

Mothers Caring for a Child at End of Life: A Systematic Review

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ABSTRACT

Background: A 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 End of Life (EOL), the mother's life is affected negatively. The mother is affected mentally, psychologically, and physically because her child is dying.

Purpose: Explore the recent studies that focused on experiences of mothers caring for a child receiving End of Life Care (EOLC) at home or a healthcare facility.

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

The included studies were published within the past five years, studies about EOL/ EOLC, hospice care, pediatric care, quantitative, qualitative, and mixed methods studies. 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. Parents were included in most studies. However, the number of mothers exceeded the number of fathers. Some researchers mentioned that there was no difference 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 has been studied in other countries. Based on this systematic review, more studies are needed related to children at EOL in Saudi Arabia.

Keywords: End Of Life, End Of Life Care, Mothers, Children, Parents.

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BACKGROUND

Throughout the world, researchers have explored parents, and particularly mothers', experiences with their children who are at end of life (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). Mother with children 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 end of life care (EOLC). Therefore, this systematic review aims to explore recent studies that focus on the experiences of mothers caring for a child receiving EOLC.

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 disease's irreversible stage 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 their children's health and illness (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 changes (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. The 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 their siblings' presence (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 by their 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 mothers, 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). For example, Youngblut et al. (2017) reported that the mother's pain, distress, and grief are greater than that experienced by the father's. Mothers adapting to their child being at EOL was found to be more difficult than fathers' adaptation (Youngblut et al., 2017). After a child's death, 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 losing 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 aspects included mothers becoming more forgiving, empathetic, and hopeful after their child's death (Laasko et al., 2002).

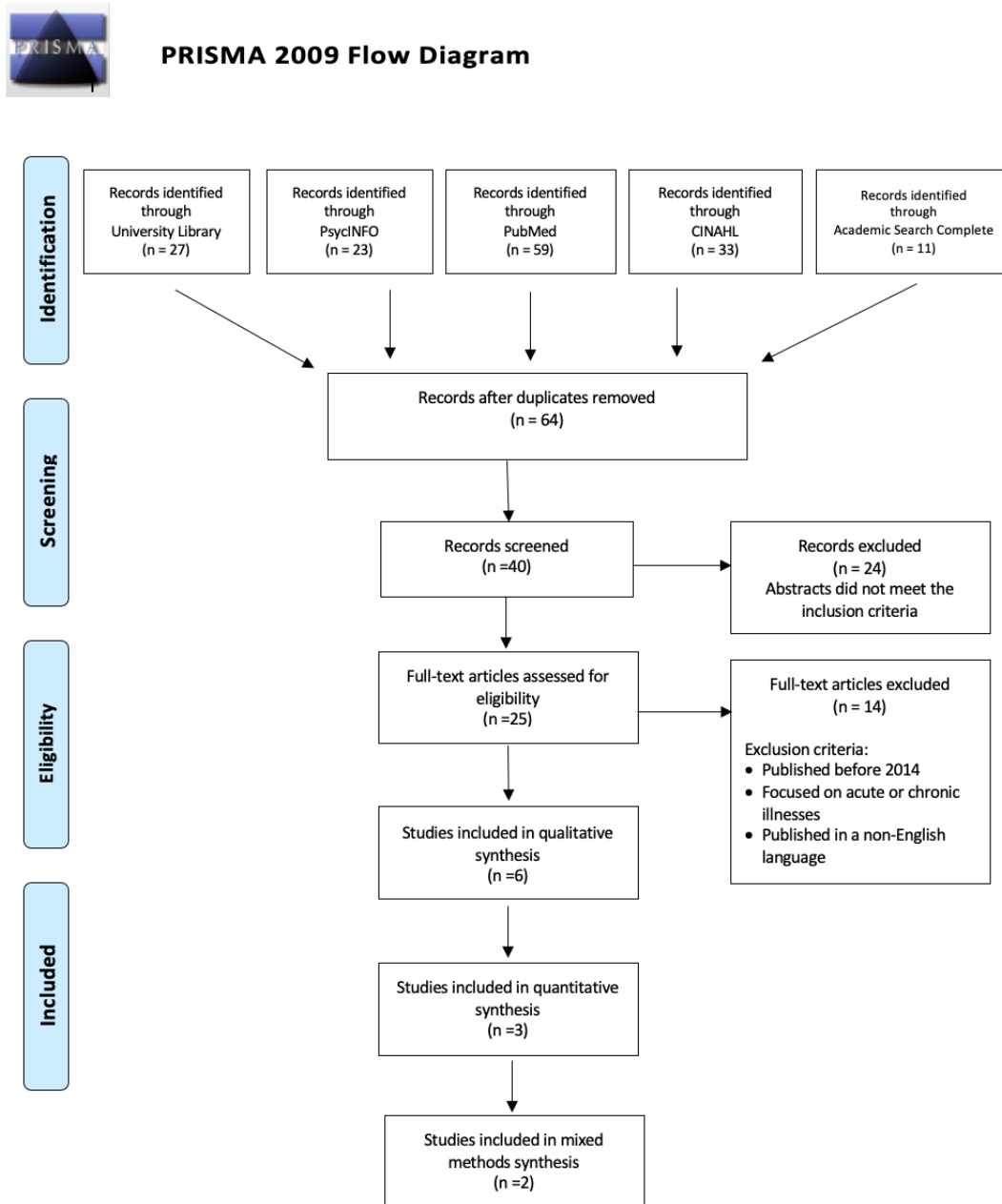
OBJECTIVE

The objective of this systematic review was to explore recent studies that focus on the 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.

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 those, 89 studies were duplicates, and most studies were excluded due to not meeting the inclusion criteria. The total number of articles screened was 40, and 11 studies were accepted (see Figure 1). The time frame of the recent five years was chosen as historically, studies conducted on EOL and EOLC have focused on perceptions of healthcare professionals and adult patients. Recent studies, however, have started to explore the perceptions of family members and children at EOL.

Figure 1. PRISMA Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

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

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 study’s strengths and limitations. Therefore, each study’s main concepts 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.

Table 1. 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 oncologica l disease recurrence phase of her child’s treatment	<ul style="list-style-type: none"> • 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: <ul style="list-style-type: none"> • Facing the impond- erable and seeking to make sense of the experience • Facing losses on the relational sphere • Experiencin g the relapse of the son with the perspective of death 	Strengths: <ul style="list-style-type: none"> • Highlighted the importance of empathy and sympathy between HCPs and mother Limitations: <ul style="list-style-type: none"> • One participant
2.Arutyuny an, Odetola, Swieringa, & Niedner 2018 United States	<ul style="list-style-type: none"> • Understa nd whether parents of children admitted to PICU would want their physicia 	<ul style="list-style-type: none"> • Observatio nal cross- sectional study • 162 parents/ guardians of children admitted for more than 48 	Modified survey about spiritual well-being Univariate and bivariate analyses were performed	<ul style="list-style-type: none"> • 48% of parents of wanted their physicians to ask about their religious or spiritual beliefs • 78% of parents had 	Strengths: <ul style="list-style-type: none"> • 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
	ns to ask about their religious or spiritual beliefs <ul style="list-style-type: none"> • Explore whether the child's underlying illness or parental characteristics influence the responses to our primary objective 	hours to the PICU		a strong preference regarding prayer <ul style="list-style-type: none"> • 33% felt comfortable discussing their spiritual beliefs with various providers 	spiritual history Limitations: <ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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 • 12 physicians and 20 nurses who 	<ul style="list-style-type: none"> • Participant observation • Semi-structured interviews with mothers, physicians, and nurses Constant comparison	<ul style="list-style-type: none"> • 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 impact on the child) 	Strengths: <ul style="list-style-type: none"> • Large sample number • Participants included mothers, physicians, and nurses • Data was collected through observation and interviews • Culture was addressed Limitations: <ul style="list-style-type: none"> • The observation

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
		were involved in the care of the children		<ul style="list-style-type: none"> • Mothers requested details about their children’s condition for second opinion, online search, or asking other parents in the same situation 	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Mixed-method study design (cross-sectional) 29 mothers, 16 fathers representing 31 infants	<ul style="list-style-type: none"> • Demographic data from infants’ medical records • Individual in-depth interviews or completing a survey Content analysis to develop themes (qualitative) <ul style="list-style-type: none"> • Independent-sample <i>t</i> tests and X^2 analyses 	Themes identified: <ul style="list-style-type: none"> • Parents were partners in care • Communication with the healthcare team • Relationships with staff • Bereavement support 	Strengths: <ul style="list-style-type: none"> • Provided perspectives of mother and fathers • Developed recommendations based on participants’ experiences Limitations: <ul style="list-style-type: none"> • Limited number of fathers in the study compared to mothers • Retrospective reports could have been subject to bias • Limited sample diversity

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
5. De Vos et al. 2015 Netherlands	<ul style="list-style-type: none"> • How do physicians and parents communicate about decisions to withhold or withdraw LST? • To what extent do parents share in the decision-making process? 	<ul style="list-style-type: none"> • 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 	<p>Conversations between researchers and participants were audio recorded, ranging from 1 to 8 meetings per participant</p> <ul style="list-style-type: none"> • Coding schemes were developed • Then the codes were qualitatively and quantitatively analyzed • Then the analyzed data/ results were discussed <p>is several discussion rounds with all researchers</p>	<p>Physicians and parents communicate about:</p> <ul style="list-style-type: none"> • 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 <p>The extent of communication includes:</p> <ul style="list-style-type: none"> • Asking about the preferred role in the decision-making process • Asking about the values and preferences regarding continuation 	<p>Strengths:</p> <ul style="list-style-type: none"> • Themes were clearly identified • Examples were provided <p>Limitations:</p> <ul style="list-style-type: none"> • 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
				n or discontinua tion • 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/ palliative care at home, to assess if new strengths emerge and if SG serves as an effective interventio n	<ul style="list-style-type: none"> • Descriptive study conducted using a qualitative grounded theory design • Quantitative component using PSRS before and after the interview (constant comparative analysis) • Total of 8 participants (parents) who are caring for their children at home 	<ul style="list-style-type: none"> • Parents were recruited from Trinity Kids Care in California • One-on-one in-depth interviews • PSRS surveys before and after the interviews Constant comparative analysis	The attributes of strength were: <ul style="list-style-type: none"> • Handling emotions • Solving problems • Spirituality • Finding meaning • Taking care of self • Taking care of family • Taking care of others in the community • Positive attitude • Resourcefulness • Sense of hardiness • Being with nature 	Strengths: <ul style="list-style-type: none"> • Participants were comfortably interviewed in their homes • The SG was found to be an effective intervention • Themes were thoroughly discussed Limitations: <ul style="list-style-type: none"> • Small sample size • No variety between participants
7. Katooa, Shahwan- Akl, Reece & Jones	Describe and explore the coping patterns of	<ul style="list-style-type: none"> • Quantitative descriptive design 	Survey questionnaires <ul style="list-style-type: none"> • QOL scale 	Mothers coped by finding support from:	Strengths: <ul style="list-style-type: none"> • Both parents were

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
2015 Saudi Arabia	Saudi Arabian parents and in particular the mothers as primary caregivers of chronically ill children	<ul style="list-style-type: none"> • Total of 122 parents with chronically ill children 	<ul style="list-style-type: none"> • GSC scale • SSQ SPSS	<ul style="list-style-type: none"> • Family • Friends • Government association • The healthcare facility (hospital) 	included in the study <ul style="list-style-type: none"> • Participants were from different hospitals Limitations: <ul style="list-style-type: none"> • Small sample size • Number of fathers included in the study was minimal • Participants were from one city in Saudi Arabia (Jeddah)
8. Lou, Mu, Wong & Mao 2015 Taiwan	Explore the essence of the maternal experience s related to the anticipatory loss of families of a child with advanced cancer	<ul style="list-style-type: none"> • 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 <ul style="list-style-type: none"> • Losing hope of cure • Encountering death • Establishing a protective role toward the child • Intertwining the chaos and strengths of family life 	Strengths: <ul style="list-style-type: none"> • Mothers with different years of struggle were included • Culture and religion were discussed Limitations: <ul style="list-style-type: none"> • Participants were limited to the members of CBTA-Taiwan • The data collected

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
				<ul style="list-style-type: none"> • Contending against death 	was retrospective and relied on participants' memories (within 3 years)
9. Ohs, Trees & Gibson 2015 United States	<ul style="list-style-type: none"> • What are the competing discourses about EOL decisions constructed by families making medical decisions for a family member at the EOL? • How do families make sense of contradictory discourses? 	<ul style="list-style-type: none"> • 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 included in the study 	<ul style="list-style-type: none"> • In-depth interviews • Prior to the interview, a questionnaire was provided to gather background information • Contrapuntal analysis • The Relational Dialectics Theory (RDT) was used to analyze the discourses around the struggle between holding on and letting go 	<ul style="list-style-type: none"> • All participants reported the struggle of letting go of a family member • Family interaction was important to manage the decision of 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 emotionalit 	Strengths: <ul style="list-style-type: none"> • Participants had different experiences • Valuable insight on families' decision-making process • HCPs roles were mentioned Limitations: <ul style="list-style-type: none"> • The majority of participants were females • Participants constructed accounts of good decisions, which limits the transferability of the findings

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
				y versus rationality	
10. Popejoy 2015 England	Understand the lived experience of parents throughout the process of making and revising EOLC decisions for their child	<ul style="list-style-type: none"> • Qualitative exploratory design • Three mothers who had been bereaved 	Semi-structured interview Interpretive phenomenological analysis	Themes and sub-themes identified: <ul style="list-style-type: none"> • Making decisions • Timing of discussions • Decision makers • Values • Revising and implementing EOLC plans • Barriers and facilitators to implementation • Revisiting plans 	Strengths: <ul style="list-style-type: none"> • Individual interviews were conducted • Consultants and child bereavement team were involved in the study for support and recruitment plans Limitations: <ul style="list-style-type: none"> • Small sample size • Participants were from one hospital
11. Zimmermann et al. 2016 Switzerland	<ul style="list-style-type: none"> • Describe specific parental experiences in relation to the underlying medical condition causing the child's death • Explore differences 	<ul style="list-style-type: none"> • Cross-sectional design • Total of 124 participants (parents) who had children who had died due to a cardiac, neurological, oncological condition, or during the neonatal period in the 	<ul style="list-style-type: none"> • Cross-sectional questionnaire survey was distributed to parents • Recruitment done between July 2013 and March 2014 at 8 children's 	Parents' experiences included: <ul style="list-style-type: none"> • Support of the family • Communication with physicians • Shared decision making • Relief of pain and other symptoms • Continuity and 	Strengths: <ul style="list-style-type: none"> • Positive and negative experiences were discussed • Several centers were used for recruitment Limitations: <ul style="list-style-type: none"> • Small sample

Author Year Country	Purpose/ Question	Design Sample	Data Collection & Analysis	Findings	Strengths & Limitations
	nces in parental perspectives between 4 common medical conditions responsible for childhood death (cardiology, neonatology, neurology oncology)	years 2011-2012	hospitals in Switzerland Descriptive statistics	coordination of care • Bereavement support Positive and negative experiences and quality of life	<ul style="list-style-type: none"> • The data collected was retrospective and relied on participants' memories • Findings could be biased based on parents' favorable experiences

Table 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	Health 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

RESULTS

Four themes related to parents and family members who had an experience with a child at EOL, emerged from the thematic analysis. 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 for making 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, the 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 available EOLC options (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 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 experiences 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 the spiritual beliefs that supported them while 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 Tables 1 and 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 bias and enhance the trustworthiness of qualitative research. Furthermore, most of the interview data in the studies were analyzed using a constant comparative method. A single study used Colaizzi's methodology 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). A major limitation of these studies was the small sample size (ranging from 83 to 124) which limited generalizability of the findings to the general population of mothers. (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). The data was then 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). For example, 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 the 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' 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 available EOLC options (Ohs et al., 2015; Popejoy, 2015; Zimmermann et al., 2016). Ongoing communication 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 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 make EOLC decisions for their dying child (De Vos et al., 2015) because parents felt the strength and comfort from the support 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 their child's death, some even starting to grieve 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 losing 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 tough for the parents to let go and say goodbye to their child (Ohs et al., 2015).

Limitations

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. The studies chosen for this systematic review were limited to those published between 2015-2019. Including studies prior to 2015 might have provided additional insights, however the aim was to report the most recent perspectives on EOL.

Gaps in the Literature/ Science

This systematic review identified the most recent studies conducted about EOL globally. There was a specific focus on recent studies and those conducted in Saudi Arabia. because a study was 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 reported 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), who often must 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 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 (Alifita, n.d.). The mother's decision is considered if the father's decision does not align with the physician's judgment (Alifita, 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.

CONCLUSION

Based on this systematic review, more studies are needed relating to children at EOL in Saudi Arabia. Studies have been conducted globally; but, the number of studies conducted

in Saudi Arabia is limited. In Saudi Arabia, the studies were mostly quantitative, focused on healthcare professionals, adult patients, and religious/ Islamic perspectives. There is limited information about children and their family members' experiences at EOL/ EOLC in Saudi Arabia as presented in other countries. This systematic review aimed to support the importance of a study to explore mothers' experiences caring for a child receiving EOL care in Saudi Arabia. Mothers' experiences with their children at EOL can provide insight into the EOLC process in Saudi Arabia. The finding present EOLC experience of mothers from different perspectives and highlight the psychological, physical, social, and financial toll of EOL faced by families. The findings also highlight the necessity of foundational knowledge about the understudied population of Saudi Arabian mothers caring for their dying children in for future research.

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