Exploring Bereavement in Pediatric Nursing: A Systematic Review

Konstantinos Athanasiou, RN, MSc(c), MSc in “Wound Care and Treatment”, Department of Nursing, Faculty of Health & Caring Sciences, University of West Attica, Athens, Greece

George Vasilopoulos, PhD
Associate Professor, Department of Nursing, Faculty of Health & Caring Sciences, University of West Attica, Athens, Greece

Martha Kelesi - Stavropoulou, PhD
Professor, Department of Nursing, Faculty of Health & Caring Sciences, University of West Attica, Athens, Greece

Maria Pilikandrioti, PhD
Professor, Department of Nursing, Faculty of Health & Caring Sciences, University of West Attica, Athens, Greece

Evangelos Dousis, PhD
Associate Professor, Department of Nursing, Faculty of Health and Care Sciences, University of West Attica, Athens, Greece

Correspondence: Evangelos Dousis, Koumoundourou 130, Piraeus, 18544, Athens, Greece. E-mail: edousis@uniwa.gr

Name and the postal address of the place where the work was carried out: MSc “Wound Care and Treatment”, Department of Nursing, Faculty of Health & Caring Sciences, University of West Attica, Athens, Greece, trauma@uniwa.gr

Abstract

Introduction: The management of parent’s and family’s bereavement, before, during and after the death of a child is a great challenge for health care professionals (HCPs).

Aim: The purpose of this study was to investigate bereavement in pediatric nursing before, during and after the death of a child.

Method: A systematic literature review was performed in PubMed, Scopus, and Open Archives for the years 2013-2023. PRISMA methodology was followed for selection of the articles and PICOS method for the inclusion criteria of an article in the study.

Results: Therapeutic relationship between HCPs and parents/families is reported as moderate to high. Parents mention several factors that negatively affect this relationship, such as lack of strategic assessment for the needs of the bereaved, lack of bereavement care provision usually after death and non-systematicbereavement care provision. Parents agree that follow-up parent meetings after child’s death are helpful and physicians seem more comfortable discussing child’s death. Parents report several needs related to grief management, caregiving, relationships with HCPs and decision-making.

Conclusions: Effective communication among parents and HCPs, meaningful contact between HCPs, and the care and support of parents before and after the death of the child are done by HCPs. It is important for the farewell process parents learn how to take care of their child, essentially re-creating the parenting role, with HCPs directing the entire process of caring. After death, supportive relationship lets parents grieve, trying not to remain in prolonged grief, empowering them emotionally to create outlets, moving on in their lives with respect and dignity.

Keywords: Bereavement, death, children, parents, families, health care professionals, hospital services.

Introduction

The loss of a child, regardless of the cause, is a traumatic and devastating experience for parents. Children are expected to outlive their parents; the disruption in this natural order can destroy parent’s hopes and dreams for the future, as well as a radical change in their roles (October et al., 2018). The intensity of parental grief is believed to be due to the close and enduring relationships parents have with their children (October et al., 2018), that’s why
parental grieving is among the most intense, painful, traumatic and enduring forms of bereavement (Polita et al., 2020). Furthermore, during bereavement, grief reactions can cause deterioration in parent’s health, affecting physical, existential or spiritual, psychological, social, cognitive and behavioral domains (Polita et al., 2020; Weaver et al., 2023). The risk of morbidity and mortality is increased compared with adults, who experienced loss of parents or spouses (Polita et al., 2020), including higher rates of acute and post-traumatic distress and major depression (Helton et al., 2022).

Numbers of neonatal deaths fell from 5 million in 1990 to 2.4 million in 2020, due to rising living standards, worldwide (WHO, 2022). In USA, Center for Disease Control and Prevention (CDC) reports that in 2021 3.816 children aged 1-4 and 5.975 children aged 5-14 died with a percentage of 25 and 14.3 deaths/100.000 population respectively, due to various causes such as traffic accidents, birth defects, cancer, suicide and homicides (CDC, 2023).

Because of the psychological, social and physical health impacts of parental bereavement, several different interventions, such as pharmacotherapy, psychotherapy and counseling have been studied to support bereaved individuals (McNeil et al., 2020). World Health Organization (WHO) defines palliative care as the prevention and relief of suffering of adult and pediatric patients and their families facing the problems associated with life-threatening illness (WHO, 2018). Provision of high-quality bereavement care creates a culture of compassion and can improve the patient and family experience. Bereavement services have the potential to impact the metrics of healthcare systems by improving patient outcomes and satisfaction (Woo & Catlin, 2019).

Aim of the study was to investigate bereavement before, during and after the death of a child.

Methods

Study design: A systematic literature review was conducted from 2013–2023.

Search strategy: PubMed, Scopus bibliographic databases were searched for relevant studies. The keyword used were: (Bereavement OR Grief) AND (Children OR Paediatric) AND (Parents OR Families) AND (Health care professionals) AND (Hospital services). Open Archives bibliographic database was searched for Greek literature studies with the above keywords in Greek language. Inclusion criteria of articles are presented in Table 1. For the purposes if the study, bereavement refers to the experience of having lost someone very close (Pop-Jordanova et al., 2021).

Article selection process: PRISMA methodology was applied for selection of articles that includes identification, screening, eligibility and included (Liberati et al., 2009) (Figure 1).

Identification: The databases yielded a total of 2401 articles (Figure 1).

Screening: 605 articles involving duplicate entries were rejected and 1796 articles were assessed (Table 1).

Eligibility: After title screening, 1489 articles were rejected and the title of 307 articles was assessed. 203 articles were rejected after evaluation of the abstract, 51 articles were rejected after evaluation of the text, and 42 articles were rejected after evaluation with the PICOS process (Table 1).

Included: After the thematic analysis of the full text of the articles, 11 articles were included in the study (Figure 1). The authors evaluated the quality of the articles using the PRISMA methodology (Liberati et al., 2009). They used the “Checklist of items to include when reporting systematic reviews” (7 sections, 27 items) to evaluate the quality of the articles (Liberati et al., 2009). The 11 articles included in the study were considered to be of high (or moderate to high) quality and related to the aim of this systematic review.

Data Analysis: The thematic analysis of the studies included 3 stages: preparation, organizing, reporting. In the preparation stage, the results of the full text of the articles were read several times in order to fully understand their meaning and conclusions drawn. Following the content of each article, bereavement before, during and after the death of a child was evaluated and relevant information was highlighted for the second stage of data analysis. When organizing the data, we organized the content of the text using codes, creating categories and grouping the codes under headings. In the final step, we reported the results of bereavement before, during and after the death of a child. For each article, data was extracted from a pre-configured spreadsheet. Data fields include first author, year of publication, country, aim, sample/setting, methods, main inclusion
criteria, main results. The findings of the studies included were summarized in Table 2 and 3.

Results

Characteristics of studies

The subject of this study were 11 articles, 4 were quantitative studies and the remaining 7 were qualitative studies. Results of published studies on bereavement management after the death of a child are summarized in Tables 2 (quantitative studies) and 3 (qualitative studies).

Articles of present study concern the investigation of therapeutic alliance between physicians and parents (n = 1), the application of Psychological Standards of Care (n = 1), the benefits of follow-up meetings (n = 1), the communication among health care professionals (HCPs) about the death of a child (n = 1), the role of general practitioner in palliative care of a child with cancer (n = 1), the impact of cultural diversity on how neonatal and pediatric intensive care nurses care for Muslim families before & after the death of a child (n = 1), interactions & social processes among parents & HCPs when a child dies in Pediatric Intensive Care Unit (PICU) (n = 1), early and ongoing relationships between parents & health care providers when a child dies in PICU (n = 1), the bereavement program for parents who have experienced a loss of a child (n = 1), experiences of parents of infants at the end of life in the Neonatal Intensive Care Unit (NICU) (n = 1), newborn end-of-life care & upcoming palliative care by HCPs (n = 1), the spiritual needs of families at the end of their newborn’s life in NICU (n = 1).

Evaluation of quality of studies

Methodological quality of the research designs was high. All studies (n = 11) were rated with high (or moderate to high) quality. Research questions were clear and data collections method appropriate.

Analysis

Results of 11 studies concerned the investigation of bereavement before and/or during and/or after the death of a child in 380 parents, in 20 people supporting parents and in 344 HCPs and were divided in 2 sections: quantitative and qualitative studies (Tables 2 & 3).

1. Quantitative studies

More specifically, regarding the quantitative studies (Table 2), Suttle et al. investigated the extent of the therapeutic relationship between physicians and bereaved parents during their child's stay in a PICU. Human Connection Scale (HCS) scores were statistically significant (p = 0.025) between black and white parents with trust, caregiving, and honest communication showing the greatest mean difference, concluding that among parents who lost a child in the PICU the therapeutic relationship with physicians is moderate to high (Suttle et al., 2021).

Wiener et al., evaluated of the implementation of Psychosocial Standards of Care in care centers of children with cancer (they recommend maintaining at least one meaningful contact between the health care team and bereaved parents to identify families at risk of negative psychosocial outcomes and to support bereavement), as well as the obstacles to their implementation. Sixty five percent of the participants reported that there was no assessment strategy of the oncology group for the needs of bereavement, 59% that their center often or always provides bereavement care after the death of a child, 28% that their center does not have systematic contact with bereaved families after the death of the child, and 70% that the HCPs who comes in contact with the bereaved parent knew the family personally before the death of the child and is usually the social worker of the center (76%). The length of grief care was variable and is often described as “inconsistent”. Few centers (5%) use a bereavement screening or assessment tool. Statistically significant was the correlation between facilities with a special pediatric palliative care program and longer bereavement care (p = 0.042) (Wiener et al., 2018).

Meert et al., evaluated the perceived benefits of conducting follow-up meetings after the death of a child in a PICU according to the Collaborative Pediatric Critical Care Research Network (CPCCRN) framework. The results showed that PICU physicians performed 12 out of 20 behaviors according to the framework in ≥89% of the encounters. The average quality score was high for 17 out of 20 behaviors. Overall adherence to the framework reached 79% and the overall quality of behaviors was M±SD: 4.3 ± 0.2. Seventy five percent of PICU physicians agreed or strongly agreed that they complied with the follow-up meeting framework and 92% that the
framework was manageable, 92% agreed or strongly agreed that the meeting was beneficial for parents, 89% that the meeting was beneficial for them. Ninety two percent of parents agreed or strongly agreed that the meeting was useful for parents and 85% that the meeting was beneficial for them (Meert et al., 2014).

Harrison et al., was investigated communication among HCPs about death in children. Health care professionals who felt comfortable discussing end-of-life care options with colleagues felt more comfortable: initiating a discussion about the impending death of a child with his or her family (r = 0.42), discussing terminal care options with a family (r = 0.58), discussing death with families with different cultural backgrounds (r = 0.51), guiding parents in appropriate discussions about death with their children (r = 0.43), identifying and seeking advice from a professional standard about coping concerns (r = 0.40), or interacting with the family after the death of a child (r = 0.51). Physicians were more comfortable discussing death and were more likely to initiate a discussion about the impending death of a child (F =13.07, p = 0.07). Practices of counseling in HCPs are associated with a higher level of comfort in initiating a discussion of child death (Harrison et al., 2014).

2. Qualitative studies

Regarding qualitative studies (Table 3), Neilson et al., investigated the role of the general practitioner in the palliative care of a child with cancer and the support of family bereavement in the impending death. The analysis showed 4 categories of issues related to bereavement support: a) timing of contact, b) mode of contact, c) contact enablers and inhibitors and d) physician training and resources (Neilson et al., 2020).

Al Mutair et al., explored the impact and influence of cultural diversity from the care of Muslim families before and after the death of infants or children by PICU nurses. The analysis highlighted 5 issues: a) respect for diversity, b) communication, c) care of the family, d) caring of the infant/child before and after death and e) care of self (Al Mutair et al., 2019). Butler et al., investigated the interactions and social processes between parents and HCPs when a child died in PICU and their impact on the overall experience of the parents. Results showed that relationships between parents and HCPs are dynamic and complex. The basic process that takes place is a transitional partnership relationship, which exists in 3 phases: a) "welcoming expertise", b) "becoming a team" and c) "gradually disengaging" (Butler et al., 2018a). Also, Butler et al., explored early and ongoing relationships between parents and HCPs of children who died in PICUs. The results show 3 phases: a) saying goodbye, b) going home process and c) seeking supports (Butler et al., 2018b).

Berrett-Abebe et al., explored a bereavement care program for parents who have experienced loss of a child to cancer. The analysis revealed 4 main categories of issues: a) live experienced of grief, b) importance of relationships with the hospital-based team, c) bereavement support from hospital-based providers and d) extension of bereavement care (Berrett-Abebe et al., 2017). Currie et al., investigated the experiences of parents in NICUs, end-of-life infant care, and palliative care by HCPs. Parents' experiences from the NICU highlighted three categories: a) challenges in raising children in the NICU, b) decision-making challenges in the NICU and c) parent support (Currie et al., 2016). In the last study Sadeghi et al., explored the spiritual needs of families whose infant died in NICUs, from the perspective of both families and HCPs. The results resulted in 3 categories of spiritual needs: a) spiritual belief in a supernatural power, b) need for comfort of the infant's soul and c) human dignity for the newborn (Sadeghi et al., 2016).

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<tr>
<th>Table 1: PICOS and criteria for including articles in the study</th>
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<tr>
<td><strong>PICOS Questions:</strong></td>
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<tr>
<td>1. How do bereaved parents or/and HCPs manage bereavement before, during and after the death of a child?</td>
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<tr>
<td>2. Which factors prevent and which facilitate bereavement management before, during and after the death of a child?</td>
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</table>
3. What are the needs of parents/families about bereavement management before, during and after the death of a child?

**Population (P):** parents or/and family or/and HCPs, before, during or after children’s death.

**Intervention (I):** with or without intervention.

**Comparator (C):** with or without comparison.

**Outcomes (O):** Qualitative, Quantitative or mixed studies on bereavement before, during and after the death of a child, effect of intervention on the quality of life of parents and/or family and/or HCPs, evaluation of implementation of intervention.

**Setting (S):** Hospital, community.

**Inclusion criteria**

- Quantitative, Qualitative or mixed studies.
- Published from 2013-2023.
- Exploring bereavement before, during and after the death of a child.
- Published in English or Greek language.
- Published in peer reviewed journals.

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**Figure 1.** Article selection process.

1. **Identification**
   - Articles from PubMed, Scopus, Open Archives (n = 2401)

2. **Screening**
   - Articles after removal of duplicates (n = 1796)

3. **Eligibility**
   - Articles reviewed (n = 1796)
   - Rejected articles (n = 1489)
   - Articles reviewed (n = 307)
   - Articles rejected after evaluation of the: Abstract (n = 203) Text (n = 51) PICOS (n = 42)

4. **Included**
   - Total articles included (n = 11)
<table>
<thead>
<tr>
<th>Author, Year, Country, Aim</th>
<th>Methods</th>
<th>Sample</th>
<th>Intervention</th>
<th>Tools</th>
<th>Main Results</th>
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</thead>
<tbody>
<tr>
<td>Suttle et al., 2021, U.S.A. Exploring therapeutic alliance between bereaved parents and health care providers during their child’s pediatric intensive care unit (PICU).</td>
<td>Multicenter observational study.</td>
<td>233 biological parents and/or legal guardians of 157 deceased children.</td>
<td>Human Connection Scale – HCS. Patients’ medical file.</td>
<td>Mean HCS was M ± SD: 51.4 ± 11.1 for all parents, M ± SD: 52.6 ± 9.0 (white) &amp; M ± SD: 47.0 ± 13.7 (black). HCS scores were significantly different (p = 0.025) between black &amp; white parents. HCS items about trust, caring and honest communication showed the greatest mean difference between black &amp; white parents, therapeutic alliance is moderate to high.</td>
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<td>Wiener et al., 2018, U.S.A. Evaluation of implementation of Psychological Standards of Care for centers serving pediatric cancer patients in current healthcare &amp; palliative care practices, as well as barriers to their implementation.</td>
<td>Cross-sectional clinical study.</td>
<td>100 HCPs in pediatric oncology centers.</td>
<td>Psychological Standards of Care. Questionnaire.</td>
<td>Parents reported: a) There was no policy for the oncology team to routinely assess bereavement needs (65%) b) HCPs provided always or often bereavement care after a child’s death (59%) c) There was no systematic contact with bereaved families after the death of the child (28%) d) HCPs, who comes into contact with bereaved parents personally, knew the family before the child’s death &amp; usually is the social worker (70%) e) Length of bereavement care was variable (76%) Few centers (5%) reported using a formal bereavement assessment tool to assess bereavement needs. Physicians (75%) agreed or strongly agreed that they complied with follow-up meeting framework &amp; 92% of them was easy to use it. Ninety two percent of physicians agreed or strongly agreed that meeting was beneficial to parents &amp; 89% that it was beneficial to them. Fifty</td>
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<tr>
<td>Meert et al., 2014, U.S.A. Evaluation of benefits of conducting follow-up meetings after a child’s death in the PICU.</td>
<td>Prospective observational study.</td>
<td>36 follow-up meetings, 54 parents of deceased children, 17 parent support persons, 23 critical care</td>
<td>Follow-up meetings. Questionnaire, Video recorded, Meeting evaluation.</td>
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evaluation meetings were completed by parents, 92% agreed or strongly agreed that they found the meeting useful, 89% that meeting was helpful to others they brought along & 78% that meeting will help them cope with in the future. Forty six evaluation meetings were completed by others HCPs, where 89% agreed or strongly agreed that meeting was beneficial for parents & 85% that meeting was beneficial for them.

Harrison et al., 2014, U.S.A. Understanding communication among HCPs regarding death and dying in pediatrics.
Contemporary comparative study.
45 physicians, 67 nurses, 20 psychosocial clinicians.
Questionnaire.
Physicians were more likely to initiate discussion with regards to a child’s impending death (F = 13.07, p = 0.07).

Table 3: Characteristics of qualitative studies

<table>
<thead>
<tr>
<th>Author, Year, Country, Aim</th>
<th>Methods</th>
<th>Sample</th>
<th>Intervention</th>
<th>Tools</th>
<th>Main Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neilson et al., 2020, U.K.</td>
<td>Qualitative study</td>
<td>11 families (12 bereaved parents) &amp; 18 general practitioners</td>
<td>Digitally recorded semi-structured interviews.</td>
<td>4 categories are related to bereavement support: a) timing of contact, b) mode of contact, c) contact enablers and inhibitors, d) GP training and resources.</td>
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<tr>
<td>Al Mutair et al., 2019, Saudi Arabia</td>
<td>Qualitative study</td>
<td>13 nurses PICU.</td>
<td>Semi-structured interviews.</td>
<td>5 themes emerged: a) respect for diversity, b) communication, c) care of the family, d) caring of the infant/child before &amp; after death e) care of self.</td>
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<tr>
<td>Butler et al., 2018a, Australia.</td>
<td>Qualitative study</td>
<td>26 bereaved parents (18 mothers &amp; 8 fathers) of 18 deceased children.</td>
<td>Semi-structured interviews.</td>
<td>Basic process that takes place after the death of a child is a transitional relationship of companionship, which exists in 3 phases: a) welcoming</td>
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was dying in PICU & impact this had on the overall experience of parents.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Participants</th>
<th>Setting</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Butler et al., 2018b, Australia. Exploring early &amp; ongoing relationships between parents &amp; HCPs when a child dies in PICU.</td>
<td>Qualitative study</td>
<td>26 bereaved parents (18 mothers &amp; 8 fathers) of 18 deceased children.</td>
<td>Semi-structured interviews.</td>
<td>Parents build on the relationships they had developed with their child’s HCPs immediately, not just lingering, after the child’s death. The importance of maintaining these ongoing relationships while the family remains in hospital, allows parents to feel able to continue physical care in post-death period &amp; reduces parental feelings of isolation in the immediate aftermath of the child’s death.</td>
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<td>Berrett-Abebe et al., 2017, U.S.A. Exploring of a bereavement care program in parents who had experienced a loss of a child from cancer.</td>
<td>Qualitative phenomenological study.</td>
<td>8 parents from 6 families.</td>
<td>Focus groups.</td>
<td>Parents report that grieving the loss of a child is different from any other grieving. They indicated the great value of constant communication &amp; connection with HCPs. The parent-HCPs connection is important &amp; helps to externalize traumatic experiences and emotions.</td>
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<tr>
<td>Currie et al., 2016, U.S.A. Exploring parents’ experiences related to their infant NICU hospitalization, end-of-life care &amp; palliative care consultation.</td>
<td>Qualitative study.</td>
<td>10 parents deceased infants.</td>
<td>Semi-structured interviews.</td>
<td>‘Life and death in the NICU environment’ emerged as the primary theme with the following categories: a) ups and downs of parenting in the NICU, b) decision-making challenges in the NICU and c) parent support. Parents encountered challenges with areas for improvement for end-of-life and palliative care in the NICU.</td>
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<tr>
<td>Sadeghi et al., 2016, Iran. Exploring spiritual needs of families at the end of their baby’s life in NICU, from the perspective of both families &amp; HCPs.</td>
<td>Qualitative study.</td>
<td>24 participants (9 mothers, 2 fathers, 3 grandmothers, 9 nurses, 1 physician).</td>
<td>Semi-structured interviews.</td>
<td>3 categories of spiritual needs are mentioned: a) spiritual belief in a supernatural power, b) the need for comfort of the newborn’s soul and c) human dignity for the newborn.</td>
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</table>
Discussion

The analysis of the quantitative studies found two main issues, 1) parents seek contact with their health care providers after the death of their child because of the poor psychological state in which they find themselves (Suttle et al., 2021; Wiener et al., 2018; Meert et al., 2014) and 2) the importance of communication between fellow HCPs, which determines the discussion of death, that is an event that causes negative emotions anyway and the discussion of the death of a child with the family (Harrison et al., 2014).

Regarding the first issue, researchers observed that the extent of the therapeutic alliance reported by the bereaved parents was on average moderate to high. This is also shown that parents at the time of their child's death have informational, emotional and other needs and rely on HCPs to meet these needs (Suttle et al., 2021). Continuous contact of parents with a member of the group of HCPs is beneficial, causes positive emotions and helps the acute phase of bereavement (Wiener et al., 2018), while it is possible to conduct follow-up meetings between physicians-parents or nurses/social workers-parents, as it seems that the experiences from the meetings are favorable and significant benefits are identified for both parents and HCPs (Meert et al., 2014). However, the therapeutic alliance also identifies significant differences mainly in the areas of trust, care and honest communication (Suttle et al., 2021). In addition, not all of the HCPs are aware of the substantial psychosocial challenges faced by parents during bereavement, therefore showing that there is a need for continuous training and education in the use of the meeting-monitoring framework, there is a significant gap between the recommendations provided in the standards of bereavement and in the care of bereavement actually provided, and finally, although several centers provide care for bereavement, concerns are raised that bereavement services are not all implemented consistently (Wiener et al., 2018; Meert et al., 2014; Harrison et al., 2014).

In the second topic, authors emphasize the importance of communication among HCPs. The tendency of HCPs to seek advice and support from colleagues was directly correlated with the level of comfort in discussing death in general as a topic and in discussing with family members the death of their child. Offering counseling services could improve communication between HCPs, offering more comfort to HCPs discussing issues involving death, and perhaps enhanced communication and increased comfort will lead to increased satisfaction of family members and fulfillment of the 6 priorities of parents, which are: honest and complete information, access to HCPs, communication and care coordination, emotional expression and support from HCPs, maintaining the integrity of the parent-child relationship, and spiritual faith (Harrison et al., 2014).

From the analysis of the data of the qualitative studies, the main points include 4 categories, which are: 1) effective parent-HCPs communication, 2) care and support of parents before death, 3) child care and support and 4) support of parents in the long-term after the death of the child (Neilson et al., 2020; Al Mutair et al., 2019; Butler et al., 2018a; Butler et al., 2018b; Berrett-Abebe et al., 2017; Currie et al., 2016; Sadeghi et al., 2016). In all studies the need for effective communication is crucial. This relationship changes and goes through various stages. Initially, parents, due to their child's illness, view HCPs with suspicion, but once they understand the imminent death, they understand that the HCPs has the necessary know-how and skills for medical and nursing care. Providing information first about the illness and then about the child's care and death signals effective communication and greater quality in the relationship (Al Mutair et al., 2019). Parents want direct and honest communication, while arguing that parents of children hospitalized in PICU preferred simple information that was presented in a positive way due to the importance of maintaining hope in the decision-making process and the possibility of a medical miracle (Currie et al., 2016). In addition, HCPs must provide accurate and objective information and support parents in making decisions (Butler et al., 2018a).

The care and support of parents is a consequence of good communication. Parents often, due to the traumatic experience they experience, recreate a new parental role in the PICU environment, which depends on the relationship with HCPs (Butler et al., 2018a). Health care professionals can create the conditions for support and care beyond information to facilitate the farewell process, in various ways such as ensuring visiting hours for parents to spend as much time as possible with their children, training parents in body care before and after death, creation of memories with
children and support in prayer (Al Mutair et al., 2019; Butler et al., 2018a; Butler et al., 2018b). Also, HCPs can inform parents when they are not present in the hospital or even show their support by pointing out to parents that despite the traumatic experience they are experiencing, it is important to take care of themselves with proper rest and nutrition so that they do not collapse (Currie et al., 2016). In the third category, the child's care is carried out either by the HCPs of the PICU, when the child is hospitalized there, or by the HCPs involved in palliative care program. However, researchers argue that it is important for families to feel and observe that HCPs outside of intensive care interventions respect families' cultural and religious preferences (Al Mutair., 2019; Sadeghi et al., 2016). It is likely that a change in PICU policy will be helpful to better support parents in the area of spiritual faith.

Health care professionals can help by showing empathy in safeguarding the human dignity of the child before and after death, in providing spiritual care, and in seeking hope for their later lives (Sadeghi et al., 2016). Supporting parents after the death of the child is a basic prerequisite for the duration of bereavement, non-attachment to the past and the continuation of their lives. A meaningful contact between HCPs and bereaved parents is suggested as a standard of care (Berrett-Abebe et al., 2017). Neilson et al., report that the initiation of family contact after the death of a child, provides the opportunity for assessment and observation of abnormal grief reactions by HCPs. In addition, the way of contact and communication (e.g. telephone calls, exchange of messages) is also important to benefit both sides, so that the contact is not interrupted (Neilson et al., 2020). Also, in 2 studies it is stated that a close relationship must remain supportive and continue for a long time, while it is proposed to implement monitoring programs and contact with HCPs, (Butler et al., 2018a; Berrett-Abebe et al., 2017) because otherwise a feeling of abandonment is created by HCPs, which begins after leaving the hospital (Butler et al., 2018a). Finally, parents expressed wishes and proposals for expanding programs with the possibility of providing long-term support, while at the same time they proposed that in programs with limited resources a comfort basket could be provided, personalized for each family, which would contain child memorabilia, educational material and a letter from the HCPs that reflects the relationship between HCPs, parents, child, so as to continue contact and not to interrupt the feeling of familiarity (Butler et al., 2018b).

Limitations: This systematic review presents some limitations. Number of included articles is relatively small. Included studies were published only in English language. Some studies have small number of participants. Some studies have been conducted in a mere hospital or in a mere city. Most of the participants had to speak the English language for taking part in a survey. Parents’ participation in a large number of surveys was voluntary. Therefore, more in-depth research for both qualitative and quantitative studies is needed to extract further conclusions.

Conclusions: In conclusion, the present systematic review investigated bereavement after the child's death and found 3 main points, 1) effective communication between parents and HCPs, 2) meaningful contact between HCPs and 3) care and support of parents before and after the child's death. Proper communication in the parent- HCPs relationship is what will determine the quality of the relationship and its continuation after discharge from the hospital. Perhaps more empathy and HCPs training are needed, first to better understand the traumatic situation and approach the issue with respect and dignity, and second to help families overcome prolonged grief in line with standards of supportive care. The issue of death is important and causes negative emotions even only when the word is heard, which is why HCPs often refuse to deal with it. Education and counselling for HCPs is important, helping to better understand the issue and address it by implementing bereavement care standards. The care and support of parents before and after the child's death concerns HCPs. It is important for the farewell process, the parents learning how to take care of their child, essentially recreating the role of the parent, with HCPs directing the whole care process. At the same time, support is provided before death to prepare parents for the event. After death, the supportive relationship lets parents grieve, trying not to remain in prolonged grief, empowering them emotionally to create outlets to move forward with respect and dignity.

References


