 adult and pediatric ICUs, in the U.S. The nurses reported that educating patients and their families about the illness and treatment options helped them make EOLC decisions.

Support is a critical element that family members need while caring for a child who is dying. Families could be supported by offering group meetings with other families going through similar experiences. Pask et al. (2018) explored the perceptions of patients, family members, and professionals on the complexity of palliative care. The participants (N = 65) were recruited from six healthcare centers in the UK. Patients and their families expressed their appreciation of having participated in the support groups. The group sessions provided needed emotional and spiritual support to patients at EOL and family members. The investigators recommended that participants be offered support groups, to allow them to connect with others on many levels.

Primary caregivers in this study expressed their exhaustion from constantly caring for their child at the hospital. Some participants shared that they needed time to spend with their families without worrying about their child being alone. Therefore, hospitals could offer respite services for primary caregivers. Whitmore and Snethen (2018) explored in the U. S. the perceptions of parents of children with special needs. Focus groups were conducted with the participants, as their children were all attending a community sponsored respite care program. Parents (mothers = 15, fathers = 7) shared in focus groups that their child's constant care demands made them feel overwhelmed and exhausted. The investigators research findings suggest that offering parents a respite program gave them the opportunity to relax and enjoy leisure time. Healthcare organizations should consider offering primary caregivers with respite services to support their psychological, physical, and social needs while caring for their child at EOL.

Policy

There are ethical dilemmas related to EOLC decision-making for neonates and pediatrics. Therefore, end of life care policies need to be clearly explained to patients and their families. Clear detailed policies guide healthcare professionals in assisting family members in the decision-making process. According to Butler et al. (2019), there is lack of knowledge on how parents understand hospital policies regarding children at EOL. Therefore, Butler et al. used a constructivist grounded theory approach in Australia, to explore parents' experiences with their child in the ICU. The investigators focused on parents' (N = 26) understanding of hospitals' system and policies, and their role as parents in the ICU. It was reported that parents felt comfortable and well-informed when HCPs explained: pediatric EOLC policies; HCPs role in EOLC decision-making; and parents' role and boundaries in the PICU. The parents shared that understanding the hospital’s policies made them decide if the hospital’s system was suitable for their child’s EOLC.

Healthcare organizations need to reconsider policies regarding visitation hours for patients in neonatal and pediatric intensive care units. Carmela et al. (2019) conducted a study on the emotional impact of visiting hours on parents with children in the PICU and NICU, in Italy. Parents (n = 11) had restricted visiting hours to see their infants in the NICU. Whereas the other parents (n = 11) had a 24-hour open visitation to see their children in the PICU. Investigators examined parents’ anxiety levels regarding hospital visitation hours. In general parents were anxious because of their child’s health condition. However, ten out of 11 parents reported moderate to severe anxiety levels due to the restricted visitation hours in the PICU. Parents (n = 9) with infants in the NICU reported their relief at having 24-hour open visitation hours, yet their anxiety level remains high.

Historically, research has clearly found that limiting visitation of infants and children who are hospitalized has a seriously negative impact on both the infants and children, and their parents (Saria et al., 2019; In et al., 2019, Smith, 2018). Unfortunately, some children report lifelong memories of the terror of being alone in the hospital when they are sick (Şahin & Topan, 2019). In response to that research, family centered care has become the goal of child health centers (Coats et al., 2018). Family centered care focuses on the needs of the child and family, and not on the comfort or needs of the healthcare providers or agency (Barnard-Brak et al., 2017). Therefore, it is recommended that 24-hour visitation policies be developed for healthcare facilities in which infants and children receive care. Parents and close family members must be allowed to spend time with their infant or child to provide the love, care, and support that is needed. Familial presence is especially important when the infant or child are at EOL, as those are precious moments that need to be spent together as a family. Additionally, 24-hour visitation allowing parents and family members to visit benefits everyone psychologically and emotionally, the infants and children, primary caregivers, and healthcare providers.

Research

It is not common for a male to be a primary caregiver for a child in Saudi Arabia. Mothers are the primary parent when a child is sick, though male family members (father, grandfather, brother, etc.) are involved in the decision-making process related to the child's EOLC (MOH, 2018). Limited research has been specifically done on fathers with children at EOL (Xiu et al., 2016). However, multiple studies have been conducted worldwide to examine parents' experiences with their child at EOL (Youngblut et al., 2017; Tom et al, 2017; Lyu et al., 2019). Parents have shared about their experiences with grief (Proulx et al, 2016), coping (Hussin & Aho, 2020) and the process of decision-making (Leemann et al., 2020) while their child was dying. There continues to be limited research on the fathers' experiences when their infants or children are at EOL, or require EOLC. Therefore, further research is recommended to explore the fathers' experiences caring for their child at EOL.

Future studies also need to focus on the experiences of siblings when their brother or sister is at EOL. It is known that siblings of children who are hospitalized are affected psychologically (Niinomi & Fukui, 2018) by the pending loss. However, limited studies were found regarding assisting ill children's siblings through the EOL process. It is important to consider the well-being of the whole family, including the siblings.

Children who survived a life threating illness appreciated being listened to when they shared their preferences while they were ill (Jalmsell et al., 2016). Understanding the child at EOLs feelings and behaviors is essential to provide high quality nursing care (Darcy et al., 2019). Yet, there remains limited information in the literature on children at EOL, their thoughts, and feelings. Therefore, the journey that children at EOL go through needs to be further explored. Gaining a greater understanding of the needs of the child at EOL and their families can assist care providers to ensure they receive the highest quality of care.

Ethical Issues

The participants were informed verbally and through written consent that participating in the study was voluntarily. Participants were assured that their children's medical care will not be affected, regardless of their participation decision. The interviews were digitally recorded, and the recordings were transcribed in Arabic, and translated into English by the investigator. Then the transcripts were back translated into Arabic by the graduate level research assistant. The recordings and transcribed documents were stored electronically in a de-identified form on the investigator and major professor's encrypted hard drives (double password protection). The English transcription of the interviews will be shared with the researcher's major professor, and the graduate level research assistant who is back translating the data. Findings will be anonymously presented in aggregate form in publications and conferences using the de-identified data. Upon completion of the study, the recordings were permanently destroyed. However, the transcribed documents will be saved for future analysis and dissemination, until the process in completed, at which point they will be destroyed. Finally, female primary caregivers with children who are at EOL are considered a vulnerable population; therefore, their rights will be guaranteed and respected.

Limitations

The findings of the study provided insight into the experiences of Saudi Arabian primary caregivers caring for their children receiving EOLC. Generalizability was not the aim.

However, it is important to note that the participants pool was limited to three hospitals and a nonprofit organization in Jeddah, Saudi Arabia. Also, the study focused on female caregivers instead of male care givers.

There were multiple challenges during the recruitment process. There were a couple of participants (mothers) were in distress from their child's condition and were not approachable (n=4). Other mothers refused to be recorded and be included in a research study (n=10). A few guardians (husbands) did not give permission for the mother to participate in the study (n=4). Also, a couple of children passed away before the scheduled time of the interview (n=4). Some mothers changed their minds on the interview day (n=5). Furthermore, two hospitals were initially chosen to conduct the research at, children and maternity hospitals, were under renovation during the time of the study. Other hospitals were approached; however, the IRB approval would take months to obtain.

It was expected that primary caregivers would be difficult to recruit. Because, the caregivers' willingness to participate depended on the child's condition, and most were critical or unstable. The investigator was understanding and respected their wishes for not wanting to participate. However, the challenges faced during the data collection were mostly overcome by expanding the recruitment to other hospitals. After obtaining IRB approvals from other hospitals, the participants' pool increased, and caregivers were recruited. Additionally, the investigator visited hospitals all week, and spent longer hours floating between different units. Moreover, the investigator was in touch, daily, with social workers at the nonprofit organization for updates on potential participants.

Dissemination of Findings

The plan is to submit this study to high impact journals, such as the Journal of Family Nursing and Western Journal of Nursing Research. The Journal of Family Nursing publish articles related to families in health and illness. The Western Journal of Nursing Research publish original research studies. Both journals are a good fit for this study that focusses on primary caregivers' experiences caring for a child at EOL. In addition, the findings will be presented in conferences as poster or oral presentations. Moreover, there is a plan to use the data to develop other manuscripts. The manuscripts will be discussing other aspects related to primary caregivers' experiences with a child who is dying. For example, other aspects will include decision making, and difficult events primary caregivers had to go through with the child at EOL.

Conclusion

This study shed a light on the experiences of primary caregivers caring for a child at EOL, in Saudi Arabia. Similar to what has been reported in the literature, primary caregivers were affected psychologically, physically, socially, and financially while caring for a child at EOL. Multiple studies in the literature discussed the importance of having support systems available at EOL. In this study, the support system was very broad, encompassing the participants husband/child's father, family, friends/ neighbors, and HCPs.

Previous studies demonstrated that religion and culture have an impact on EOL and EOLC. This study also presented the impact of Islam and the Saudi Arabian culture on primary caregivers' experiences with a child who is dying. The findings of this study can be used to provide for improving the education, practice, and policies of nurses, as well as contribute to the body of knowledge on EOLC in Saudi Arabia and worldwide.

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Appendices

Appendix A

Table 1.8

Evidence Table (Manuscript 1)

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
1. Arruda-Colli, De Lima, Perina & Santos 2016 Brazil	Understand the maternal experience during an oncological disease recurrence phase of her child's treatment	• Descriptive exploratory qualitative design A 39-year old mother responsible for her child's treatment during a cancer relapse phase	Semi-structured interview Thematic content analysis	The themes identified: • Facing the impond-erable and seeking to make sense of the experience • Facing losses on the relational sphere • Experiencing the relapse of the son with the perspective of death	Strengths: • Highlighted the importance of empathy and sympathy between HCPs and mother Limitations: • One participant
2.Arutyunyan, Odetola, Swieringa, & Niedner 2018 United States	• Understand whether parents of children admitted to PICU would want their physicians to ask about their	• Observational cross-sectional study • 162 parents/ guardians of children admitted for more than 48 hours to the PICU	Modified survey about spiritual well-being Univariate and bivariate analyses were performed	• 48% of parents of wanted their physicians to ask about their religious or spiritual beliefs • 78% of parents had a strong	Strengths: • Highlighted the importance of spirituality • Encouraged physicians to be taught basic skills to approach

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
	religious or spiritual beliefs • Explore whether the child's underlying illness or parental characteristics influence the responses to our primary objective			preference regarding prayer • 33% felt comfortable discussing their spiritual beliefs with various providers	spiritual history Limitations: • Small sample size • Limited diversity of participants • Single site Bias due to self-report measures
3. Atout, Hemingway & Seymour 2017 Jordan	Explore the experience of decision-making in the care of children with palliative care needs in Jordan, from the perspective of their mothers	• Collective qualitative case study approach • 24 mothers of children between the ages of 1-12 years old admitted in pediatric units diagnosed with a condition eligible for PC	• Participant observation • Semi-structured interviews with mothers, physicians, and nurses Constant comparison	• Jordanian mothers seek to transfer the role of decision-making to the physicians • Worry about future guilt • Mothers feared to make the wrong decisions (adverse	Strengths: • Large sample number • Participants included mothers, physicians, and nurses • Data was collected though observation and interviews

Author Year Country	**Purpose/ Question**	**Design Sample**	**Data Collection & Analysis**	**Findings**	**Strengths & Limitations**
		• 12 physicians and 20 nurses who were involved in the care of the children		impact on the child) • Mothers requested details about their children's condition for second opinion, online search, or asking other parents in the same situation	• Culture was addressed Limitations: • The observation period varied significantly for each case study • No follow up with parents after the death of their children
4. Baughcum et al. 2017 United States	Examine parents' perspectives of their infants' EOL experience 3 months to 5 years after their infants' death in the NICU	• Mixed-method study design (cross-sectional) 29 mothers, 16 fathers representing 31 infants	• Demographic data from infants' medical records • Individual in-depth interviews or completing a survey Content analysis to develop themes (qualitative)	Themes identified: • Parents were partners in care • Communication with the healthcare team • Relationships with staff • Bereavement support	Strengths: • Provided perspectives of mother and fathers • Developed recommendations based on participants' experiences Limitations: • Limited number of fathers in the study compared to mothers

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
			- Independent-sample t tests and X^2 analyses		- Retrospective reports could have been subject to bias - Limited sample diversity
5. De Vos et al. 2015 Netherlands	- How do physicians and parents communicate about decisions to withhold or withdraw LST? - To what extent do parents share in the decision-making process?	- Prospective exploratory study - Total of 27 physicians, 37 parents, and 19 children who have been involved in the decision to withhold or withdraw LST - Conducted in the PICUs of 2 Dutch University Medical Centers	Conversations between researchers and participants were audio recorded, ranging from 1 to 8 meetings per participant - Coding schemes were developed - Then the codes were qualitat-ively and quantitatively analyzed - Then the analyzed data/ results were discussed is several	Physicians and parents communicate about: - Information about the actual situation and treatment effects - Information about the prognosis - Information about remaining options, including pros and cons - Providing summary of the situation and any additional questions	Strengths: - Themes were clearly identified - Examples were provided Limitations: - Research was limited to 2 centers - Multiple researchers were involved in data collection - The data analysis was not clearly defined

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
			discussion rounds with all researchers	The extent of communication includes: • Asking about the preferred role in the decision-making process • Asking about the values and preferences regarding continuation or discontinuation • Expressing objections to treatment • Sharing emotions, grief, fear, despair, and frustration	
6. Haley & Walker 2016 United States	Explore the expanded use of the SG with a population of parents caring for their child in hospice/	• Descriptive study conducted using a qualitative grounded theory design • Quantitative component using PSRS before and	• Parents were recruited from Trinity Kids Care in California • One-on-one in-depth interviews	The attributes of strength were: • Handling emotions • Solving problems • Spirituality • Finding meaning	Strengths: • Participants were comfortably interviewed in their homes • The SG was found to be an effective intervention

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
	palliative care at home, to assess if new strengths emerge and if SG serves as an effective intervention	after the interview (constant comparative analysis) • Total of 8 participants (parents) who are caring for their children at home	• PSRS surveys before and after the interviews Constant comparative analysis	• Taking care of self • Taking care of family • Taking care of others in the community • Positive attitude • Resourcefulness • Sense of hardiness • Being with nature	• Themes were thoroughly discussed Limitations: • Small sample size • No variety between participants
7. Katooa, Shahwan-Akl, Reece & Jones 2015 Saudi Arabia	Describe and explore the coping patterns of Saudi Arabian parents and in particular the mothers as primary caregivers of chronically ill children	• Quantitative descriptive design • Total of 122 parents with chronically ill children	Survey question-nnaires • QOL scale • GSC scale • SSQ SPSS	Mothers coped by finding support from: • Family • Friends • Government association • The healthcare facility (hospital)	Strengths: • Both parents were included in the study • Participants were from different hospitals Limitations: • Small sample size • Number of fathers included in the study was minimal • Participants were from one city in Saudi Arabia (Jeddah)

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
8. Lou, Mu, Wong & Mao 2015 Taiwan	Explore the essence of the maternal experiences related to the anticipatory loss of families of a child with advanced cancer	• Retrospective study using Husserl's phenomenological approach • 10 mothers of children (ages 1-14 years) who died within the past 3 years due to a brain tumor • Mothers who are members of CBTA-Taiwan	In-depth face-to-face interviews Colaizzi's method for analyzing phenomenological data	Mothers discussed their experiences with • Losing hope of cure • Encountering death • Establishing a protective role toward the child • Intertwining the chaos and strengths of family life • Contending against death	Strengths: • Mothers with different years of struggle were included • Culture and religion were discussed Limitations: • Participants were limited to the members of CBTA-Taiwan • The data collected was retrospective and relied on participants' memories (within 3 years)
9. Ohs, Trees & Gibson 2015 United States	• What are the competing discourses about EOL decisions constructed by families making medical decisions for a family	• Qualitative study design • Total of 15 participants over the age of 18, who had been involved in an EOL medical decision of a close family member were	• In-depth interviews • Prior to the interview, a questionnaire was provided to gather background information • Contrapuntal analysis • The Relational	• All participants reported the struggle of letting go of a family member • Family interaction was important to manage the decision of letting go	Strengths: • Participants had different experiences • Valuable insight on families' decision-making process • HCPs roles were mentioned

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
	member at the EOL? - How do families make sense of contradictory discourses?	included in the study	Dialectics Theory (RDT) was used to analyze the discourses around the struggle between holding on and letting go	- Struggle to decide who makes the decision and who should be involved in the decision - Contradictions between the patient and family's wishes - Contradictions between discourses of emotionality versus rationality	Limitations: - The majority of participants were females - Participants constructed accounts of good decisions, which limits the transferability of the findings

10. Popejoy
2015
England
	Understand the lived experience of parents throughout the process of making and revising EOLC decisions for their child	- Qualitative exploratory design
		- Three mothers who had been bereaved
			Semi-structured interview
			Interpretive phenomenological analysis
				Themes and sub-themes identified:
				- Making decisions
				  - Timing of discussions
				  - Decision makers
				  - Values
				- Revising and implementing EOLC plans
				  - Barriers and facilitators to
					Strengths:
					- Individual interviews were conducted
					- Consultants and child bereavement team were involved in the study for support and recruitment
					Limitations:
					- Small sample size

Author Year Country	**Purpose/ Question**	**Design Sample**	**Data Collection & Analysis**	**Findings**	**Strengths & Limitations**
				implementation • Revisiting plans	• Participants were from one hospital
11.Zimmermann et al. 2016 Switzerland	• Describe specific parental experiences in relation to the under-lying medical condition causing the child's death • Explore differe-nces in parental perspe-ctives between 4 common medical condit-ions respon-sible for childhood death (cardiol-ogy, neonatolo-gy, neurology oncology)	• Cross-sectional design • Total of 124 participants (parents) who had children died due to a cardiac, neurological, oncological condition, or during the neonatal period in the years 2011-2012	• Cross-sectional questionnaire survey was distributed to parents • Recruitment done between July 2013 and March 2014 at 8 children's hospitals in Switze-rland Descriptive statistics	Parents' experiences included: • Support of the family • Communication with physicians • Shared decision making • Relief of pain and other symptoms • Continuity and coordination of care • Bereavement support Positive and negative experiences and quality of life	Strengths: • Positive and negative experiences were discussed • Several centers were used for recruitment Limitations: • Small sample • The data collected was retrospective and relied on participants' memories • Findings could be biased based on parents' favorable experiences

Table 2.8

Abbreviations (Manuscript 1)

Abbreviation	Definition
CBTA-Taiwan	Childhood Brain Tumor Association-Taiwan
EOL	End of life
EOLC	End of life care
GSE	General self-efficacy scale
HCPs	Heath care professionals
ICU	Intensive care unit
LST	Life-sustaining treatment
NICU	Neonatal intensive care unit
PC	Palliative care
PICU	Pediatric intensive care unit
PSRS	Personal Strengths Rating Scale
QOL	Quality of life scale
SG	Strengths Guide
SPSS	Statistical package for the social sciences
SSQ	Social support questionnaire

Table 3.8

Demographic Data (Mothers)

Demographics	Options
Age	Over 18 years old
Relation to the child	Mother, grandmother, aunt, stepmother, sister etc.
Marital status	Married, divorced, widow, single etc.
Occupation	Housewife, teacher, nurse etc.
Number of children	One or more
City or area of residency – geographical location	Cities in Saudi Arabia
Financial support	Self-pay, insurance, charity organization etc.

Table 4.8

Demographic Data (Child)

Demographics
Age (1 day – 14 years old)
School grade (if applicable)
Health diagnosis
Disease prognosis
Duration of illness
Length of stay at the hospital

Table 5.8

Interview Guide

Stage	Interview Questions
Stage 1 Introduction	Hello, my name is Shahad Hafez. Thank you for your participation and your willingness to meet with me today. How is your day so far?
Stage 2 Introducing the research	I am interested to explore the experiences of mothers/ primary care givers caring for a child who has serious illnesses in Saudi Arabia. I would like to remind you that your participation is voluntary and highly appreciated. In this interview, I am interested to learn about your experience caring for your child at home and at the hospital. The interview will last one to two hours, and it will be audio recorded. Because I will not be able to write exactly what you are saying during the interview. The recording will be anonymous, confidential, transcribed by me, then translated into English. The raw data will be shared with my major professor after transcription and translation. After completing the study, the audio recordings will be destroyed, while the transcription will be used for future research. Some of your answers will be anonymously published. I will ask you a number of questions, and there are no right or wrong answers. Please, take the time you need to answer. You do not have to answer all the questions or share information you are not comfortable sharing. None of the information you provide me will affect your child's plan of care in the hospital. Feel free to ask me questions or ask for a break. Are you ready to get started? I will ask you questions about your demographic data.
Stage 3 Beginning the interview (Demographics)	Mother/ care giver age: Relation to the child: Marital status: Occupation: Number of children: City or area of residency – geographical location: Financial support: Child's age: School grade (if applicable):

Health diagnosis:
Disease prognosis:
Duration of illness:
Length of stay at the hospital:

Stage 4
During the interview

1. Tell me the story about your child’s diagnosis.
2. How did you feel when you were informed about your child’s [illness]?
3. How does caring for your child influence you:
    - Psychologically
    - Physically
    - Socially
    - Financially
4. What decisions you have/ had to make regarding your child’s treatment options?
5. What influenced your decision about your child’s treatment or management?
    - Religion/ Islam
    - Culture and traditions
    - Family or friends
    - Healthcare system/ healthcare providers
6. How do/ did you feel about the decisions made about your child’s treatment or management?
7. How much you were involved in the decision-making process?
8. What was the most challenging situation you had to go through with your child?
    - How do you feel about the challenging situation?
9. What are the sources of support you have?
    - Family or friends
    - Hospital staff
10. What can we do for you as healthcare professionals to make your experience better during the extremely difficult time?
11. Would you like to add any more on what you shared?

Thank you very much for sharing your experience.

Stage 5
Ending the interview

Please, let me know if I could be of any assistance.

Stage 6
After the interview

Lastly, how are you feeling after the interview?

Table 6.8
Participants Age

Range	Number of Participants
18-30 years	5
30-40 years	12
40-50 years	7

Table 7.8
Participants Education Level and Occupation

Education Level	Number of Participants	Occupation	Number of Participants
Elementary school	2	Housewife	20
Middle school	7	Nurse	1
Highschool	2	Nanny	1
Some college degree or diploma	5	Teacher	1
Graduate degree	1	Student (older sister)	1

* Not all participants responded to the Education Level question

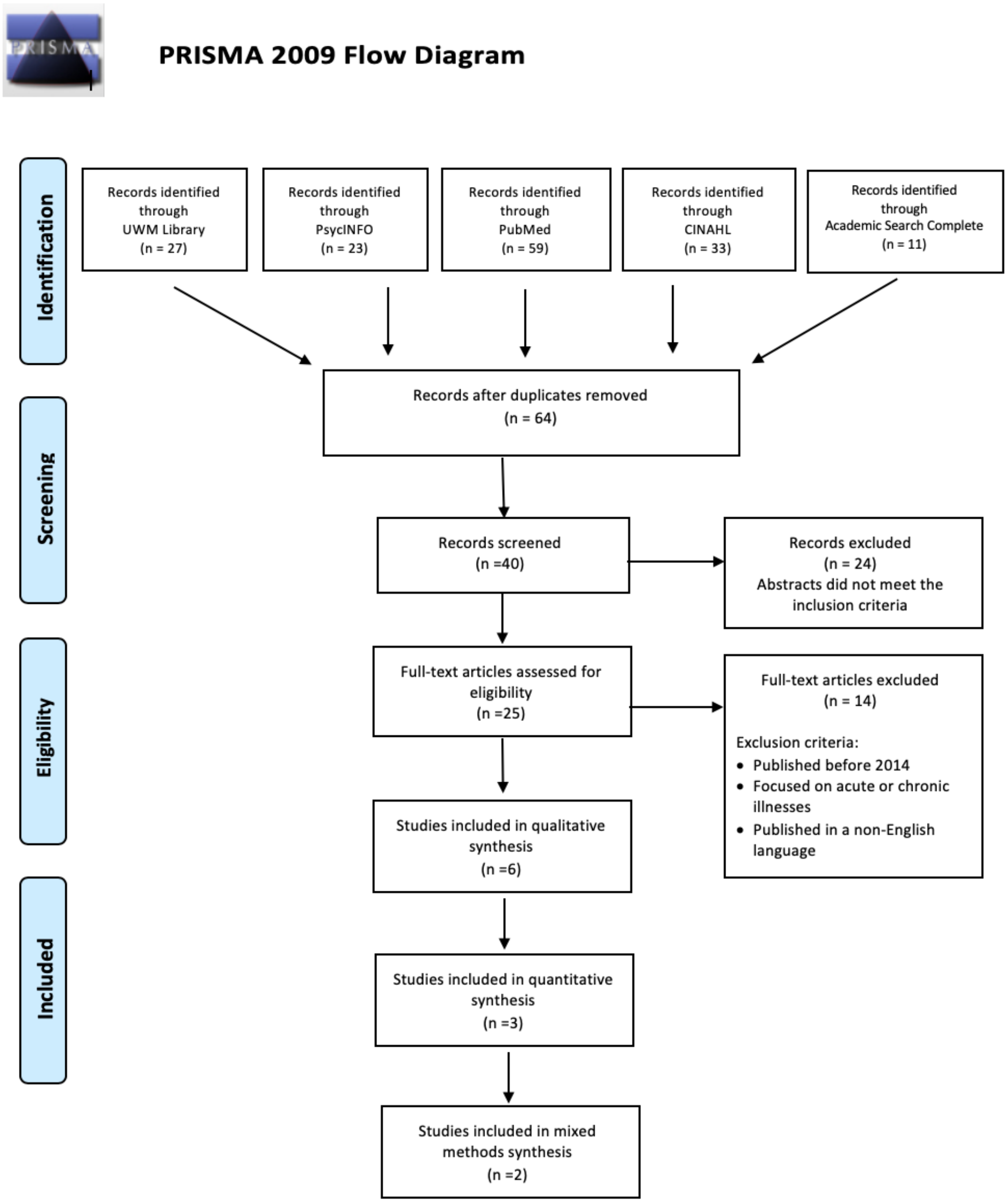
Table 8.8
Child Age, Gender, and Duration of Receiving EOLC

Range (<1 mo.-13 yrs.)	Children (n = 25)	Males (n =12)	Females (n = 13)	Duration of EOLC (n = 25)
< 1 month	1	1	0	1
1-4 months	1	0	1	2
4-8 months	3	0	3	6
8-12 months	0	0	0	3
1-4 years	7	4	3	8
4-8 years	5	3	2	1
8-12 years	6	3	3	2
12-13 years	2	1	1	1

Appendix B

Figure 1.8

PRISMA Flow Diagram (Manuscript 1)



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal. pmed1000097

For more information, visit www.prisma-statement.org.

Figure 2.8

Conceptual Model (Chapter 3 Methodology)

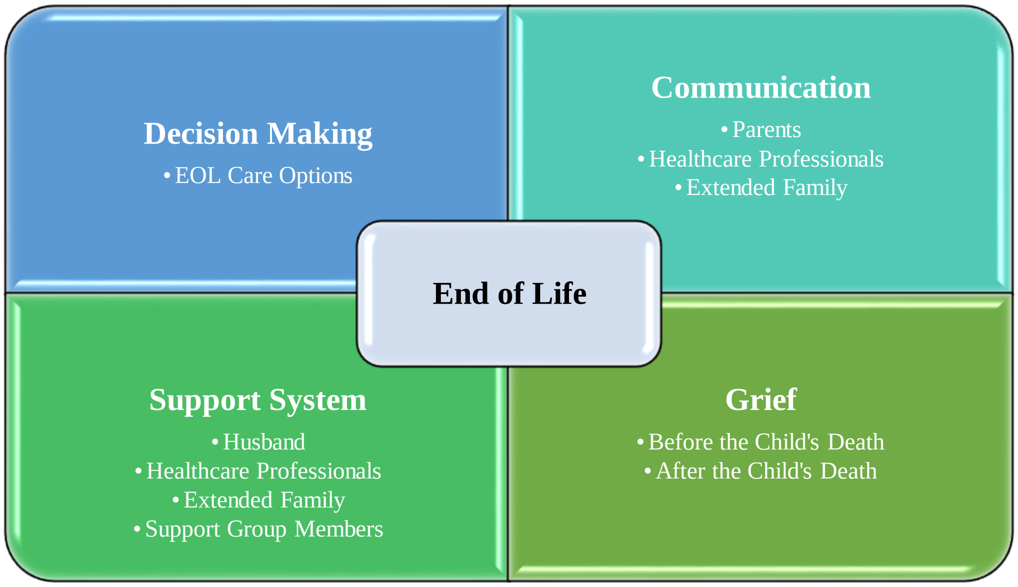


Figure 3.8

Conceptual Model (Manuscript 2)

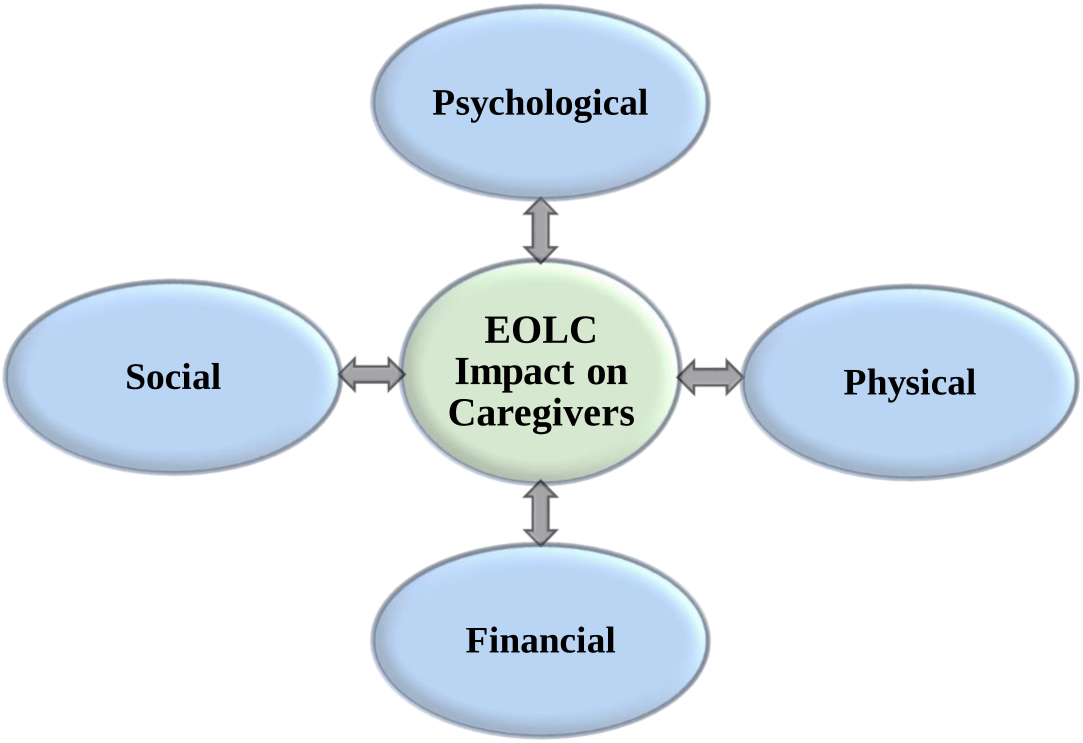


Figure 4.8
Conceptual Model (Manuscript 3)

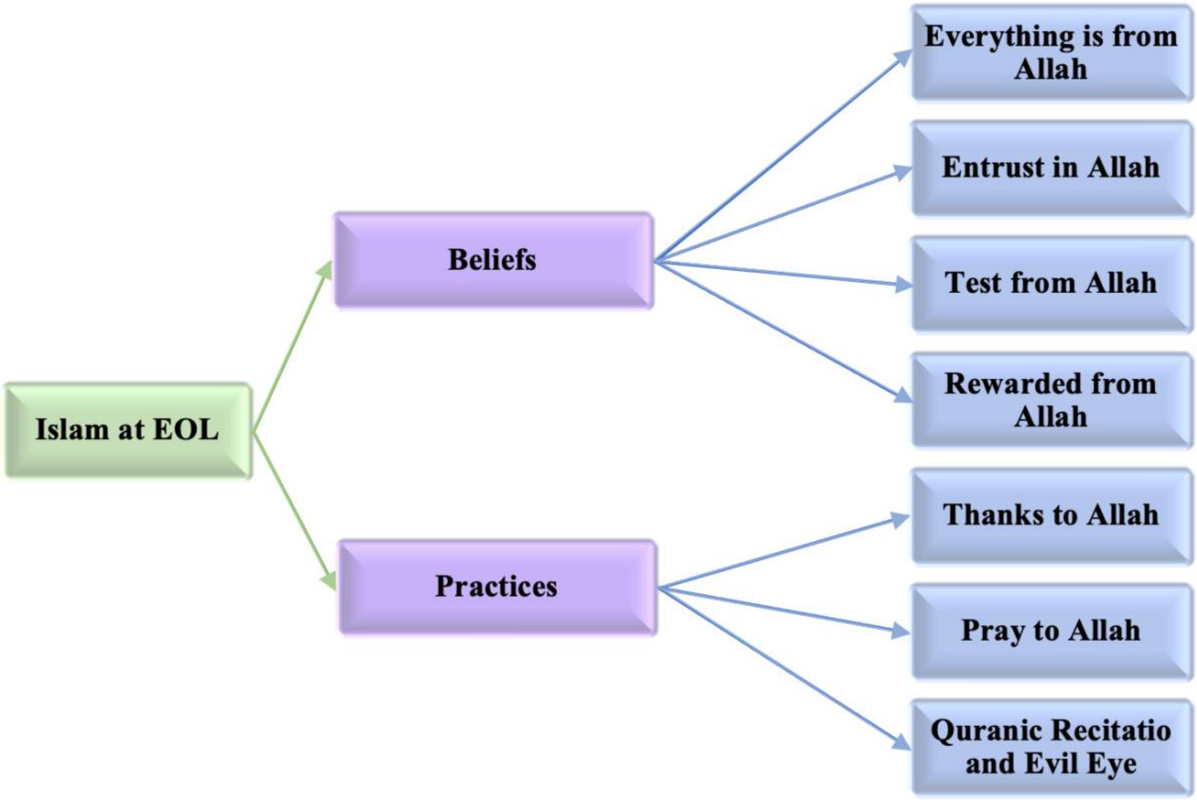
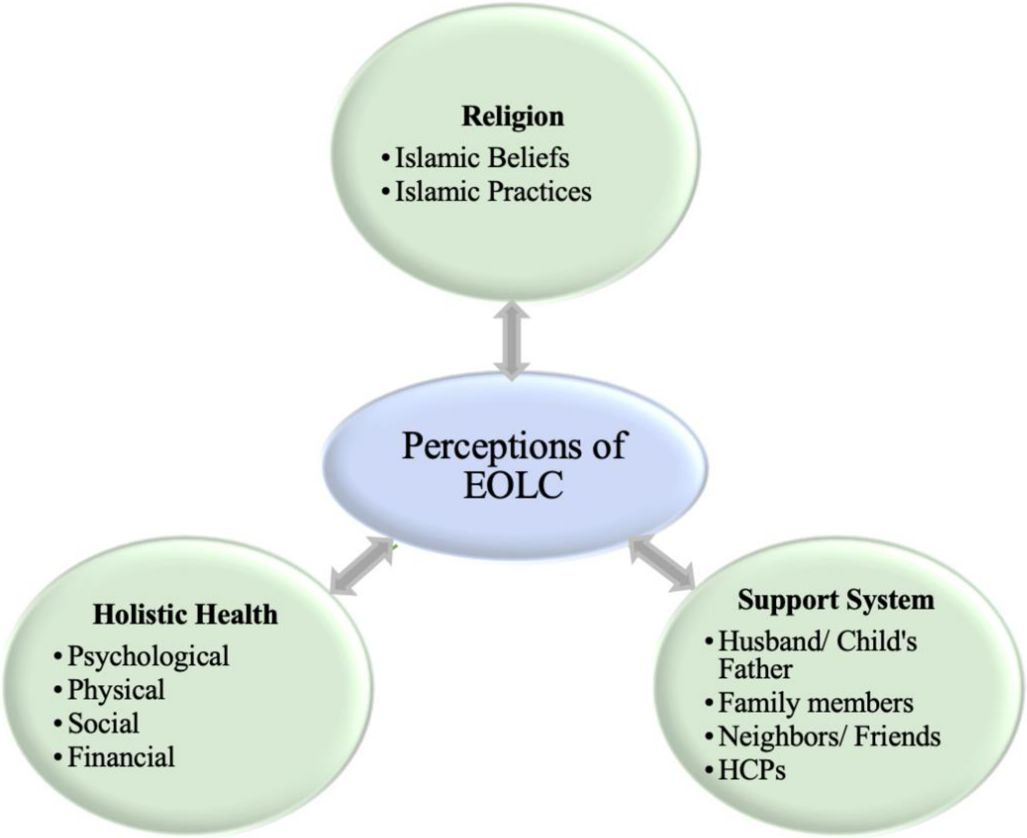


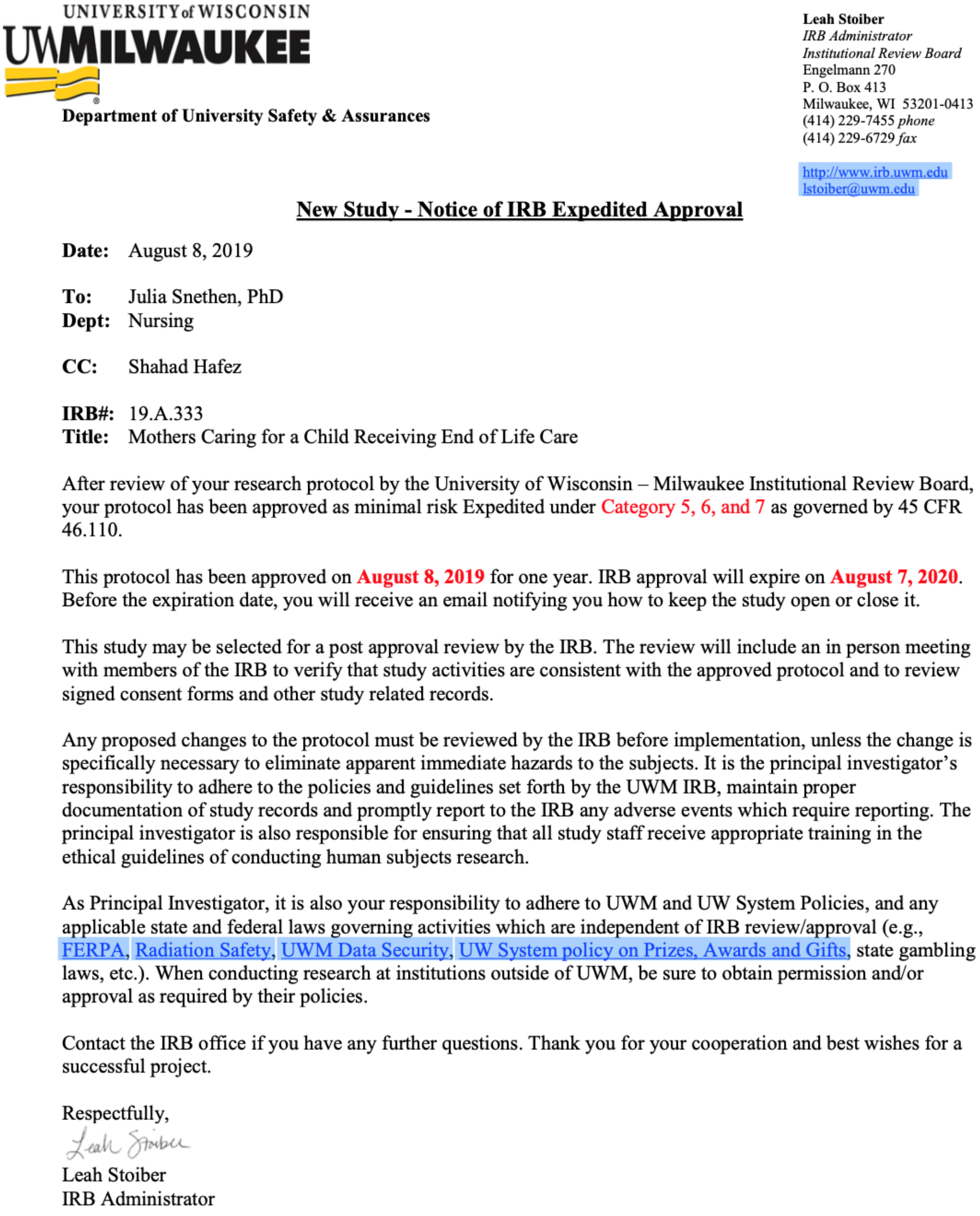
Figure 5.8

Modified Conceptual Model for the Study



IRB Approvals

University of Wisconsin-Milwaukee



UNIVERSITY of WISCONSIN
UWMILWAUKEE
Department of University Safety & Assurances

Leah Stoiber
IRB Administrator
Institutional Review Board
Engelmann 270
P. O. Box 413
Milwaukee, WI 53201-0413
(414) 229-7455 *phone*
(414) 229-6729 *fax*

http://www.irb.uwm.edu
lstoiber@uwm.edu

New Study - Notice of IRB Expedited Approval

Date: August 8, 2019

To: Julia Snethen, PhD
Dept: Nursing

CC: Shahad Hafez

IRB#: 19.A.333
Title: Mothers Caring for a Child Receiving End of Life Care

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been approved as minimal risk Expedited under Category 5, 6, and 7 as governed by 45 CFR 46.110.

This protocol has been approved on **August 8, 2019** for one year. IRB approval will expire on **August 7, 2020**. Before the expiration date, you will receive an email notifying you how to keep the study open or close it.

This study may be selected for a post approval review by the IRB. The review will include an in person meeting with members of the IRB to verify that study activities are consistent with the approved protocol and to review signed consent forms and other study related records.

Any proposed changes to the protocol must be reviewed by the IRB before implementation, unless the change is specifically necessary to eliminate apparent immediate hazards to the subjects. It is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the UWM IRB, maintain proper documentation of study records and promptly report to the IRB any adverse events which require reporting. The principal investigator is also responsible for ensuring that all study staff receive appropriate training in the ethical guidelines of conducting human subjects research.

As Principal Investigator, it is also your responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities which are independent of IRB review/approval (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.). When conducting research at institutions outside of UWM, be sure to obtain permission and/or approval as required by their policies.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project.

Respectfully,
Leah Stoiber
Leah Stoiber
IRB Administrator

Saudi Arabian Ministry of Health

المملكة العربية السعودية
Kingdom of Saudi Arabia
مديرية الشؤون الصحية بمحافظة جدة
Directorate of Health Affairs - Jeddah
(٢٠٢/٢٧٥)

وزارة الصحة
Ministry of Health

الموضوع: تسهيل مهمة باحث

الإدارة: إدارة البحوث والدراسات

سعادة مدير / مستشفى شرق جدة ، مستشفى الملك عبدالعزيز(المحجر)،مستشفى الثغر، مستشفى العزيزية ، مجمع الملك عبدالله الطبي المحترمين ،،،،،،

السلام عليكم ورحمة الله وبركاته...

نفيدكم بأن الباحثين اسمهم أدناه سوف يقومون بإجراء البحث وجمع البيانات اللازمة لذلك

أسماء الباحثين	**شهد حافظ، جوليا سنثن**
عنوان البحث	**Mothers Caring for a Child Receiving End of Life Care**
أسماء جامعي البيانات	**شهد حافظ، جوليا سنثن**
مدة البحث	**سنه واحدة فقط**
رقم البحث	**٠١٠٨٧**

وبعد الاطلاع ودراسة منهجية البحث من قبل اللجنة العلمية ولجنة أخلاقيات البحث العلمي المسجلة لدى اللجنة الوطنية للأخلاقيات الحيوية والطبية برقم (H-02-J-002) وجد أنه لا مانع من إجراء البحث.

لذا نأمل تسهيل مهمة الباحثين في إجراء البحث في منشأتكم، مع مراعاة الآتي:

١. **اتباع قوانين اللجنة الوطنية للأخلاقيات الحيوية والطبية.**
٢. **في حال أي تغيير في خطة البحث يجب الحصول على موافقة إدارة الأبحاث.**
٣. **عدم تأثر الخدمة في المرافق المعنية.**
٤. **المحافظة على حقوق الأشخاص الخاضعين للبحث وخصوصياتهم.**
٥. **استخدام المعلومات لأغراض البحث العلمي فقط.**
٦. **تقديم تقرير عن سير الدراسة لإدارة البحوث كل ستة أشهر.**

شاكرين تعاونكم.

وتفضلوا بقبول أطيب تحياتي،،

مدير إدارة البحوث والدراسات
د/ علا أكرم عبد الرشيد

مساعد مدير الشؤون الصحية
للتخطيط والتحول
د / نهى أحمد دشاش

Email:Research-Jeddah@moh.gov.sa

Tel#: 0126347308

الرقم: ٢٣٢٧ / ٤٨٦٦ /٤٧/ج التاريخ: ٣ / ١ / ١٤٤١هـ المشفوعات: ....

National Guard Hospital

Kingdom of Saudi Arabia
Ministry of National Guard - Health Affairs

المملكة العربية السعودية
وزارة الحرس الوطني - الشؤون الصحية

King Abdullah International Medical Research Center
(KAIMRC)
☎ (84) 46669 1515 94466 irb@ngha.med.sa

IRB NCBE Registration No.:
H-01-R-005

IRB Office

Memo Ref.No. IRBC/1364/19 **E-CTS Ref. No.** **JED-19-427780-109935**

Study Number:	**SP19/340/J**
Study Title:	**Mothers Caring for a Child Receiving End of Life Care (EOLC)**
Study Sponsor:	**Non Grant**
IRB Approval Date:	**20 August 2019**
IRB Review Type:	■ **Expedited** Review ☐ **Full Board**
Study site(s):	**Western Region**

KAIMRC
APPROVED
IRB

Dear **Dr. Abdullah Abobaker Baothman**
Consultant, Pediatric Hematology/Oncology and BMT, PNOC, and
Asst. Professor of Pediatrics, KSAU-HS, Jeddah
Ministry of National Guard – Health Affairs

Sub-investigator: Shahad Amr Hafez

After reviewing your submitted research proposal/protocol and related documents, the IRB has APPROVED the submission.

The approval includes the following related documents:

Document/Title	Version	Date
Research Proposal	01	20 August 2019
Informed Consent	01	20 August 2019
Data Collection	01	20 August 2019

The approval of the research study is valid for **one year** from the above approval to expiration date.

Terms of Approval:

- **Annual Reports:** An Annual report must be submitted for approval to avoid termination/suspension of your research.
- **Financial report:** If your study is funded project, details financial report should be submitted with the scientific report.
- **Final Report:** After completion of the study, a final report must be forwarded to the IRB.
- **Retention of original data:** The PI is responsible for the storage and retention of original data pertaining to the project for a minimum of five years.
- **Reporting of adverse events or unanticipated problems:** The PI is responsible to report any serious or unexpected adverse events or unanticipated problems, which could involve a risk to participants or others.
- **Biological samples:** No biological samples to be shipped out of the Kingdom of Saudi Arabia without prior IRB approval.
- **Participant incentives:** No financial compensation or gifts to be given to participants without prior IRB approval.
- **Storage of biological samples:** All biological samples collected for the purpose of this research must be stored in the KAIMRC related repository.

20 AUG 2019

Dr. Abdallah Adlan
Chairman, Institutional Review Board (IRB)
Head, Biomedical Ethics Section - KAIMRC
Ministry of National Guard - Health Affairs

AA/HK/rla

P.O. Box 22490, Riyadh 11426
Tel. 8011111
Telex : 403450 NGRMED SJ
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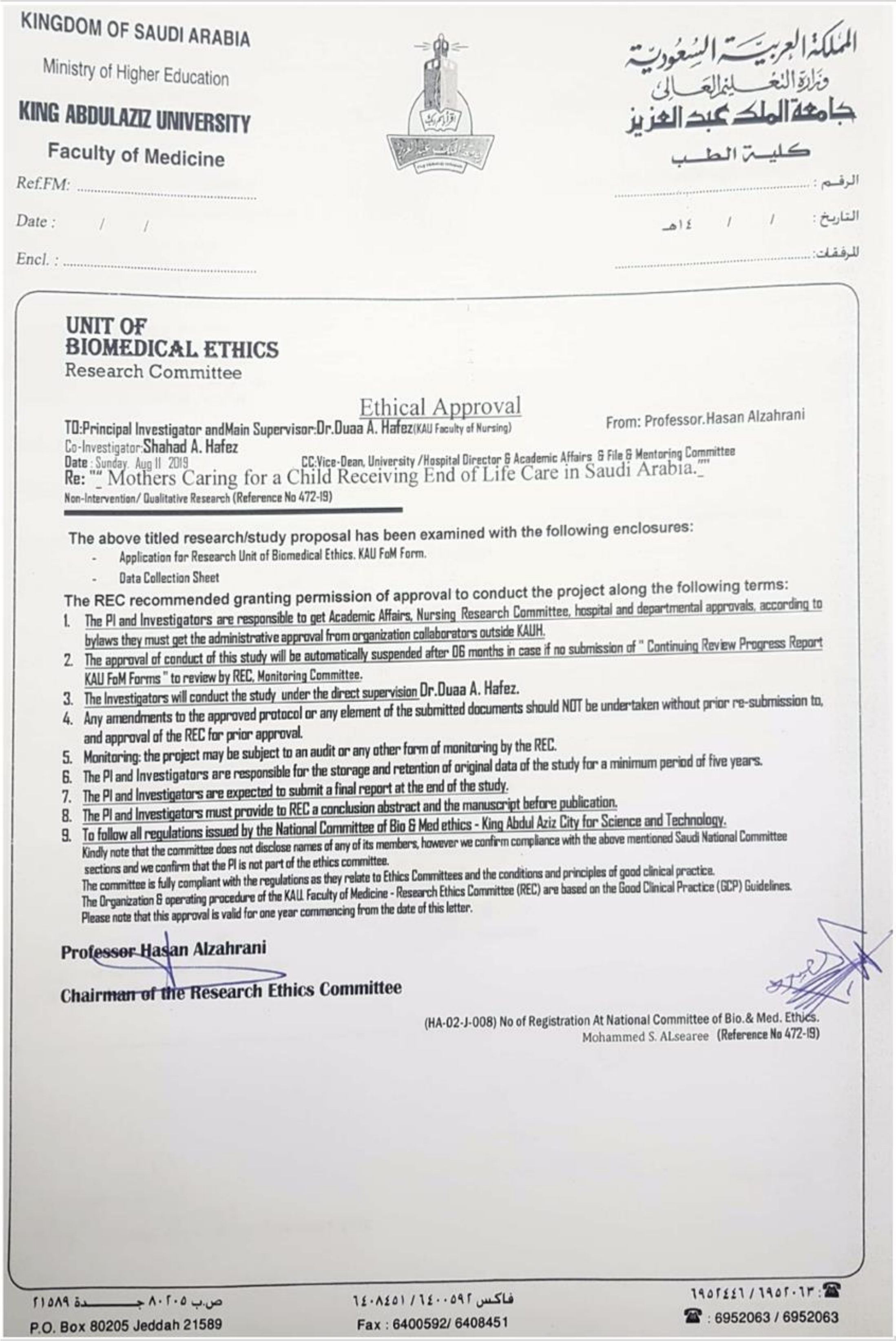
تلكس ٤٠٣٤٥٠

King Abdul Aziz University Hospital



KINGDOM OF SAUDI ARABIA
Ministry of Higher Education
KING ABDULAZIZ UNIVERSITY
Faculty of Medicine

المملكة العربية السعودية
وزارة التعليم العالي
جامعة الملك عبد العزيز
كلية الطب

Ref.FM: ....
Date : / /
Encl. : ....

الرقم : ....
التاريخ : / / ١٤ هـ
المرفقات: ....

UNIT OF
BIOMEDICAL ETHICS
Research Committee

Ethical Approval

TO:Principal Investigator andMain Supervisor:Dr.Duaa A. Hafez(KAU Faculty of Nursing) From: Professor.Hasan Alzahrani
Co-Investigator:**Shahad A. Hafez**
Date : Sunday. Aug 11 2019 CC:Vice-Dean, University /Hospital Director & Academic Affairs & File & Mentoring Committee
Re: ""_ Mothers Caring for a Child Receiving End of Life Care in Saudi Arabia._""
Non-Intervention/ Qualitative Research (Reference No 472-19)

The above titled research/study proposal has been examined with the following enclosures:

- Application for Research Unit of Biomedical Ethics. KAU FoM Form.
- Data Collection Sheet

The REC recommended granting permission of approval to conduct the project along the following terms:

1. The PI and Investigators are responsible to get Academic Affairs, Nursing Research Committee, hospital and departmental approvals, according to bylaws they must get the administrative approval from organization collaborators outside KAUH.
2. The approval of conduct of this study will be automatically suspended after 06 months in case if no submission of " Continuing Review Progress Report KAU FoM Forms " to review by REC, Monitoring Committee.
3. The Investigators will conduct the study under the direct supervision Dr.Duaa A. Hafez.
4. Any amendments to the approved protocol or any element of the submitted documents should NOT be undertaken without prior re-submission to, and approval of the REC for prior approval.
5. Monitoring: the project may be subject to an audit or any other form of monitoring by the REC.
6. The PI and Investigators are responsible for the storage and retention of original data of the study for a minimum period of five years.
7. The PI and Investigators are expected to submit a final report at the end of the study.
8. The PI and Investigators must provide to REC a conclusion abstract and the manuscript before publication.
9. To follow all regulations issued by the National Committee of Bio & Med ethics - King Abdul Aziz City for Science and Technology.

Kindly note that the committee does not disclose names of any of its members, however we confirm compliance with the above mentioned Saudi National Committee sections and we confirm that the PI is not part of the ethics committee.
The committee is fully compliant with the regulations as they relate to Ethics Committees and the conditions and principles of good clinical practice.
The Organization & operating procedure of the KAU. Faculty of Medicine - Research Ethics Committee (REC) are based on the Good Clinical Practice (GCP) Guidelines.
Please note that this approval is valid for one year commencing from the date of this letter.

Professor Hasan Alzahrani

Chairman of the Research Ethics Committee

(HA-02-J-008) No of Registration At National Committee of Bio.& Med. Ethics.
Mohammed S. ALsearee (Reference No 472-19)

ص.ب ٨٠٢٠٥ جـــدة ٢١٥٨٩
P.O. Box 80205 Jeddah 21589

فاكس ٦٤٠٠٥٩٢ / ٦٤٠٨٤٥١
Fax : 6400592/ 6408451

☎: ٦٩٥٢٠٦٣ / ٦٩٥٢٤٤٦
☎ : 6952063 / 6952063

Participant Informed Consent

UNIVERSITY of WISCONSIN
UWMILWAUKEE

Informed Consent for Research Participation
IRB #: 19.A.333
IRB Approval Date: August 8.2019

Study title	Mothers Caring for a Child in a Critical Condition in Saudi Arabia
Researcher	Shahad Hafez MPA, RN, BSN College of Nursing at the University of Wisconsin-Milwaukee Julia Snethen PhD, RN, FAAN, College of Nursing at the University of Wisconsin-Milwaukee

We're inviting you to participate in a research study. Participation is completely voluntary. If you agree to participate now, you can always change your mind later. There are no negative consequences, whatever you decide.

What is the purpose of this study?

We want to learn about your experience caring for your child in a critical condition, and how it affects you psychologically, physically, socially, and financially.

What will I do?

I will be interviewing you individually for almost one hour, depending on how much information you would like to share. The interview will be about your experience caring for your child in a critical condition. The questions will be about the story of your child's diagnosis, the decisions you had to make on behalf of your child about his/her medical care, and the sources of support you have or need during this time.

Risks

Possible risks	**How we're minimizing these risks**
Some questions may be personal or upsetting	• You can take your time responding to questions. • You have the right to express your emotions, for example crying. • You can end the interview at any time. • You can refuse to answer any question they are not comfortable answering. • You can ask for a break during the interview (about five to 15 minutes) • There are no consequences for stopping/ ending the interview, participation is voluntarily. • If you want, I can direct you to professional help after the interview if needed by a psychologist or social worker at the hospital, home healthcare department,

	community health center, or a religious person for comfort - I might provide emotional support for you through physical contact (touch therapy). For example, hold your hand, tap/you're your shoulder, or give you a hug if you are comfortable with physical contact. - Water, coffee, dates, and tissues will be available.
Breach of confidentiality (your data being seen by someone who shouldn't have access to it)	- All identifying information is removed and replaced with a study ID. - We'll remove all identifiers after completing the analysis. - We'll store all electronic data on a password-protected, encrypted computer. - We'll store all paper data in a locked filing cabinet in a locked office. - We'll keep your identifying information separate from your research data, but we'll be able to link it to you by using a study ID. We will destroy this link after we finish collecting and analyzing the data.

There may be risks we don't know about yet. Throughout the study, we'll tell you if we learn anything that might affect your decision to participate.

Other Study Information

Possible benefits	There are no direct benefits, however: - Chance to express your feelings and emotions while caring for your child in a critical condition - Provide support needed by families going through similar experiences in the future
Estimated number of participants	30-50 participants
How long will it take?	Estimated interview time is 1 hour depending on how much information you would like to share.
Costs	You'll pay for your own transportation
Compensation	- 50 Saudi Riyals gift card. - You will receive the gift card even if you did not complete the interview or did not answer all the questions. - If you decide to withdraw from the study before conducting the interview, you will not receive the gift card and your/ the male guardian consent form will be discarded.
Future research	De-identified (all identifying information removed after the interview, such as your name, your child's name, and father's name and phone numbers) and study numbers will be used. The Arabic and English interview transcripts will be shared with

	other researchers. You won't be told specific details about these future research studies.
Recordings	We will audio record your interview. The recordings will be used for transcription. The Arabic and English transcripts will be used in future research. The recording is necessary to this research. If you do not want to be recorded, you should not be in this study.
Medical records	Demographic data regarding the child will be obtained through the medical records (child's age, diagnosis, and prognosis).
Funding source	Sigma Theta Tau International

What if I am harmed because I was in this study?

If you're harmed from being in this study, let us know. If it's an emergency, get help from 911 or your doctor right away and tell us afterward. We can help you find resources if you need psychological help. You or your insurance will have to pay for all costs of any treatment you need.

Confidentiality and Data Security

The data collected will de-identified using a study ID. Your name will be linked to the study ID but it will be stored separately from their interview responses.

Where will data be stored?	The audio recordings and transcribed documents will be stored electronically in a de-identified form on myself and my major professor's encrypted hard drives.
How long will it be kept?	The recordings will be destroyed after 5 years, and transcripts after 10 years.

Who can see my data?	**Why?**	**Type of data**
The researchers	To conduct the study and analyze the data	Audio recordings and transcribed documents will be stored electronically in a de-identified form using a study ID
The IRB (Institutional Review Board) at UWM The Office for Human Research Protections (OHRP) or other federal agencies	To ensure we're following laws and ethical guidelines	Audio recordings and transcribed documents will be stored electronically in a de-identified form using a study ID
Anyone (public)	Share the findings in publications or presentations	Arabic and English transcripts • De-identified (no names, birthdate, address, etc.) • If we quote you, we'll use a pseudonym (fake name)

Translator	Translate the Arabic transcripts into English	Arabic transcripts • De-identified (no names, birthdate, address, etc.)

Contact information:

For questions about the research	Shahad Hafez	+966 504608809/ sahafez@uwm.edu
For questions about your rights as a research participant	IRB (Institutional Review Board; provides ethics oversight) (English speakers)	011 414-229-3173/ irbinfo@uwm.edu
	Saudi Arabian Ministry of Health (Arabic and English speakers)	012 6347334 research-jeddah@moh.gov.sa

Signatures

If you have had all your questions answered and would like to participate in this study, sign on the lines below. Remember, your participation is completely voluntary, and you're free to withdraw from the study at any time.

____
Name of Participant (print)

____ __________________
Signature of Participant
Date

____
Name of Researcher obtaining consent (print)

____ __________________
Signature of Researcher obtaining consent
Date