



Supporting Parents That Lose Their Child Suddenly

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ABSTRACT

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This bachelor's thesis is a narrative literature review about how the healthcare professionals could support parents that have lost their child suddenly. The objective of our thesis is to help nurses understand what kind of support grieving parents need and how to support them. With the help of our literature review nurses can find tools useful for them when dealing with grieving parent/s. The purpose of this thesis is to do a literature review to collect information for nurses and midwives dealing with grieving parents that have lost their infant suddenly. The information is collected from already existing studies and materials.

We conducted a data search from reliable online databases. The databases for this literature review we ended up using were CINAHL and Pubmed. For the background information we used CINAHL, Pubmed, Andor and Google Scholar. The data was collected between May and August in 2021. We included eight studies in this review

Through the literature review we found out that grieving bereaved parents look for good, sensitive and empathetic attitude and care from the health care staff when facing the loss of their baby. Many parents need spiritual support, but also emotional and psychosocial support. Continuity of the care and ongoing relationship between the bereaved parents and care provider was found beneficial for the parents' grieving process. Parents also found it helpful when they received photographs or memory boxes of their lost child.

Key words: sudden death, infant, bereavement, parent, support, nursing

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1 INTRODUCTION

Perinatal loss is very traumatic and painful experience for parents, that has biological, psychological, social, and spiritual consequences. Perinatal death refers to unintended miscarriage before 20 weeks' gestation. Stillbirth is the death of a baby after 20 weeks' gestation and before or during birth. Neonatal death means the death of infant within the first 28 days of their life. It has been found that despite technological advances, 2% of the pregnancies still end in stillbirth. (Camacho Avila et al 2020.)

2.5 million stillbirth and neonatal deaths have been estimated to occur each year around the world. Despite stillbirth and neonatal deaths occurring amongst all type of women, there are some risks that increase it, such as smoking during pregnancy, obesity, substance abuse, high blood pressure and diabetes. Multiple pregnancies and previous perinatal loss also increase the risk of stillbirth. (Camacho Avila et al 2020.)

The child's death is an unimaginable and devastating event which tends to leave surviving parents in deep grief. Grieving parents frequently experience paralyzing feelings of shock, helplessness, and guilt, and the grief journey for many parents can really be intense and prolonged. (Snaman et al 2016.)

The death of a child can have significant effects on parents' health and coping and has been reported as one of the most difficult and traumatic experiences that a parent can have during their lifetime. Parental experience of grieving of a child is unique and it can manifest in many ways. Studies have shown that families found a compassionate attitude with clear and open communication useful during the grieving process. (Martinez et al 2021.)

In 2019 there was a thesis made about the topic how the nursing degree prepares nursing students to support a person after a sudden loss. The results

showed that most of the students felt like they were not provided with enough skills in this field and were not ready enough to face these situations in working life. (Mäkinen & Tornainen 2019.) Studies like this show the importance of addressing this issue and providing nursing professionals more information and tools to be more comfortable facing the grieving family members.

This thesis is going to be a literature review of the already existing literature of our topic. In this thesis we are answering the study question: 'How can a nursing professional support parents after the loss of an infant?'.

2 THEORETICAL STARTINGPOINTS

2.1 Grief and bereavement

Everybody grieves differently, but as a healthcare professional it is good to identify different stages of grief to better address grieving parents' needs. Elisabeth Kübler-Ross, a psychiatrist, created the theory of five stages of grief and loss, also known as Kübler-Ross model. The model identifies five most common emotional responses to a loss: denial, anger, bargaining, depression and acceptance. The grief process is not a straight line, and these different stages might come in different order and some stages might come again after some time. (Casabianca 2021.)

It has been proven that perinatal death is a painful experience for parents. Each year around 5 million cases of neonatal and stillbirths are recorded globally. For some parents, perinatal loss has been associated to high levels of psychological anguish both at the time of the loss and during subsequent pregnancies. (Agwu Kalu et al 2018.)

Perinatal loss might not only lead to several emotional and psychosocial distress for certain parents, but it can also increase the obstetric risk for women. Many parents' outcomes are dependent on the midwives' knowledge and capacity to provide adequate grieving assistance. Healthcare professionals' inability to provide adequate care to the grieving parents has been proven to have an adverse effect on their experience. (Agwu Kalu et al 2018.)

Healthcare professionals are required to have the confidence to support parents in the grieving journey. In this study confidence was defined as bereavement support knowledge and skill. Studies have shown that many healthcare professionals still lack these skills. (Agwu Kalu et al 2018.)

2.2 Difference between fathers' and mothers' experiences of grief

Traditionally men are to act, solve problems, not to express their emotions. It is said that grieving fathers tend to busy themselves with work or chores. Women are said to be more of intuitive grievers. These types of grievers express their pain/grief by showing emotions and talking about their feelings. Therefore, men grieve differently from women, but they do not grieve less than women. (Martinez et al 2021.)

Fathers were forbidden to entry in the delivery room up until early 1970s. Now a days they are more included in the care and support of their partner during and after childbirth. Fathers are often forgotten and left without an essential care after the loss of an infant, due to their role not being clearly identified. The ability to recognize, understand and validate the fathers' emotions during and after the loss of his child is important step to begin the healing process. When taking care of bereaved families, healthcare professionals must take into consideration the differences between mothers and fathers, and the aspect of religion and culture. (Cholette 2012.)

2.3 Bereavement interventions

It is crucial that bereaved families receive professional care to prevent them from developing short and long-term negative outcomes. Bereaving parents have been identified to be high risk group for complicated grief. Up to 25% of these parents suffer from severe symptoms years after losing their child. The support mother receives after losing her child is single most important factor predicting the type of grieving process she will go through. (Ellis et al 2016.)

Healthcare professionals expressed that caring for a bereaved families being stressful and emotionally challenging. Many healthcare professional feel like

they are not fully prepared and lack training on how to deal with these types of situations. Healthcare professionals see this very traumatic and painful experience for families as clinical problem and whilst the parents see it as traumatic experience. This mismatch between the emphasis on clinical rather than personal has caused the parents distress and anxiety. (Ellis et al 2016.)

Parents complained about the diagnosis not being conveyed in adequate manner and not being given enough time to come to terms with the news. It was shown that healthcare professionals' attitude and actions have impact on the parents. Showing empathy and caring attitude had positive impact on the parents. (Ellis et al 2016.)

2.4 Pregnancy after stillbirth or perinatal death

Stillbirth and neonatal death have psychological, social, and financial consequences for parents. According to studies conducted in the UK, 35% of bereaved mothers and 13% of bereaved fathers experienced four or more negative psychological symptoms nine months following the birth. This is three times higher than the rate of livebirths, when 8-13% of mothers and 3% of fathers experienced depressive symptoms at a similar point of time. The psychological impacts of stillbirth and perinatal mortality can be seen in parent-child interactions in later pregnancies. Parents showed happiness at being pregnant again, but they worry of suffering another stillbirth or perinatal death. Women also expressed their doubts about carrying healthy child. (Heazell et al 2019.)

Pregnancy after stillbirth or perinatal death is associated with higher risk of poor biological and psychological consequences. Stillbirth occurred in 2,5% of women with a previous history of stillbirth, compared to the 0,4% of women whose previous pregnancy resulted in livebirth. (Heazell et al 2019.)

3 PURPOSE, OBJECTIVE AND RESEARCH TASK

The purpose of this thesis is to do a literature review to collect information for nurses and midwives dealing with grieving parents that have lost their infant suddenly. The information is collected from already existing studies and materials.

The objective of our thesis is to help nurses understand what kind of support grieving parents need and how to support them. With the help of our literature review nurses can find tools useful for them when dealing with grieving parent/s.

Our research task:

1. How can a nursing professional support parents after the loss of an infant?

4 METHODOLOGY AND IMPLEMENTATION

4.1 Narrative literature review

The method we chose for this thesis is literature review, in detail narrative review. There are different reasons to choose different types of reviews, depending on the need. Narrative literature review is one of the most used types of reviews. It can be described as a general review that is not bound with strict and specific rules and regulations. Narrative review is the type of method that gives a broad picture of the studied issue (Salminen 2011.)

In literature review there are 9 steps to follow. First step is selecting the topic. A literature review may concentrate on either an emerging topic with the goal of developing theoretical foundations or a mature topic with the goal of analyzing and synthesizing the current literature. Second step is identifying the goal and formulating the research question. Third is developing and validating review procedure. Fourth step is searching the literature. Good databases, search terms, keywords. The fifth step is selecting the literature. Choosing which articles will be included in the review and which will be omitted. Sixth step of literature review is analysing the articles. Extracting data and making sense of it is referred to as analyzing. This includes reading and rereading the selected documents, systematically extracting relevant knowledge from the articles. The last three steps are synthesizing, concluding and reporting (Juntunen & Lehenkari 2019.)

4.2 Data collection

The information used in this bachelor's thesis was conducted from three reliable databases; Andor, CINAHL and PubMed. For the background information we searched for academic articles and studies that were done about our topic. We also used some of the articles' references to back up our introduction to the topic.

These were the search terms we used for our literature review search of articles: (“sudden death” OR “death, sudden” OR “Sudden Infant Death” OR “Infant Death” OR bereavement) AND (parent* OR mother* OR father*) AND (support* OR coping) AND (nurse* or nursing)

Database	Results with time limit 2010-2021, English language, full text, abstract available	Selected according to the title	Selected according to the abstract	Selected according to the full text
CINAHL	44	14	7	3
PubMed	112	21	11	5

TABLE 1. Search phrases

To avoid any biased selection of articles, the two of us did the searches together. First we searched articles from CINAHL database with the search phrase mentioned above. We limited the search with publication year, language, full text and abstract available. We came up with 44 results and went through the titles, only 14 of the article titles were related to our topic. After that we read through the abstracts and chose 7 of those articles. After reading through these 7 articles we were left with 3 articles that were related to our topic.

Same kind of data search was conducted on PubMed as well, but that database had more articles to review. With the same limitations we got 112 results. According to the title we chose 21 of those, then read the abstracts and chose 11. After reading all 11 of those articles we were left with 5 articles which we included in our literature review.

Most of the excluded articles were talking about end-of-life care and palliative care of pediatric cancer patients, or were focused on nurses' challenges on facing the grieving parents, so these articles did not quite answer our study question.

The quality of the researches chosen for this thesis was analyzed with quality appraisal criteria by Kangasniemi et al. (2013). In a high quality research article the aims and objectives are clearly described. The study design is adequately described, the research methods are appropriate for the study, theoretical framework is explicit, limitations and implications are discussed. These criterias are marked as y=yes, p=poor and nr=not reported. You can find this on table 3.

4.3 Prisma flow chart

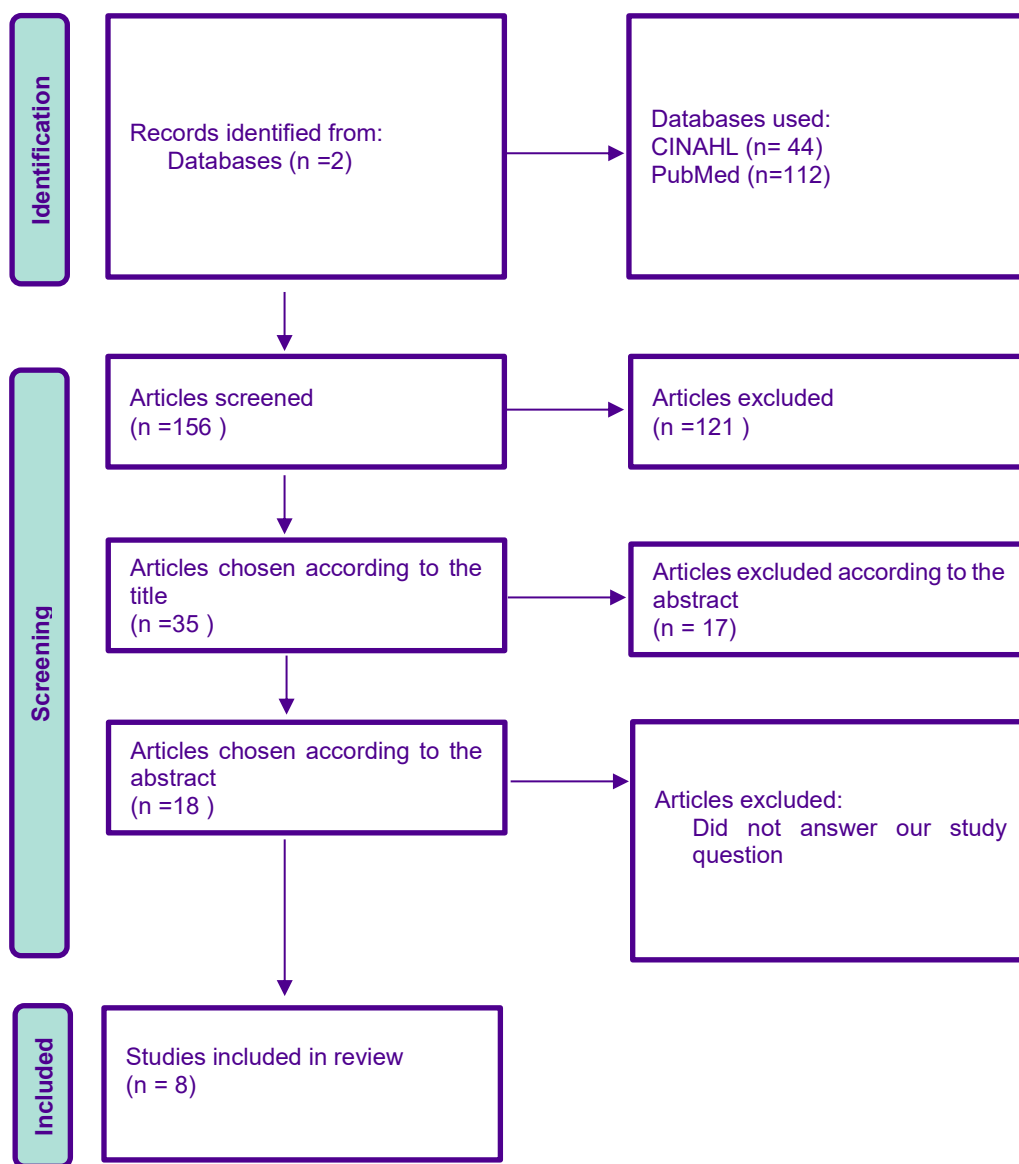


TABLE 2. Prisma flow chart

Authors, year, coun- try	The purpose of the re- search	Main find- ings	Study method	Quality ap- praisal cri- teria: y=yes, p=poor, nr=not re- ported
Kalanlar, B. 2020. Turkey	To provide comprehensive and current information on hospital practices following perinatal death.	Hospitals encouraged the parents to see and hold their deceased baby. The parents were also encouraged to receive photos of the baby.	Descriptive study, purposive sampling method	(y) Aims and objectives clearly described (y) Study design adequately described (y) Research methods appropriate (y) Explicit theoretical framework (y) Limitations presented (y) Implications discussed

<p>Camacho Avila, M., Fernandez Medina, I., Jimenez-Lopez, F., Granero-Molina, J., Hernandez-Padilla, J., Hernandez Sanchez, E. & Fernandez-Sola, C. 2020. Spain</p>	<p>The aim of this study was to describe and understand the experiences of parents in relation to professional and social support following still-birth and neonatal death.</p>	<p>Good attitude, sensitive and empathetic care. Giving chance to hold and see the deceased baby. Providing grieving parents with memory box.</p>	<p>A qualitative study based on Gadamer's hermeneutic phenomenology</p>	<p>(y) Aims and objectives clearly described (y) Study design adequately described (y) Research methods appropriate (y) Explicit theoretical framework (y) Limitations presented (y) Implications discussed</p>
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<p>Messuko, J., Turale, S., Jinrawet, U. & Niyomkar, S. 2020. Thailand</p>	<p>To develop a set of Pallia- tive Care Guidelines for Physicians and Nurses in Pediatric In- tensive Care (PCGPHPIC) caring for children and their families in a university hospital in Thailand.</p>	<p>Communica- tion, continu- ity of care, symptom management and comfort, spiritual sup- port, emo- tional and psychosocial support were the findings of this study.</p>	<p>A qualitative study using participatory action re- search</p>	<p>(y) Aims and objectives clearly de- scribed (y) Study de- sign ade- quately de- scribed (y) Research methods ap- propriate (y) Explicit theoretical framework (y) Limitations presented (y) Implica- tions dis- cussed</p>
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Steen, 2015. USA	S. To identify needs and concerns of US and Spanish nurses and midwives who have worked with perinatal death and to identify the bereavement interventions they use to help families with this experience	Interventions such as listening, giving company, discussing baptism and funeral plans had significant differences between US and Spanish nurses.	A cross-sectional study	(y) Aims and objectives clearly described (y) Study design adequately described (y) Research methods appropriate (y) Explicit theoretical framework (y) Limitations presented (y) Implications discussed
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<p>Snaman, J., Kaye, E., Torres, C., Gibson, D. & Baker, J. 2016 USA</p>	<p>To explore the role of the health care team and medical institutions in the grief journeys of parents whose child died a cancer-related death.</p>	<p>Interventions important to bereaved parents were strong/ongoing relationship between them and the health care provider, clear and honest communication.</p>	<p>Semantic content analysis</p>	<p>(p) Aims and objectives clearly described (y) Study design adequately described (y) Research methods appropriate (y) Explicit theoretical framework (y) Limitations presented (nr) Implications discussed</p>
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<p>Choumanivong, M., Karimi, S., Durham, J., Sychareun, V., Flenady, V., Horey, D. & Boyle, F. 2020 Laos</p>	<p>Explored health professionals' experiences of providing stillbirth care in the Lao People's Democratic Republic, a lower-middle-income country in South-East Asia.</p>	<p>A lack of training in managing stillbirth left health professionals often ill-equipped to support mothers and provide responsive care. Social stigma surrounds stillbirth, meaning mothers found limited support or opportunities to openly express their grief.</p>	<p>A qualitative study</p>	<p>(y) Aims and objectives clearly described (y) Study design adequately described (y) Research methods appropriate (y) Explicit theoretical framework (y) Limitations presented (nr) Implications discussed</p>
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<p>Hasanpour, M., Heidarzadeh, M. & Sadeghi, N. 2016 Iran</p>	<p>The aim was to explore of parental needs in infant end-of-life and bereavement.</p>	<p>Family's support needs and family's preparatory needs upon infant's death.</p>	<p>A qualitative study</p>	<p>(y) Aims and objectives clearly described (y) Study design adequately described (y) Research methods appropriate (y) Explicit theoretical framework (y) Limitations presented (nr) Implications discussed</p>
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Camacho Avila, M., Fernández-Sola, C., Jimenez-Lopez, F., Granero-Molina, J., Fernandez-Medina, I., Martinez-Artero, L. & Hernández-Padilla, J. 2019 Spain	To describe and understand the experiences and perceptions of parents who have suffered a perinatal death.	Emotional outpouring after the notification of the deceased baby. Loneliness and lack of information. Bereaved parents benefited from saying farewells, collecting memories of their baby and having their mourning rituals.	A qualitative study	(y) Aims and objectives clearly described (y) Study design adequately described (y) Research methods appropriate (y) Explicit theoretical framework (y) Limitations presented (y) Implications discussed
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TABLE 3. Research quality assessment table

4.4 Research ethics

The Finnish Advisory Board on Research Integrity, appointed by The Ministry of Education and Culture in Finland, updated the guidelines for the responsible conduct of research and for handling alleged violations of conduct in co-operation with the Finnish research community. The objective is to promote the responsible conduct of research while ensuring that the alleged violations are handled with competence, fairness and expediency. Transparency, meticulousness, and precision will be adhered to when conducting the research. Used references will be cited properly and according to sources used to avoid any type of plagiarism. Research findings will be conveyed in an accessible and responsible manner to ensure ethicality of the findings. (TENK 2012.)

To ensure the legitimacy of our bachelor thesis, we only used scientific databases (as specified above) and articles that have been peer evaluated professionally. We utilized a chart to review the selected articles and verified that they were legitimate.

5 RESEARCH FINDINGS

Camacho Avila et al (2020) conducted a study in Spain in which 13 mothers and 8 fathers from six families participated in. They found out in the study that good attitude from healthcare professionals with sensitive and empathetic care was beneficial for the bereaved parents. Parents being able to hold and see their deceased baby and giving the parents memory box was also mentioned to be helpful with the coping process. Some parents experienced not being heard by the health care professionals and society, not being able to express their emotions in public and the lack of psychosocial help from professionals. (Camacho Avila et al 2020.)

The key findings of the study, which had been done in Turkey by Kalanar (2020), were providing the parents photographs and mementos of the deceased baby, as well as offering them quiet room where parents and families can be alone without being disturbed. Support from a spiritual advisor and a social worker was considered crucial for parents who had lost their baby. In the case of a child's death being unclear, offering the parents the opportunity to request for an autopsy is also recommended. This relieves the parents of their guilt and uncertainty. (Kalanlar 2020.)

Four main concepts arose from a study which was conducted in USA by Snaman et al (2016). In this study eleven bereaved parents took part in two focus groups. The study found out that strong and ongoing relationship between providers and bereaved families and the importance of high-quality communication play an important role when it comes to taking care of bereaved parents. The effect of negative experiences between providers and families on parental grief was also brought up. Also the importance of the institution's role in the grief journeys of bereaved parents was one of the main findings in this study. (Snaman et al 2016.)

Study conducted by Hasanpour et al (2016) found out that family support, which was further divided into two subthemes, family support before the child's death

and family support after the child's death was one of the main needs of a bereaved family. The second finding was the family's preparatory needs following the death of an infant, which was also divided into two subthemes, treatment team management of the bad news of the child's death and family management of the bad news of the child's death. (Hasanpour et al 2016.)

Five themes that were brought up in the study conducted by Messuko et al (2020). The first is clear communication and decision-making qualities. The continuity of care was the second theme. The third theme was symptom management. Spiritual support and emotional and psychosocial support were fourth and fifth themes. (Messuko et al 2020.)

Choummanivong et al (2020) found out in their research that due to a lack of proper training the healthcare professionals are often ill-equipped to support the grieving mother and provide responsive care. That led to mothers and families receiving little to no help after a stillbirth. Also due to the stigma around stillbirth, especially mothers were often left with no support and ways to open up about their experiences after stillbirth. (Choummanivong et al 2020.)

A cross sectional study was implemented and conducted out in the United States and Spain, using research methods that were similar in both countries by Steen (2015). The Spanish nurses showed more concern about the insensitivity of others compared to that of the US nurses. US nurses relied more on religion and prayer when coping with loss of a patient. Whilst Spanish nurses coped with the fact this experience increased their knowledge and ability. Both the Us and Spanish nurses agreed that crying, praying, exercising, and keeping a journal helped them cope. They also mentioned attending funerals and following up with families were other coping strategies they found helpful. Intervention of being a good listener was found to be significantly different between groups and Spanish nurses found it to be more beneficial than the Us nurses. Spanish nurses identified needing increased communication skills more than the Us nurses. (Steen 2015.)

Camacho Avila et al (2019) studied the experiences of the parents that had gone through perinatal death. The study included 13 mothers and 8 fathers that were interviewed by two midwives and one pediatric nurse. Camacho Avila et al. (2019) found out that during an unpleasant and emotional situation, such as giving birth to a dead baby, individualized care from health care professionals can affect the experience positively. Parents described that denying partners to enter the ultrasound room when the news of the deceased baby was told to made the mothers feel lonely and helpless. It was also pointed out in the results of this research that sharing the hospital room with mothers that had given birth to living babies made the suffering of those grieving the loss of their own baby worse. (Camacho Avila et al 2019.)

Parents valued health care professionals' efforts to help cope with the pain of losing one's baby by giving a chance to say the last goodbye to the baby, to hold and see the baby and collect mementos. Some parents had experiences of nurses/midwives denying them from keeping some mementos and even seeing the baby, experiences like that only increased the suffering of the grieving parents. The ability to baptise the baby was highly valued by Christian families. The ability to perform other rituals and funeral planning as well, helped with the suffering. (Camacho Avila et al 2019.)

6 CONCLUSION

Perinatal death is very traumatic and painful experience for parents, that has biological, psychological, social, and spiritual consequents. Grieving after the loss of the baby is an individual process for both mother and father. (Heazell et al 2012.)

Studies have shown that bereaved parents find nurses and midwives with good attitude and sensitive and empathetic way of caring beneficial for their grieving process. Health care staff can also help the bereaved parents by providing different types of support. Spiritual support can be provided by spiritual advisor or hospital priest. Sometimes hospital priests can just be there for company and comfort, it does not have to do with the religion or religious needs. Amongst the spiritual needs, emotional and psychosocial support is also important for grieving parents. (Camacho Avila et al 2020; Messuko et al 2020.)

Communication is key, even with something as horrible as a loss of a child. Parents reported to prefer clear and honest communication between the health care provider and the parents even with something as sensitive as this topic. Trusting relationship between the grieving parents and the health care professional is proven to affect the experience and process positively. (Snaman et al 2016; Heazell et al 2012.)

Somewhat harmful interaction with health care staff can affect the bereaved parents long-termly in a negative way. Studies also showed that health care professionals that lack proper training on this field were ill-equipped to provide needed support and responsive care. Situation like this can lead the grieving parents with little to no help after the loss of their child. There are also many studies made on the nurses' point of view, how situations like this are stressful and emotionally challenging due to lack of training. (Choummanivong et al 2020; Heazell et al 2012; Ellis et al 2016.)

How to make these two ends meet is a challenge itself. It is clear now that health care staff needs more training on this field to be able to provide the best care and support possible for these grieving parents in this very vulnerable state. We also realised while conducting our research that it was very difficult to find studies on this topic. It would be beneficial to have more qualitative studies done with parents that have lost their child so that health care staff would be able to give better care and support in the acute phase. Also proper training would make nurses and midwives more confident when it comes to facing a grieving parent.

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