

# LOSS OF A BABY IN CULTURAL CONTEXT

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<p>Abstract</p> <p>The purpose of this study was to investigate the expectations of the parents from multicultural settings on the preferable support they can receive from nurse during perinatal loss. The aim of the study is to provide information of culturally meaningful care provided for families after the loss of a baby.</p> <p>The method of this study is a literature review. Twenty nine (n=29) articles dated 2000-2013 were selected from CINAHL (EBSCO), EBSCO Academic Search Elite, Elsevier Science Direct, Journals@OVID and manual search. The cases were from early pregnancy loss at 5 weeks to babies lost at the age of one month.</p> <p>The study found out that the most supportive interventions from the parents' point of view are validation of parents status and baby's existence, less strict visiting rules at hospital, parenting activities and time spent with the baby, creation of memories, and special attention to mother. The key position of communication process was considered, where the nurse should understand parent's condition of being filled with various emotions and adjust the message, as well as to provide information timely and in simple terms. The nurse should ask the parents about their needs and wishes, not guess them, and personalize the care to incorporate cultural and personal needs of the patient. The study also revealed the desired virtues of culturally competent nurse, such as sensitivity, empathy and sympathy, be educated in dealing with grief and be able to ensure privacy and to be present. The nurse may discuss with the parents possible coping strategies in addition to overview of life after loss, such as encouragement of religion and spirituality, keeping active lifestyle, anticipation of new pregnancy, finding meaning in loss or stay or try to forget the loss, to name a few.</p> <p>The results of the study may be of benefit to all nurses and health care providers, not only those who work in Neonatal Intensive Care Units (NICU) and maternity wards, but also in other health care institutions, because the burden of perinatal loss stays for years with suffering families.</p>		
<p>Keywords</p> <p>Perinatal, cultural competence, multicultural, coping, families, personalization, communication, literature review</p>		
Miscellaneous		

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## 1 INTRODUCTION

Recently there has been a growth of interest of cultural competency in nursing. The significance of a baby loss during pregnancy or in one month after birth is now acknowledged, as well as the fact this devastating event impacts life and health of the whole family. Nurses are in front line to support families who are facing this distressing experience. However, there is still paucity in studies of how to competently, yet culturally care for the families. Interventions predominantly are worked out for white families (Hebert, 1998, 61; Whitaker, Kavanaugh & Klima, 2010, 341) or suggested rigidly according the institution policy, regardless the families wish, expectations and background (Leon, 1992, 366-374), thus breaking the idea of cultural competence and holistic nursing.

The choice of topic is determined by the understanding that the families, who experience perinatal loss, may be encountered in many settings of health care services, not only in neonatal intensive care units, NICU. The pain of loss can be within such families for a lifetime (Arnold, Gemma & Cushman, 2005, 254; Scott, 2011, 1387), interfering with continuation of happy life.

There seems to be insufficient research evidence about how to support parents and families when they experience perinatal loss. They need to rely on theoretical models, which can differ from practice. The problem becomes even more stressful in case families are from different background that of a nurse. So there is an explicit need of further research that will summarize the relevant support for grieving families in multicultural perspectives. (Davies, 2004, 512; Leon, 2008; Robertson, Aldridge & Curley, 2011, e114.)

This study therefore is to investigate the expectations of the parents from multicultural settings on the preferable support they can receive from nurse during perinatal loss. The aim of the study is to provide information of culturally meaningful care provided for families after the loss of a baby-

## 2 PERINATAL LOSS

There has been a strong interest to the care of perinatal loss and grief connected with it for two decades (Caelli, Downie & Letendre, 2002, 127-136). Perinatal loss is the shocking experience in the lives of every family, regardless of its background. It is the loss of baby either during unwanted termination of pregnancy or infant death, which may happen within first twenty eight days after birth. The pregnancy can be terminated as an ectopic pregnancy, miscarriage, which is defined as early pregnancy loss for less than 20 weeks of length, medical termination, or stillbirth, which happens at least 16-20 gestational weeks and later (Kavanaugh, & Hershberger, 2005, 2; Callister, 2006, 227). Of all childbearing couples, more than two percent of them would face perinatal loss (Caelli et al., 2002, 127-136). Côté-Arsenault (2003, 23) cited Woods & Woods, 1997 that up to 25% of all conceptions would end with perinatal loss.

There is a still unclear definition of what period is precisely perinatal loss embraces if death happens after the birth, seven or 28 days. The World Health Organization (WHO) defines perinatal death as the death of the baby during the first seven days, distinguishing from the death up to 28 first days of life as neonatal death (Richardus, Graafmans, Verloove-Vanhorick & Mackenbach, 1998, 54-66; WHO, 2012, 51).

Despite this fact, many researchers (Malacrida, 1999, 504; Côté-Arsenault, 2003, 23; Kersting & Wagner, 2012, 187) still consider the death in first month of life as perinatal loss. Subsequently, many researches therefore include the data from the period up to twenty eight days. Considering that the significant part of research articles would otherwise be excluded, the reviewer adopted the definition of perinatal loss to be happened from pregnancy time to the end of the first month of birth.

The families would face perinatal loss almost totally unprepared, because there is no such information given during pregnancy, for example in pregnancy classes, or the information about perinatal loss is given very briefly (Malacrida 1999, 505; Lamb, 2002, 39). Another reason maybe there is taboo to dis-

cuss possible sad topic in the time of awaiting the baby to avoid causing the disaster upon family or cause negative thoughts and feelings during pregnancy.

The additional tragic moments are that the loss occurs unpredictably, and the reason often stays unidentified, even after autopsy (Caelli et al., 2002, 127-136). It ruins the plans which parents and a family already has plotted and makes all arrangements made for a new life useless (Côté-Arsenault & Dombeck, 2001, 652). It also brings the variety of distressful feelings and affects self-identity. For example, perinatal loss considerably affects woman merit in the African cultures, because the main indicator of it is proved ability for successful childbearing (Haws, Mashasi, Mrisho, Armstrong, Schellenberg, Darmstadt & Winch, 2010, 1768).

## 2.1 Culture and Perinatal Loss

Culture is the major determinant of the response for many actions, thoughts and behavior of a person (Cowles, 1996, 287-294; Fletcher, 2002, 86), even if regard culture as ever-changing set of recommendations which determine the behavior and actions (Sydnor-Greenberg & Dokken, 2000, 185-90). Consequently, the culture shapes the person, but also the person shapes the culture for one's turn.

Culture determines the expression of grief (Hebert, 1998, 76), rather than the extent. While investigating the concept of how grief and culture interact, Cowles (1996, 293) determined that person experiences grief behaves according to his or her personal characteristics. In contrast, Fletcher (2002, 88) noted that people react to loss according their own cultural prescriptions regardless the fact that grief is a universal phenomenon.

In addition, culture may add some reasons for emotional distress. For instance, for Taiwanese women the additional suffering comes from the cultural notion that they could not ensure their child received *good death*. This means

that the baby died in the infancy and did not reach the maturity age. Even the high education does not help because this feeling rises not within the woman, but overall unforgiving environment will constantly remind her, including close relatives and even nearby residents. (Hsu, Tseng, Banks & Kuo, 2004, 410) As can be seen the environment neither support the families, but serves as additional negative factors in emotionally burdening the families.

Further, in some languages, for instance, Swahili and local African languages, there is no precise translation for such biomedical terms as *miscarriage* or *stillbirth* (Haws et al., 2010, 1770), which makes communication between nurse and patient more problematical, which automatically leads to complications in providing culturally competent care.

Even in case of sharing more or less identical culture, cultural variations may arise, if they are not accepted by nurse, it may result to stereotyping (Fletcher, 2002, 87). Stereotyping is the idea that individual from any cultural background would value and share the same beliefs and principles as any other representative from that group (Giger & Davidhizar, 1995, 65). Stereotyping does not consider any variation or personal, familial or other attribute that may also influence the person.

## 2.2 Silence around Perinatal Loss

The loss is often not evident to the public (Capitulo, 2005, 390; Chichester, 2005, 314). At the same time, the society is not ready to discuss this issue. The perinatal loss is still not accepted topic for a discussion in society (Capitulo, 2005, 390). For example, just a few bereaved couples get acknowledgment from friends or neighbors with the loss. Also, the parents in some US hospitals often get in touch of rude practice not to issue both the birth and death certificates to avoid additional paperwork. In this case the parents also suffer from unclear legal status of their dead baby and their own not well-defined roles, as were they parents or not (Malacrida, 1999, 510-514).



Several aspects contribute to the invisibility of the perinatal loss: inconsistency with definition among different countries and organizations, lack of data and social tendencies aimed to hide stillbirths and accompanying family bereavement process (Lawn, Yakoob, Haws, Soomro, Darmstadt & Bhutta, 2009, S2). Society withdrawal makes this experience significantly more distressing, putting them into isolation and forcing them to find their own forces to adapt to new life (Malacrida, 1999, 505-513; Caelli et al., 2002, 127-136). Grieving pairs feel loneliness as they experience non-recognition of loss from the society (Caelli et al., 2002, 127-136).

Sometimes, societally important people intimidate the women after perinatal loss to keep silence, as for instance, in rural Tanzania the female elders warn women in loss against expressing their grief. The reasons they give vary from future health benefit for women to avoiding future problem with birth and death of the baby. In same place loss is kept unspoken in order not to let food for gossips, since it might be associated with induced abortion and subsequent divorce or even allow bewitchment. Though the loss cannot be openly expressed, it still exists silently. (Haws et al, 2010, 1768-1770.)

### **2.3 Feelings of Families**

The family experiences the whole range of feelings after the loss. Feelings may vary from self-targeted to be aimed at health care professionals. Mothers may additionally feel additional anger because women often think that health care professionals does not pay adequate attention to mothers feeling, when they feel and express their concerns that they feel something is not correct with them or with them babies (Caelli et al., 2002, 127-136). Thus, mothers assumed, the baby possibly could be saved if health care professionals acted in time.

Despite the common myth that subsequent pregnancy forces out the bitter feelings of the past loss, the memories would stay for many years. The succeeding pregnancy quite usually is filled with depression, fears of repetition of

the sorrowful time, or anxiety. (Côté-Arsenault & Dombeck, 2001, 650; Sutan, Amin, Ariffin, Teng, Kamal & Rusli, 2010, 209–217.)

Similarly autopsy itself brings many varied feelings. Often expectations for autopsy to know more and possibly avoid the reason for death are not fulfilled; the reason for loss stays unspecified. Consequently parents are left with feelings of helplessness, ambiguity, disorientation, self-blaming disgrace, and distress. (Côté-Arsenault & Dombeck, 2001, 652; Caelli, et al., 2002, 127-136.)

## 3 VARIATIONS OF LOSS

### 3.1 Gender Variations

The mother is seen as the person the most affected by the perinatal loss. It is known that the vast majority suffers very much from the silent sorrow, although a small fraction of women are quite tolerant to the loss for several reasons (Côté-Arsenault & Dombeck, 2001, 652).

In general, the most of researched are concentrated on how mothers are affected by the perinatal loss, leaving the father perceptions mainly unexplored (McCreight, 2004, 327; Badenhorst, Riches, Turton & Hughes, 2006, 245). The response to loss of mothers and fathers, nevertheless, is known to be not alike (Caelli et al., 2002, 127-136). For instance, the grief of man for one month after the loss was less intense that of women; yet, after 13 month there was no difference in gender response. Men are also prone to feel perinatal loss as failure (Barr, 2004, 498-504).

Because of social roles, men are under double pressure. They are required to be resilient and serve as primary supporters of their next of kin and on the same time they are expected to show more of their emotions (Cacciato-re, Erlandsson, Rådestad, 2013, 665). These contradicting roles only add the burden and psychological tension to fathers, so they also need support to restore their psychological balance.

### 3.2 Grief in the Family

No doubt that the perinatal loss affects siblings, but their grief is different from that of the parents'. (Lawrence, 2010, 23) The child sees the preparation for new member arrival, and then suddenly the arrival is not happened and behavior of parents becomes modified, and no explanation is given (Avelin, Erlandsson, Hildingsson, Bremborg & Rådestad, 2012, 90).

The consequences of unspoken event may be shown as negative behavior, anger outburst or mood swings of siblings, later leading to school problems. Even if parents get social support, siblings, as a rule, are omitted from the process of support, as nothing has been happened in their life (Wilson, 2001, 58-59).

The grandparents' feelings, the extent of grief and impact on their health appear to be the least studied. The grandparents are in especially uncertain situation: the bereaved parents expect support and sympathy from grandparents because they just lost their baby in spite of grandparents need support themselves, because they suffer the loss of their grandchild (Roose & Blanford, 2011, 82-83).

Parents sometimes want grandparents to actively participate in mourning, to see or hold the baby, and attend the funeral ceremony. Given that frequently both parties have exhausted their emotional potentialities and all participants hardly know how to support in this situation, they merely provide any encouragement to one another (O'Leary, Warland & Parker, 2011, 336-348). Successively, the risk for alcohol and drug abusing suicide thoughts, anxiety and depression is significantly rising among grandparents (Youngblut, Brooten, Blais, Hannan, & Niyonsenga, 2010, 352-359).

## 4 CULTURALLY COMPETENT CARE

Culturally competent care is a term defined in transcultural nursing, which is interested in study and comparing of cultures. On the basis of comparative exploration transcultural nursing tends to amass the information for planning both specific and universal cultural care. (Leininger, 1991, 28-29; Andrews & Boyle, 2012, 4)

Cultural competence is the dynamic process, where nurse efficiently works with patient from any cultural background and is able to provide care that is suitable for an individual, namely, responding to person's wishes concerning cultural, linguistic and social aspects (Campinha-Bacote, 2002, 181-184; Betancourt, Green & Carrillo, 2002, 2). It has multicomponent structure, which includes cultural awareness, cultural knowledge, cultural understanding, cultural sensitivity, and cultural skills (Rosenjack-Burchum, 2002, 5-16).

Culturally competent care includes reciprocal actions between nurses and patients and, as a result of interaction, gives the protection and the sense of presence (Kavanaugh, & Hershberger, 2005, 2). If nursing care accepts the uniqueness of the individual and implements numerous means or methods, the result is the desired culturally competent care. In contrast, if nurses are incapable to manage obstacles aroused in cultural context, the culturally congruent care is unachievable. Practical application of full transcultural assessment, however, is not always possible because of lack of time, employee shortage and other concerns (Fletcher, 2002, 86-90), so providing the list of unique and shared features desired by representatives of different background would be of great help for health professionals. However, this differences and similarities should not be used in thoughtless application to any patient or client, because this is rather a preliminary guide only.

### **Leininger's theory of Culture Care Diversity and Universality**

This study was inspired by the Leininger's theory of Culture Care Diversity and Universality. Leininger defined care as "learned, shared and transmitted val-

ues, beliefs, norms and lifeways of a particular group that guides their thinking, decisions, and actions in patterned way” (1995, 47). Important to mention, that she did not state that culture is equal to ethnicity or religion. This means that culture is solely any group with common principles, values or beliefs (Srivastava, 2007, 14-15). Thus, ethnicity, geographic location and religion or beliefs, but not necessarily limited to it, can be included in culture (Canadian Nurses Association, 2004, 2).

Leininger (1991, 34) defined her theory as “sets of interrelated concepts, meaning and experiences.” Based on her theory, she predicted to find both diverse and universal patterns and characteristics of care. She also insisted that knowledge should be collected from the people, to be seen from the emic perspective, and not to be spread from professional system, correspondingly, etic perspective, or at least regarded them as equivalent in significance. At last, the nurses should adapt their patterns of care to be able to offer clients, indeed, culturally competent care (Leininger, 1991, 36-37; Leininger, 2002, 48). In regards to visual representation of Culture Care theory, Leininger appealed that the Sunrise model should not be seen as purely theoretical. Rather, Sunrise model is a mind map to highlight the fundamental ideas and their relationship and interaction in holistic view (Leininger, 1991, 49). (See Appendix 1.)

The advantage of the theory is that it is flexible and can be applied widely (Leininger, 1991, 52; Andrews & Boyle, 2012, 6). Even though it has been created six decades ago, the theory of Culture Care Diversity and Universality is still practical.

Nevertheless, some researchers criticize Leininger for her making the trend in nursing for creating lists of main themes for some cultures explored, for searching what could be the universal and diverse in nursing care. For instance, Juntunen (2007, 83-84) stated that this is ready made lists for over-generalized stereotypes and do not include familiar determinant. The individual factors should equally be considered. Though, Leininger did consider individual and familial elements (1991, 45-49). She pointed that term *universal* is not absolute; rather it applies to similar pattern (Leininger, 1991, 47).

## 5 PURPOSE AND AIMS OF THE STUDY

The purpose of this study was to investigate the expectations of the parents from multicultural settings on the preferable support they can receive from nurse during perinatal loss. The aim of the study is to provide information of culturally meaningful care provided for families after the loss of a baby.

### **Research question:**

What are the expectations of the parents from multicultural settings on the preferable support they can receive from nurse during perinatal loss?

## 6 IMPLEMENTATION OF THE STUDY

### 6.1 Literature Review

The methodology of this thesis is a literature review with systematic approach. This is the suitable method for this study because it is a reproducible method with results, which are lessened in bias in comparison to narrative reviews. As a consequence, the work yields trustful results.

Webb & Roe (2007, 257) define literature review as “research on research” with agreed on and described beforehand procedures of searching the materials, assessing their quality and eligibility, and summarizing the data. Crucial is the preceding definition and description of the principles of accepting and rejecting the initial data reports and working with data: all is done in consideration to avoid partiality in any step in conducting the research from gathering the data to concluding the findings. The steps of working process is described precisely, thus everybody could re-create it (Fink, 2005, 3-5).

In simple terms, literature review consists of several phases: defining the question of interest, obtaining the studies, assessing the quality of founded materials and application of criteria screen to select the suitable studies, and summing up the findings (Glasziou, 2001, 4; Parahoo, 2006, 134).

A review could be perceived as reliable if extensive sources of data are examined with rigid rules applied. In addition, it is critical for researchers not to take only studies supporting their initial ideas, but also analyses of all available data, not hiding any reasonable facts that may contradict with primary ideas. (Aveyard, 2010, 9-10.)

Nowadays the significance of qualitative review rises in the health care sector. So does the tendency of qualitative review to be more and more applicable methodology in health care for several reasons (Ropay, Rogers & Williams, 1998, 342; Aveyard, 2007, 1).



Beneficial for the reviewers, all data is seen in context. Usage of the literature review as a research method allows gaining new comprehension of the facts (Aveyard, 2007, 5-8; Bryman, 2013, 105).

Beneficial for nurse practitioners, literature reviews offer ready synthesis of relevant studies, and there is no need to be acquainted with every single piece of related literature (Mead, 1996, 33-36; Aveyard, 2007, 6). Therefore, practitioners can use the synthesized researches instead of “attempting to interpret” separate facts. That is how literature reviews refers to and develops evidence based medicine (Aveyard, 2007, 7; Krainovich-Miller, 2008, 88).

Then, the literature review gives “the consistency of results”. Namely stand-alone reports may not be represented enough to give reliable answer because of small sampling to researched question. However, combination of the reports pursuing the same question allows seeing the whole picture (Glasziou, 2001, 1)

Principal goal of a literature review is to represent clear and logical overview of ideas or concepts which are prominent for the particular topic at present moment (Hart, 1998, 173; Meechan, 1999, 63; Aveyard, 2007, 5).

To conclude, literature review stands aside of narrative review owing to the fact that it employs techniques for selection, the quality assessment and summary, which are recorded before the search. Therefore results of the studies may not influence the opinion of the reviewers. This is done in order to lessen any preconception (White & Schmidt, 2005, 54-60) and validate process as truly transparent and replicable (Tranfield, 2003, 209). Thus, the literature review produces more reliable results, which is more beneficial for nursing practice.

In spite of that, Bryman (2013, 108) reminded about criticism of systematic approach: there is a tendency to value precise procedural description more than the conclusions formulated. However, its' structured composition and possibility to repeat the process ensures the researcher acted to gain objectivity of the study (Bryman, 2013, 390-393).

## 6.2 Literature Search

Thoroughly made literature review is composed of not only of materials retrieved by electronic search, but also found with manual search, exploration of references in related studies and consultations with professionals if applicable to research question (Avenell, Handoll & Grant, 2001, 509; Stevinson & Lawlor, 2004, 230-231; Fink, 2005, 42).

The reviewer performed literature search during May 2013 with preliminary test search done to refine the keywords. The test search was performed in order to ensure the data relevant for answering the thesis questions will be found. The databases suitable for searching based on content are CINAHL, EBSCO Academic Search Elite, Biomed Central, PubMed, Journals@Ovid, and Elsevier ScienceDirect. Although running more than one database consumes time, using multiple databases was done to considerably decrease the risk of relevant study to be overlooked (Avenell, Handoll & Grant, 2001, 508-509; Stevinson & Lawlor, 2004, 230-231; Krainovich-Miller, 2006, 90).

The next keywords were used: perinatal, loss, death, grief, bereavement, pregnancy, cultural, culture, practices, culturally competent care, newborn, infant, expectations, family, support, psychological, psychosocial and combinations of these keywords.

Based on test search, the next databases for searching of research articles were chosen: CINAHL (EBSCO), EBSCO Academic Search Elite, Elsevier Science Direct, and Journals@Ovid (OVID). Sometimes the articles listed in one database, for example, in CINAHL, have only abstract there or is paid article. So the article were searched in other databases, to find it as free full text if possible.

The primary intent was to perform identical search in several databases, but test searches confirmed that search strategy for every database should be considered differently. The explanation for it is that databases are not made by one structure, and, correspondingly, indexing rules and logic are different. To achieve maximal inclusion of needed material the use of Boolean search

operators (AND, OR) was implemented, because this method allows researcher to perform detailed search and be sure that no significant study is missed (Ford, 2012, 106-131).

Several searches for one database were implemented for the reason to find as much research articles as possible. The following keywords were used: perinatal loss OR perinatal death OR fetal death OR newborn Death OR still-birth or pregnancy loss; family support OR psychological support OR psychosocial support or parental grief OR bereavement. (See Appendix 2.) No keyword as “ethnic” or “ethnology” or direct mention of culture or race was used as it proved for test search to significantly narrow the results.

Many obviously relevant articles were located among paid articles, so the articles were retrieved via Google search engine to find this article for free. Nine such relevant articles were indexed in Elsevier Science Direct database. Additionally searching of the reference lists of the articles was found to be useful. Especially review articles were beneficial in finding relevant studies, most of them were not found in databases during search process.

### **6.3 Inclusion and Exclusion Criteria**

The selection criteria were created for search the research articles and related books to select needed data.

#### **Inclusion criteria**

- Choice of sources was limited to nursing and related databases and journals.
- Publication date was limited to a range from 2000 to up to date, 2013.
- Articles and reports written in English language.
- Articles available online full text.

- Articles available as free of charge.
- Articles referring to perinatal loss as to period from any pregnancy loss to babies lost at the age of one month.

### **Exclusion criteria**

- Based on content (other than physical death of the only child)
- Articles not aimed at considering parents' perceptions or expectations
- Literature review articles

## **6.4 Selection Process**

The next flow chart (Fig. 1) shows the sequence of search selection. In manual search the relevance of the article was made at once based on inclusion criteria to avoid counting the article as relevant and then remove it as not completely suitable based on selection criteria.

The articles were assessed for relevance first by titles, and then by abstracts. If no abstract was available, the article text was sought and read to check whether it is relevant to thesis question. All selected articles were checked for methodological rigor.

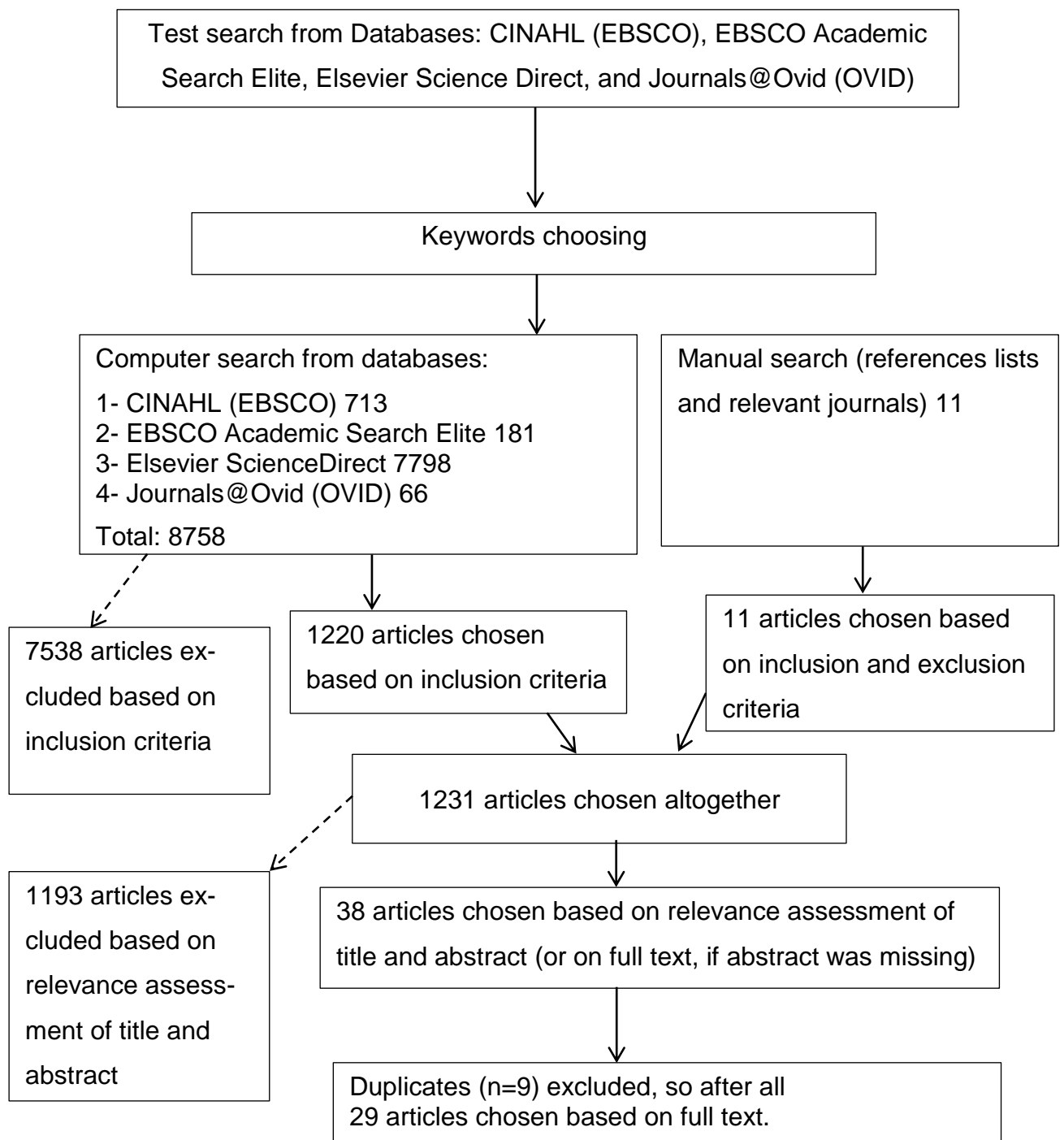


FIGURE 1. Selection process

## 6.5 Summary of Selected Articles

In total twenty nine (n=29) articles were accepted as eligible according to inclusion and exclusion criteria and based on title, abstract and free full text. (See Appendix 3.) All articles were found as free text. The representation of the articles by database is shown in table 1.

<b>Database search</b>	<b>Articles selected</b>
Ebsco Academic Search Elite	2
CINAHL	2
Elsevier Science Direct	8
Ovid	5
Manual search	12
<b>Total</b>	<b>29</b>

TABLE 1. Article selection by database

Twenty one (n=21) articles represented single cultural background, while eight (n=8) were mixed. African or African American parents views were examined in five (n=5) articles, either as US parents of African American origin, African mothers from South Africa, or Nigerian mothers. Articles, which considered specifically the viewpoints of Muslim parents were two (n=2); one article was devoted to culture of Malays Muslim mothers and one article represented mixed ethnic Muslim mothers living in Sweden. Articles, which researched views of Caucasian parents, were two (n=2), one from Ireland and one from South Africa, where respondents were deliberately selected to know either English or Afrikaans, thus excluding aboriginal mothers from participation. The rest articles referred not to ethnicity, but to cultural group living in some geographical location, without division of respondents answer according to their origin.

Researchers were mainly interested in mothers' perceptions, as this type of articles were represented by eighteen studies (n=18). Then ten studies were

concentrated on families experiences, and only one study was interested namely in men's perceptions.

Geographically articles were mostly written in US, represented by eleven articles (n=11), then four (n=4) in UK, three (n=3) for South Africa and three (n=3) for Sweden, and, finally, France, Ireland, Norway, Malaysia, Nigeria, Scotland, Taiwan and Vietnam researchers published one article each.

All but two (n=2) articles were qualitative data. Postal survey as a tool was implemented in three studies. Mainly researchers handled in face-to-face interviews with participants, or, as in three studies, mostly or partly via phone; the choice depended on wish and possibility of the respondents. The total amount of participants was 1275, with the age of participants varied from 18 to 54 years. The age of lost babies ranged from early pregnancy loss (5 weeks) to one month after birth. Generally the age of lost babies was around 22-26 weeks.

## **6.6 Analysis and Synthesis Details**

The method of data analysis was thematic analysis. This method was chosen due to its flexibility because it may be used with qualitative and quantitative data and allows inductive approach (Dixon-Woods, Agarwal, Jones, Young, Sutton & Noyes, 2008, 91). Thematic analysis now is apparently the most predominantly used method in qualitative analysis of data (Bryman (2004, 578). It shares some common traits with content analysis, but the main idea is not finding out the frequency of categorized data (Bryman, 2001, 183), but let find themes, which are constantly repeated in the data, and provide overall review of the conclusions of assessed studies (Dixon-Woods et al, 2008, 91).

The inductive approach, which is applied by thematic analysis, is such a research technique which allows the reviewer first to amass the evidences from the data and facts related to the specified topic of interest. After analysis the reviewer proposes findings. (Davies, 2007, 238) In other words, the text is

read, repetitive words, phrases or meanings are noted and recorded. Next, information is put into separate groups according to the content (leMay & Holmes, 2012, 87). Consequently, the common patterns are identified and interpreted, and finally, conclusions are made.

The articles were read several times and the analysis was made by extracting the perceptions of the parents toward care they received after perinatal loss. The perceptions were written on A5 paper, clipped to each article. After the first analysis was made, the results were tabulated in MS Excel from this paper with the subsequent time reading the article, to ensure that correct meaning is grasped. The tabulated spreadsheet consisted of 255 single ideas or topics from 29 articles. Each idea was categorized, according to its meaning and overview. After that, the categories were rechecked to ensure full relevance of ideas and categories they were allocated.

The ideas expressed by parents were subsequently grouped into seven categories and some were given metaphoric names: 1) 'most helpful interventions', 2) 'from guilt to anger', 3) 'ask instead of guessing', 4) 'communication is the key', 5) expectations of supportive health care providers, 6) self-healing strategies, and 7) 'life after loss'.

## 6.7 Critical Appraisal

Researchers agree the critical appraisal of initial research article should be done (Dixon-Woods, Fitzpatrick & Roberts, 2001, 130). However, they still do not reach agreement on how to perform critical appraisal of qualitative data (Dixon-Woods et al., 2001, 130; Hawker, Payne, Kerr, Hardey & Powell, 2002, 1292). Seale and Silverman even reminded about possibility of "methodological anarchy", if methodological quality would not be accessed, which, according to them, easily may lead mistrusting validity of the study (1997, 380). Nevertheless, the exclusion of the study should not be based exclusively on poor quality (Mays, Pope & Popay, 2005, S10).



For the purpose of assessing the quality of the research article, this study used the adapted appraisal tool originally suggested by Hawker et al. (2002, 1296-1297) and adapted by Gomes, Calanzani, Gysels, Hall & Higginson (2013, 12-17). (See Appendix 4.) The tool provides the score from 1 “poor” to 4 “good” for every element assessed in the study, such as introduction, aims, method, sample, data analysis. The total score is summed up to see the quality of the article, ranging from 9 “very poor” to 36 “good”. (Hawker et al., 2002, 1292) Later Gomes et al. (2013, 12-17) suggested dividing ethics and bias into two separate elements to assess. This is, indeed, necessary, because ethics and bias are two dissimilar components to be attempted to assess as one element.

The benefit of this tool is that it adds the consistency in evaluating quality of articles irrespectively of its design or method. So, it is practical to print out and use a single tool for all articles, instead of printing all checklists for every type of study design. Moreover, this tool helps in visually comparing the methodological rigor of every used article.

## **7 ETHICAL CONSIDERATIONS**

### **7.1 General Principles**

Integrity and objectivity are crucial in nursing research. Objectivity requires precise presentation of data (Walliman, 2011, 244). Integrity refers to performing investigation cautiously and accurately. Besides, the results of the study should be presented honestly and without distortion or selectivity. The integrity implies the concept of credibility or trustworthiness (Khanyile, Duma, Fakude, Mbombo, Daniels & Sabone, 2006, 41; Walliman, 2011, 242-244). For the purpose of declaring credibility, the research articles were cited or located in professional nursing databases.

The work followed the principles of research ethics to avoid plagiarism, falsification and fabrication, motivating the researcher to act “... honestly, meticulously and precisely.” (Ethical Principles for JAMK University of Applied Sci-

ences, 2009, 6)

**Plagiarism** is defined as not giving the credit to authors for their ideas or written work (Walliman, 2011, 240-241; Bryman, 2012, 124-125). Therefore, the authorship of ideas was indicated according to JAMK written instructions (Liukko & Perttula, 2010, 19-30).

**Falsification** is the selectivity in choosing the suitable data which confirm the initial reviewer's idea or excluding the data which does not support the idea (University of Minnesota: Center for Bioethics, 2003, 27). This was avoided by following the strict rules of selection, analyzing and synthesizing, which were defined before starting the work.

**Fabrication** is defined as the creation of false data and later on reporting it (University of Minnesota: Center for Bioethics, 2003, 27). Fabrication is not applicable to this literature review, as no data were created and reported.

The personal opinion did not influence the collection, analysis, synthesis of data and presentation of results. Eligibility criteria and critical appraisal method should be and were documented before search to lower the personal partiality (Akobeng, 2001, 847).

## 7.2 Validity and Reliability

**Validity** is defined as "The degree to which the results of a study are likely to be true, believable and free of bias" (Buckingham, Fisher & Saunders, 2008). Conformably to this study as it deals with research articles, the validity of conclusions made in literature review purely depends on the quality of research materials which were used for it (Akobeng, 2001, 846; Centre for Reviews and Dissemination, 2009, 10).

While Akobeng (2001, 846) states that only systematic approach in a review on its own is not enough to claim the review as valid. Further he hopes that unambiguous and detailed described procedures in the literature review con-

tribute to reliability. Conversely, Victor (2008, 1) opposes that itself the structure of review is advantageous. The arrangement of research process with its exhaustive search of literature and use of inclusion/exclusion criteria, critical appraisal, documented process of analysis and synthesis, makes possible assertion of getting significantly more trustworthy and valid conclusions than those got without systematic approach.

### **Risk of bias**

There are some biases that are probable threats to validity: publication bias, selection bias, language bias, availability bias, and cost bias (Rothstein, Sutton & Borenstein, 2005, 2-3; Torgerson, 2006, 90-99). Risks of each bias were assessed carefully in order to minimize chances if possible.

In this study the inclusion criteria says that the research articles data is to be in English; as not all potentially relevant reports and studies are translated into English, there can be probability that a potentially relevant report would be excluded and its data would not be considered at all (Centre for Reviews and Dissemination, 2009, 10).

Selection bias is overcome due to inclusion and exclusion criteria documented before the initial search. Consequently, systematic review is in some way protected from this bias (Torgerson, 2006, 90). From the other side, at least two reviewers should work on a review to lower the possible bias (Akobeng, 2001, 847), since if only one reviewer works on a review, it is possible that reviewer would miss on average eight per cent of relevant studies, ranging in different cases from 0 to 24 per cent (Edwards, Clarke, DiGuseppi, Prata, Roberts & Wentz, 2002, 1635).

The cost bias is also very probably as the second inclusion criteria states that only free of charge articles would be considered. So far, as this research is not funded and is performed as undergraduate research, the cost issue is quite critical.

Finally, the availability bias is efforts to overcome, for instance, sometimes the

relevant articles are listed, but not located in the same databases and is not linked to databases, so choosing the option that full free article is linked is on the same time greatly saves the time, yet impose the restriction on articles' choice. Yet, to reduce this, the reviewer aimed to search the article in other databases, not necessarily where it was cited or searched initially. Such possibility was proved by preliminary search and successful location of the articles.

**Reliability** is defined as reproducibility and that another researcher could repeat the review and gain same conclusions (Downing, 2004, 1006; Bell, 2010, 119). The careful documenting of each step while conducting this review makes possible for other reviewer to repeat the whole process. In fact, validity and reliability are closely interrelated, by way of validity follows the reliability (Bryman, 2012, 173).

## 8 FINDINGS

### 8.1 'Most Helpful Interventions'

The most assistive interventions from the parents view are the confession of parents' status and the existence of baby, less restrictive visiting rules at hospital, the significant amount of time spent with the baby, encouragement of activities, which parents may implement to feel their parenthood, correctly performing farewell rituals that are important for the family, the creation of memories and mementos and, finally, special attention to mother.

**Acknowledgement of parents' status and existence of baby** are the most often required interventions irrespectively of cultural background. The acknowledgment of parents' status as of parents and validation of the loss as real event with its tragic consequences have positive impact on physical and emotional condition of the parents. (Corbet-Owen & Kruger, 2001, 418-419; Lundqvist et al., 2002, 194-196; Hsu et al., 2002, 391; Kavanaugh et al., 2004, 8; Kavanaugh & Hershberger, 2005, 601; Simmons et al., 2006, 1939; Ar-

mentrout, 2007, 1939; Kelley & Trinidad, 2012, 1939; Branchett & Stretton, 2012, 1939; Cacciatore et al., 2013, 1939)

Of same importance is to validate the baby birth (Hsu et al., 2002, 391-392) and to respect the baby, mentioned by Swedish fathers and South-African mothers (Modiba & Nolte, 2007, 11; Cacciatore et al., 2013, 667). Same is supported by the study from South Africa, where mothers from white population revealed that it is distressing to see nurses behaving as loss never happened with them (Corbet-Owen & Kruger, 2001, 419). Nonetheless, different results were shown by Hunt, France, Ziebland, Field & Wyke study of UK women (2009, 1118), when one woman described the behavior of nurses relating to her baby as to real baby and wanted to nicely dress him up as really upsetting her, as she herself felt this was not “baby”, but “phoetus”.

**Visiting rules at hospital** should be limited and changed to be less strict. Mainly participants mentioned the best interventions during their stay in the hospital. They were: let the father to be in the same room as the mother for Swedish mothers (Lundqvist et al., 2002, 194), permission for the unlimited amount of visitors and the extended family to come to see the parents and the baby whenever they wish for South African mothers, Swedish mothers and Muslim mothers living in Sweden, (Lundqvist et al., 2002, 194; Lundqvist et al., 2003, 81; Conry & Prinsloo, 2008, 6,). Yet, some Muslim mothers noted that they choose only close relatives to be with them at that time (Lundqvist et al., 2003, 81).

**Time spent with baby** improves the psychological condition of parents. US mothers, South African mothers and Swedish parents expressed their satisfaction with letting them to hold and spend time with the baby, though mentioned spent time was felt as too short for them (Sanchez, 2001, 26; Conry & Prinsloo, 2008, 6; Säflund et al., 2004, 134).

**Parenting activities** are enjoyed by parents. Many parents from UK and US appreciated time spent with baby, such as holding, bathing, dressing (Armentrout, 2007, e7; Kelley & Trinidad, 2012, 6; Downe, Schmidt, Kingdon & Heazell, 2013, 6). Some parents (from UK study) regretted they refused to take

action in such activities. Later they disclosed they feel that nurses could and should be more convincing in discussion whether to participate (Branchett & Stretton, 2012, 42; Downe et al., 2013, 6). Even so, in Bennet et al. study the opinions about significance of parenting activities differed within the group: the majority of mothers considered holding and seeing the baby as very beneficial intervention, still some women see it unhelpful (2008, 499).

**Rituals** are very significant for Muslim mothers from Sweden. More than that, it was mentioned that special knowledge is needed. For instance, specific person should wash the baby, not the hospital staff or mother, not mentioning other aspects of farewell rituals (Lundqvist et al., 2003, 83).

**Memories and mementos**, where last are defined as tangible items, that serves are a reminder or holding memory such as baby cloth, baby locks, foot or handprint, quilt square or birth certificate, are crucial for most families. In particular, African American, South African, Norwegian women, parents from United States, Sweden, United Kingdom, and Swedish fathers acknowledged the creation of memories and taking mementos. (Sanchez, 2001, 28; Van & Meleis, 2003, 34; Kavanaugh & Hershberger, 2005, 601; Conry & Prinsloo, 2008, 6; Kelley & Trinidad, 2012, 6; Cacciatore et al., 2013, 668.)

**The importance of creating memories** is shown in several studies. Trulsson & Rådestad (2004, 194) noted that without them anxiety level rises considerably. While Säflund, Sjögren & Wredling (2004, 135) who studied Swedish parents got answers that such tangible memories assist and ease the process of grieving. UK parents confessed they prefer to have such photos just in case they would like to see them later, not necessarily immediately after the perinatal loss. All parents, except those, whose baby was surgically terminated, appreciatively took photos. Furthermore, even in case of surgical termination, two women after such surgery regretted they did not have photos (Hunt et al., 2009, 1117-1118). UK parents (Downe et al., 2013, 5) mentioned photos as "one of the most important" interventions. Couples from UK study of Branchett & Stretton (2012, 42) lamented afterwards that have insufficient amount of photos.

In contrast, Muslim women mentioned that any mementos are provoked more grieving and, thus, are not assistive, but making it worst, as a constant reminder. Some women nonetheless said they may agree to take photos while the baby is still alive, but not after passing away (Lundqvist et al, 2003, 82).

**Special attention to mother** is felt as supportive, that included as nurse holding mother's hand, combing mother's hair and talking to her (Sanchez, 2001, 26; Lundqvist et al., 2002, 194). Opposing findings were from US study of Freda et al., (2003, 22) where all women wanted to be left alone for some period.

## 8.2 'From Guilt to Anger'

Parents go through various emotions and feelings, affecting their psychological and physical condition. Nurses have to take it into serious consideration as the emotional state of parents affects their ability to understand and express themselves, as well as the ability to participate in the process of interaction with health care providers after perinatal loss.

**Guilt and self-blame** are the most prominent feelings for parents. This obvious feeling was mentioned by parents from South Africa, Taiwan, US, African American, Vietnam, Malaysia, UK, Sweden (Corbet-Owen & Kruger, 2001, 420; Hsu et al., 2002, 391; Freda et al., 2003, 20-21; Maker & Ogden, 2003, 410-411; Säflund et al., 2004, 135; Kavanaugh & Hershberger, 2005, 599; Modiba & Nolte, 2007, 7; Gammeltoft et al., 2008, 49; Sutan & Miskam, 2012, 7; Branchett & Stretton, 2012, 44; Downe et al., 2013, 3).

The feeling of guilt is often happens because mothers do not know the real reason for baby death and supposed their body, health condition, lifestyle or actions were the main cause of the baby's death (Simmons et al. , 2006, 1943; Maker & Ogden, 2003, 410 ). A very supportive involvement that often helps mothers is that it is enough to know that no intervention could change the happening (Corbet-Owen & Kruger, 2001, 420).

**Anger and irritation** are constant feelings, mentioned in several studies, with predominantly white respondents, Irish mothers, studies for US and UK mothers and Malaysian Muslim mothers. (Freda et al., 2003, 20; Maker & Ogden, 2003, 407; Bennet's et al., 2008, 497; Kelley & Trinidad, 2012, 8; Sutan & Miskam, 2012, 7; Mulhivill & Walsh, 2013, 7; ) Freda et al., 2003, 20, who have studied the perinatal loss of women previously suffered from infertility, also pointed out that these women distinguished their grief as more profound in comparing to women who seemingly have another chance to conceive and sometimes directed their anger at other women who followed their pregnancy seemingly successfully or at God. Anger may also be pointed at nurses or other health care staff or even family (Kelley & Trinidad, 2012, 8) or at baby (Modiba & Nolte, 2007, 7). Needed to say, UK women remarked that "anger and sadness" diminished with the flow of time. These feelings were significantly less intensive at the moment of interview, which was approximately five weeks later (Maker & Ogden, 2003, 407-412).

**Isolation** can be felt even in in presence of other people, as US mothers stated (Kelley & Trinidad, 2012, 8; Freda et al., 2003, 21). Separation with the baby increased impression of isolation for UK parents (Downe et al., 2013, 3). Swedish father admitted that inclusion of parents into the process as participants is important and was promised in words by health care professionals, but in reality this inclusion does not happen (Cacciatore et al., 2013, 667-668). UK parents indicated that they feel more positively when actually included into process; and if receive no support, they experience isolation (Maker & Ogden, 2003, 410; Branchett & Stretton, 2012, 44).

**Attitude toward pregnant women** is complicated by mixed feelings. UK and Ireland parents expressed difficulty to meet with other pregnant women. Such encounters intensified their suffering and provoked unpleasant thoughts (Mulhivill & Walsh, 2013, 8; Branchett & Stretton, 2012, 43).

**Other feelings** are the sense of disorientation, shock condition, "feelings of denial and upset", vulnerability, high level of distress, and worthlessness was likewise mentioned in studies of Swedish mothers, South African mothers, UK,



US and Ireland parents (Lundqvist et al., 2002, 194; Freda et al., 2003, 20; Maker & Ogden, 2003, 408; Bennett et al., 2008, 497; Kelley & Trinidad, 2012, 4-6; Mulhivill & Walsh, 2013, 7). UK mothers mentioned they experienced feelings of "anxiety and pressure", because the woman could not give birth (Maker & Ogden, 2003, 412). Study of Corbet-Owen & Kruger (2001, 423) revealed the contradictory viewpoint of white mothers of South Africa concerning talking about hope: while someone wishes the nurse would talk with them about hope, the other prefers not to hear about hope at all.

### 8.3 'Ask Instead Of Guessing'

**Asking parents instead of guessing** is the important advice from the families. They prefer to be asked directly, so the interventions are suited for the needs and demands of particular person or family couple (Corbet-Owen & Kruger, 2001, 420; Lundqvist, et al., 2002, 194; Trulsson & Rådestad, 2004, 194; Kavanaugh & Hershberger, 2005, 602; Kelley & Trinidad, 2012, 6-7).

**Both parents are equally important** for addressing the interventions. The nurse should not pick up only mother as main object of asking and caring, or address the interventions to the father, assuming that mother is too exhausted or the father might not be interested. Such one-sided attention may bring additional emotional misbalances and worsen emotional condition of neglected parent (Sanchez, 2001, 27; Kelley & Trinidad, 2012, 6-7).

### 8.4 'Communication is the Key'

**Communication** is a very powerful and supportive intervention. For instance, all parents from mixed study of Armentrout (2007, e8) for white, Hispanic, and African American parents revealed that non-critical discussion about the event and the baby with a friend or someone who experienced the same, brings the maximum relief for the parents. It could be considered under interventions theme, but due to a large amount of answers and notions about communica-

tion after perinatal loss, it positioned into separate topic. Communication itself helps parents to be the “part of the process” as Norwegian women stated (Trulsson & Rådestad, 2004, 190-193) and is very essential as confessed by Irish parents (Mulhivill & Walsh, 2013, 5).

**More information** is required by parents. The topics for discussion are various: about current situation, future procedures and what would be in the future, what should parents do, and whom to call to and when; baby health status, cause of baby death, grieving support, and possible coping strategies. This strong request was expressed by parents from Sweden, Vietnam, US, UK, and South Africa (Sanchez, 2001, 27; Lundqvist et al., 2002, 196; Gammeltoft et al., 2008, 50-51; Conry & Prinsloo, 2008, 7; Sejourne et al., 2010, 407; Branchett & Stretton, 2012, 43-44; Kelley & Trinidad, 2012, 4-8).

**Full, honest information and simple terms** should be used during communication with parents. Understandable and truthful information gives the impression of empowerment, as parents got impression as now being able to control their lives. This is true for parents from UK, and white mothers of South Africa (Corbet-Owen & Kruger, 2001, 420; Simmons et al., 2006, 1942-1943; Branchett & Stretton, 2012, 43).

**Carefully chosen words and encouragement** are significant for US mothers and parents (Sanchez, 2001, 27; Kavanaugh et al., 2004, 8). A ruthless word could severely harm the condition of the families and should be avoided.

**Timely given information** should be provided exactly when it is needed, not beforehand because parents may not be able to keep that in mind for long, or afterwards, when it is not required anymore, and, in addition, to give parents time to process it, as parents from UK and Sweden noted (Säflund et al., 2004, 134; Hunt et al., 2009, 1114; Downe et al., 2013, 6). Parents from United Kingdom, in particular, mentioned they were given information brochure after they have made certain decision, and if they get brochure before, it would affect their decision, so they could have more options to consider (Hunt et al., 2009, 1115).

**Wish to talk and to be listened** is expressed by parents as mentioned in study of African American women to be listened without “criticism and judgment” (Van & Meleis, 2003, 22). Fathers and mothers from Ireland, African American origin, parents from US, likewise pointed out such desire (Van & Meleis, 2003, 35; Kavanaugh et al., 2004, 7; Modiba & Nolte, 2007, 7; Mulhivill & Walsh, 2013, 9). US parents admitted that they feel distressing when try to talk that (Kelley & Trinidad, 2012, 9). Mothers from South Africa from white population described they were ignored if they asked questions or wanted to discuss the event (Corbet-Owen & Kruger, 2001, 418).

## 8.5 Expectations of supportive Health Care Providers

Parents in their answers clarified the features of the supportive nurse as a representative of health care providers, whose actions, behavior and characteristics will show that these families are truly cared for.

**Notice of parents’ condition** is expected by parents from nurses. The ability to notice the emotional condition of parents, which influences parental well-being, guides the actions and affects the understanding of what has been said. Therefore the thoughtfulness of their decision and inclusion into the process depend on the parents’ condition. (Kelley & Trinidad, 2012, 6; Downe et al., 2013, 3)

**Sensitivity, empathy and sympathy** are the most important features of the nurse while dealing with parent. As an illustration, the comment from a nurse of possibility later to have another, alive, baby for a US mother was felt as strongly insensitive and inappropriate (Kelley & Trinidad, 2012, 8.) Then Modiba & Nolte (2007, 11) noticed insensibility of health care providers mentioned by one South African mother. She did not get proper attention because she was delivering a stillborn. Quite often parents from UK, US and Sweden indicated that phrases or manners of health care professionals were perceived as tactless and indelicate (Simmons et. al., 2006, 1942; Kelley & Trinidad,

2012, 8; Branchett & Stretton, 2012, 42; Cacciatore et al., 2013, 668; Downe et al., 2013, 6).

Subsequently empathy is the awaited from and nurses, in the first place, and other health care providers (Branchett & Stretton, 2012, 42; Kelley & Trinidad, 2012, 6). UK women noted the obvious deficiency of empathy of health care providers in the Simmons et al. study (2006, 1942). On the contrary, Swedish mothers reported that for the most part nurses and health care providers showed empathy toward them (Lundqvist et al., 2002, 194). Expressed emotions such as tears, are regarded as positive sign of empathy, not as unprofessionalism. Accordingly, US parents mentioned that they are grateful to see they are not alone in their suffering (Kelley & Trinidad, 2012, 7). The empathy changes and shapes the message to be perceived as more appropriate and compassionate (Säflund et al., 2004, 134-135). Sympathy is the sense eagerly awaited from nurses by Swedish mothers and African American parents (Lundqvist et al., 2002, 194; Kavanaugh et al., 2004, 8).

**Personalization of care** is especially welcomed by African American parents, white mothers from South Africa and Swedish mothers. Personal care is ensured by asking by nurse what are parents' needs and wishes at the present moment (Lundqvist et al., 2002, 194; Kavanaugh & Hershberger, 2005, 599). South African white mothers confirmed they feel indeed special if the care is matched to their needs (Corbet-Owen & Kruger, 2001, 421).

**Presence of the nurse** helps parents from Sweden and United States. Being present means not only that nurse is at place when parents call for her, but also checking their condition and supporting them from time to time by her/his own urge. (Lundqvist et al., 2002, 194; Kavanaugh et al., 2004, 7; Kelley & Trinidad, 2012, 7; Cacciatore et al., 2013, 667)

**Other expectations of the supportive nurse** include the special education in dealing with grieving parents. South African white mothers expressed their wish to communicate with the specially educated person, who knows how to interact with parents in grief (Conry & Prinsloo, 2008, 7). Mothers from United Kingdom also noticed the health care providers do not in fact have knowledge

of support, so parents would appreciate the availability to interact with nurse educated how to work together with grieving parents (Simmons et al., 2006, 1943).

**Proper administration** is awaited from health care providers. Mothers from US noted that health care administration should suggest and organize suitable variants for residence. Most say they are very displeased to hear the crying of other babies and understand that other women happily gave birth to their babies. They would prefer other ward rather than maternity ward. (Sanchez, 2001, 27; Freda et al., 2003, 21-22; Downe et al., 2013, 6) Though, Irish mothers say that not necessarily maternity ward is unsuitable, women may prefer any ward, including ward with mothers and babies (Mulhivill & Walsh, 2013, 6-7).

**Ensuring privacy** is the wish expressed by numerous respondents of studies of Irish, Vietnam, Malaysia Muslim women, US and UK parents. The noise, sounds and observation of other's normal life like pregnancy or living babies is difficult to stand and constantly remind their situation of loss to parents. (Gammeltoft et al., 2008, 50; Sutan & Miskam, 2012, 7; Kelley & Trinidad, 2012, 6; Branchett & Stretton, 2012, 42; Mulhivill & Walsh, 2013, 7.)

Studies of Freda et al. (2003, 21-22) and Kelley & Trinidad (2012, 6) also revealed improper ward management, such as, specifically, badly organized information flow and care chain. As a result mothers have to explain constantly to nurses that they have just lost the babies. Even if the information paper is on the door of the room, sometimes mothers have to clarify to every coming nurse the absence of the baby in the room. The parents also mentioned they have to correct errors in documentation. (Sanchez, 2001, 27; Branchett & Stretton, 2012, 43.)

## 8.6 Self-Healing Strategies

Nurses may support mothers by finding the appropriate coping strategy which answers the women need and wishes (Van & Meleis, 2003, 35; Bennett et al., 2008, 504). It is important to remember that not all strategies could be applied to all parents, but these strategies were useful for some parents in certain periods of time (Armentrout, 2007, e8). So, as African American women noted, the best way to find the most appropriate strategy is to let women to listen to her “inner voice of healing”, which would prompt the proper way of recovery (Van, 2001, 236).

**Religion, Meditation, Faith or Spirituality** are often mentioned as self-healing approach. For African American women in Van’s study (2001, 237) it is helpful to think that the baby now is “in safe place”. Parents in study with mixed cultural background (thirteen white, one Hispanic, and one African American) felt positive to consider that in a time to come they will meet again with the their baby (Armentrout, 2007, e9). Malaysian Muslim mothers think that religion alleviates their sorrow (Sutan & Miskam, 2012, 7-9). African American parents and couples from United States mentioned that religion, meditation or spiritual activity let them feel better (Van & Meleis, 2003, 33; Van & Meleis, 2003, 33; Kavanaugh & Hershberger, 2005, 602).

**Anticipation of new pregnancy** is one of best coping strategy for several families from Taiwan, US and African American origin, as “..a healthy subsequent pregnancy would be part of healing” (Hsu, Tseng & Kuo, 2002, 391-392; Van & Meleis, 2003, 34; Kavanaugh & Hershberger, 2005, 602). However, some parents are very careful in thinking about new pregnancy and postpone at least the emotional condition is more stable (Kavanaugh & Hershberger, 2005, 602).

**Keeping active lifestyle** is found useful by several parents of African American and US parents; they suggested going out, meet with friends and keep themselves occupied (Van, 2001, 236; Kavanaugh et al., 2004, 10; Kavanaugh & Hershberger, 2005, 602).

**Finding meaning in loss** is important for couples from United States and African American women (DiMarco, Menke & McNamara, 2001, 138; Van, 2001, 236; Kavanaugh & Hershberger, 2005, 602). UK women accepted the loss as an event into their life, which allows them understand themselves better (Maker & Ogden, 2003, 412-413).

**Staying away from thinking about the loss** helped African American women and a group of 92% white, five percent African, two percent Asian and one percent Latino origin (Van, 2001, 236; Van & Meleis, 2003, 32; Bennett et al., 2008, 495) or "distract themselves" as French speaking mothers (Sejourne et al., 2010, 408).

Other strategies named by several parents from studies with several cultural origins were: turning to counseling services, or social support, or to use group therapy with the women of same experience; using possibility of medical follow-up, and the option to communicate with health care specialists any time via phone or Internet. Additionally, therapeutic listening, talking to friends and relatives, exhaustive dialogue to their doctor, or keeping diary or journal or making baby commemoration books, and attending baby's burial place are also help parents. (DiMarco, Menke & McNamara, 2001, 138; Armentrout, 2007, e8 ; Bennett et al., 2008, 495; Sejourne et al., 2010, 406-408; Kelley & Trinidad, 2012, 11.)

## 8.7 'Life after Loss'

Afterwards, nurse can support families by helping to find the source of support either in family, support services organized by hospital or outside parties, whatever better suits the needs of the parents.

**Family is the main source of support**, not the nurses, according to responses. The group of US parents consisting of 27 African American parents and four Caucasian parents disclosed that the biggest part of support comes from their own family, relatives and friends (Kavanaugh et al., 2004, 7), and

not from outside parties or organizations. The same is true for Malaysian Muslim women (Sutan & Miskam, 2012, 7). For Irish and Nigerian mothers the first supporting person is the father of the baby (Kuti & Ilesanmi, 2011, 206; Mulhivill & Walsh, 2013, 8). Study of African American women shows if woman gets true support from her family, she does not feel need in outside counseling services (Van & Meleis, 2003, 32).

**The importance of follow-up** varies greatly in the answers from Swedish Muslim mothers who generally see it as “waste of time” (Lundqvist et al., 2003, 83-85) to , for instance, approximately 20% of South African mothers who appreciate follow-up program (Conry & Prinsloo, 2008, 7). The invitation to participate in such sessions should be initiated by health care providers or nurses, but not parents (Mulhivill & Walsh, 2013, 9). Home visits as the form of support was suggested by Nigerian women and UK parents (Kuti & Ilesanmi, 2011, 206, Branchett & Stretton, 2012, 43). US parents added phone calls to visits as another form of follow up (Kavanaugh et al., 2004, 7-8). Irish mothers almost exclusively voted for phone calls as for form of follow up support, while one mother mentioned “written contact” as the preferred form (Mulhivill & Walsh, 2013, 9). Despite the overall interest to follow-up program, participants poorly attended such meetings: the number of parents participated in such follow up meetings ranges from up 12.5% (Mulhivill & Walsh, 2013, 9). Another form of follow up what was appreciated by US mother is the receiving “once-a-year remembrance card” from hospital (Sanchez, 2001, 26).

**Recovery time** is quite extended. The follow up may be quite lengthy program. For instance, US mother admitted that they do not feel entirely recovered from perinatal loss even after nine years of incident (Sanchez, 2001, 25-26).



## 9 DISCUSSION

This study investigated the perceptions of the parents from multicultural settings on the preferable support they can receive from nurse during perinatal loss. The parents' responses were grouped into seven categories: the most supportive interventions from the parents' view, the range of feelings, inquiring parents about their needs and wishes, the process of communication, the expectations of supportive nurse, coping approaches and life after the tragic incident.

The interventions are seen as any action of the nurse aimed at parents while dealing with them and could be divided into the immediate interventions and the distant ones. The immediate interventions are those which are performed in the hospital just after the loss. They cannot be done later. That is the reason why it is especially important to use the time spent in hospital wisely and make a positive basis for parents for faster healing. Woodroffe (2013, 100) and Warland & Davis et al. (2011, 2-3) confirm that parental activities are useful for the mothers and fathers to feel their parenthood. In contrast, these findings contradict with prior results of Badenhorst & Hughes (2007, 253-254) and Hutti (2006, 633), who speculated that performing parental activities with dead baby cause later post-traumatic stress disorder, and has negative impact on mother's attachment relations with future baby and slows down the healing process. Nevertheless, it is important to remember that only parents can decide whether they prefer to hold their baby, although the nurse can suggest and explain probable positive and negative consequences.

When choosing the appropriate interventions or while dealing with parents, the nurse should understand what range of feeling the family is affected by. The unstable emotional state of parents is governed by mixed and changing feelings of guilt, self-blame, worthlessness. After that, feelings of anger and irritation, which may be directed at health care providers, family, baby itself or God, can occupy the mind of parents. Women may be even irritated to see other pregnant women and babies. Physical and psychological isolation likewise affects negatively the state of parents. Parents may be in state of disorientation and shock and reject the situation. Such emotional condition severely im-

pedes the communication and requires from the nurse sufficient knowledge and tact to restore it. (Wigert, H., Blom Dellenmark, M. & Bry, K. 2013, 2-12)

As it has been noted, communication is important part of interaction between parents and health care representatives. Parents want to get significantly more information, which should be not only full and honest, without false hope, but also in plain expressions, which are understandable for people far from medicine. The information should be given in appropriate time and using the carefully chosen words and encouragements, as supported by findings of Brooten, Youngblut, Seagrave, Caicedo, Hawthorne, Hidalgo & Roche, (2013, 40-41). The communication process depends on many factors, one of which is the condition of the parents. People may be looked like they communicate successfully, but in reality they may not follow the message, as confirmed by Woodroffe's (2013, 99-100). To the same degree is significant to pay attention to the language of communication. Whereas the language is common, it is not necessarily that both sides equally proficient in it. On the contrary, when parents are from other cultural background, their language proficiency may be not enough, and it is needed to invite interpreter. Even when the language skills are enough; stress may significantly lower parents' ability to understand; this is in accordance with remarks of Henley & Shott (2008, 328).

Next, the responses of parents help to identify the desired virtues of the nurse. The nurse should be able to notice parents' condition, be present, be sensitive, empathic and, additionally, to personalize care. On the same time it is highly desirable for the nurse to possess specific knowledge how to communicate with mournful parents. These findings correspond to Woodroffe (2013, 102) and Gold (2007, 233-234) who noted that such special education is not only of assistance to parents, but also for nurses, who have to help parents and also perform their supportive role despite their own overwhelming emotional pressure.

Above all, the administration issues should be well thought: for instance, the provision of privacy and letting mother to choose preferred ward, sufficient communication chain between health care providers, continuity of care, and, lastly, correctly filled documents. All of these bring positive feelings of quality

and non-interruptive care. These results support earlier results of Gold (2007, 232), who assumes that improved communication channel between caregivers serves fuller and timely information supply for parents and has positive results.

At the same time, in many studies it is clearly expressed that nurse should find out what parents want instead of guessing, using his/her own ideas what they may want, even based on extensive nursing experience and cultural knowledge, or utilizing protocolled interventions. Parents want to be asked what they prefer. In the second place, parents prefer to be addressed equally, if religion does not prescribe the opposite. These findings are similar to Chichester study (2005, 314-318) and Scott (2011, 1388) as they advise to ask parents since they know better their needs. In addition, there are so many different religious and cultural details that may be important for that particular family.

Parents mentioned coping approaches that were helpful in dealing with unbalanced emotional condition and easing their return to normal life. Some approaches are connected with the intensifying the memory of the baby, like keeping diary or journal or making baby commemoration books or albums, and attending baby's burial place. Interesting to note, that keeping memories of the baby has no negative effects as from touching and holding baby, as Hutti discussed earlier (2006, 633). Then, some strategies are aimed at strengthening the inner world of parents. Specifically, seeking relief in religion, meditation, faith, spirituality or finding meaning in loss or integration the loss into the life canvas. On the contrary, certain part of coping strategies is aimed at reinforcement of social bond from within to outside. For instance, keeping active lifestyle, for example, going out or sport activities; turning to counseling services, medical follow-up, social support, using group therapy with the people of same experience, talking to friends and relatives. Standing aside, anticipation of new pregnancy as a coping strategy is a certainly questionable approach, as repetitive failure to deliver baby will cause more prolonged suffering. Besides, even in successful pregnancy the feeling and emotional condition of the woman would be very troublesome, as she would be upset about pregnancy flow and baby health. This is in agreement with Woodroffe (2013,

102), who remarked that new pregnancy if to come would not be free from troubles and emotional pressure or perinatal loss recurrence. The last coping approach is to stay away from thinking about the loss and this could be used together with strengthening social links, but without those strategies which may remind about baby and event.

The importance of coping strategies agrees with the findings of Shear & Shair (2005, 263) and Badenhorst & Hughes (2007, 251), who stated that grieving person does not actually participate in the society, and, therefore, suffers from additional stress from isolation. Thus, encouragement of strengthening social ties helps to plan and see the future and, thereupon, facilitates the healing. Additionally, findings of Kersting et al. (2007, 440-442) confirm that the strong social links and devoutness helps most of all in returning to normal life.

Nurse can help affected mothers and fathers to locate the resource of support knowing that the main source for most people comes from the family. The significance of follow-up programs varies greatly depending on cultural background from total rejection of Muslim families to one of support sources for people from other cultural and religious background. The findings of scheduling and choosing place of follow-up also coincide with Woodroffe's notions (2013, 101) that best time for such visit is better to schedule upon parents' needs, not the hospital's wishes. Additionally, the place is preferably to be located outside of the hospital, or at least, not in the same wards, which are associated with the incident of perinatal loss.

The complete or even partial recovery time is difficult to predict or estimate. The prolonged time of recovery is consistent with Badenhorst & Hughes (2007, 254) and Kersting et al. (2007, 441), who found that predominant sorrow feelings are normal in first two years and that prevalence of psychiatric condition in women after a year of perinatal loss is as high as one in every sixth woman.

These findings correlate with the theory of Leininger, who anticipated finding the differences and similarities in behavior and expectations both within and across universalities in different cultural groups. Equally correct, regardless of

clear trends seen in each cultural group, there were always contradictions, which prove that, indeed, differences and similarities exist. As can be seen, such data of similar and different patterns should not be used for strictly categorized care, rather this information serves as the points to further explore or topics to assess and discuss with patients while caring, to make sure these points are of value of individual patient or, on the contrary, plays little or no role. The data what is commonly shared and what is diverse make simpler for nurse to be oriented in the caring and let her/his to put efforts into developing the relationships.

### **9.1 Limitation of the Study**

The results would be more precise if more studies, which are devoted to single culture, would be available. Although it praiseworthy that studies include respondents from different cultural backgrounds into one study, showing that the researchers do not possess any predisposition or prejudice, it is practically impossible to differentiate what culture prefers what.

In addition, the amount of studies available for review was lessened because of many seemingly interesting from abstract studies was unavailable as free text. After that, some studies have included parents of babies of age significantly more than one month. For example, several researchers joined the responses of parents of babies and children from one day to 18 years old in their studies; because of this reason, such studies were excluded.

## 9.2 Conclusion and Suggestions for Future Research

Despite the fact medicine knowledge base and medical technology have significantly stepped further, the loss of pregnancy, stillbirth or perinatal death still occur, even in developed countries. Nurses cannot prevent this event, but could lessen the impact on the affected family.

The aim of the study was to provide information of culturally meaningful care provided for families after the loss of a baby. The purpose of this study is to explore cultural differences in perceptions of parents what did they see as beneficial for them after baby loss in perinatal period, and to investigate how nurses' support can meet the cultural expectations of the families. The study revealed that there are obvious similarities in parents' expectations of culturally competent care; yet, differences exist in every group. This finding correlates the Leininger's theory of Culture Care Diversity and Universality, who predicted to find both similar and different preferences among and within different cultural groups.

Knowledge and experience when providing the support combined with cultural competence is essential, but could not replace the communication and close interaction with the family. It is important to remember that parents know what their needs and wishes are. The nurse should ask and discuss these needs and wishes with the family. Bearing in mind that culture is dynamic concept, and has many determinants, such as ethnic, religious, familial, to name a few, it is understandable that each person has its own culture. Therefore, there could be no always appropriate rules; care should be personalized for each parent, according to their needs and requests. This is the demanding, yet rewarding task for every nurse who works with the family affected with perinatal loss.

Two suggestions for further research rose from this literature review. First of all, the needs and wishes of parents from cultural background should be better studied. Therefore, it is better to perform studies, addressing to a separate ethnic or cultural group for clearer results and better distinguishability of the people preferences. Then again, culture is always modifying, hence the re-

sponses of parents may be different from the similar parents given is similar situation.

Secondly, the topic, that in particular people theoretically welcomed follow-up services, but in reality poorly used this opportunity, should be explored better. It is desirable to clear out whether the services in their current conception are not well suited to parents' needs and required to be restructured, or there is any other reason that keeps people away from using these services. Surely, optimizing the follow-up services will accelerate the healing of the part of the parents.

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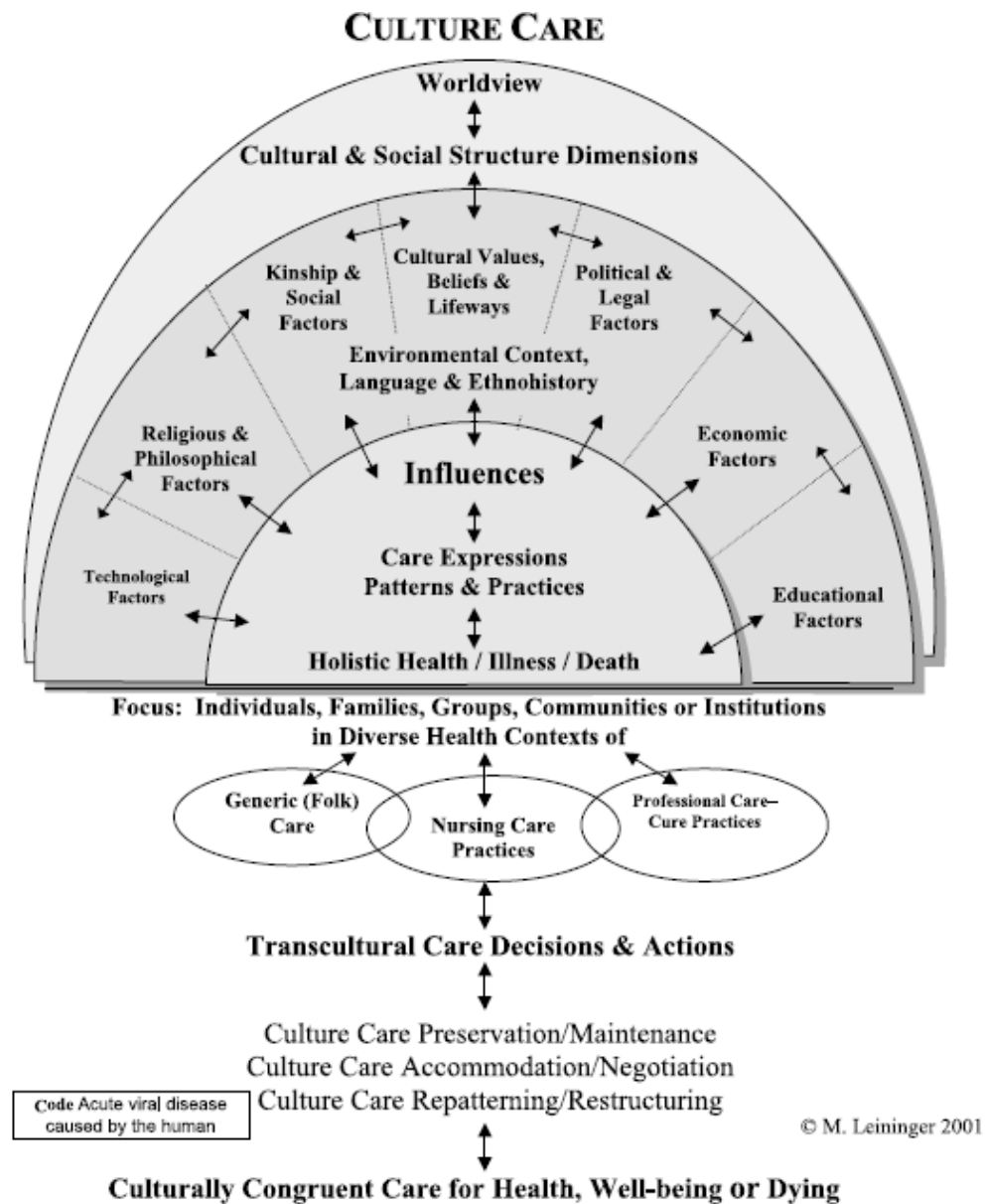
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## Appendix 1. Leininger's Sunrise Model



**Source:** Leininger M. 2002. Culture care theory: a major contribution to advance transcultural nursing knowledge and practices. *Journal of Transcultural Nursing*, 13, 3, 189-192.

## Appendix 2. Databases search results

<b>Data-base</b>	<b>Date of search</b>	<b>Keywords</b>	<b>Hits</b>	<b>After applying selection criteria</b>	<b>After assessment of title and abstract</b>
CINAHL	28.05.2013	Perinatal loss OR perinatal death OR fetal death OR newborn Death OR still-birth or pregnancy loss AND parental grief OR bereavement	372	28	2
	28.05.2013	Perinatal loss OR perinatal death OR fetal death OR newborn Death OR still-birth or pregnancy loss AND Family support OR psychological support OR psychosocial support	341	17	1
Ebsco Academic Search Elite	28.05.2013	Perinatal loss OR perinatal death OR fetal death OR newborn Death OR still-birth or pregnancy loss AND parental grief OR bereavement	149	29	1
	28.05.2013	Perinatal loss OR perinatal death OR fetal death OR newborn Death OR still-birth or pregnancy loss AND Family support OR psychological support OR psychosocial support	32	8	2
Elsevier Science	28.05.2013	Perinatal loss OR perinatal death OR fetal death OR	374	240	0

Direct		newborn Death OR still-birth or pregnancy loss AND parental grief OR bereavement			
	28.05. 2013	Perinatal loss OR perinatal death OR fetal death OR newborn Death OR still-birth or pregnancy loss AND Family support OR psychological support OR psychosocial support	620 7	132	0
		Perinatal loss OR perinatal death OR stillbirth AND grief or experiences or parents	167	142	1
		FULL-TEXT(Perinatal loss OR perinatal death OR fetal death OR newborn Death OR stillbirth or pregnancy loss) and TITLE-ABSTRACT-KEY(perceptions or experiences or expectations)	791	431	5*
		4. Perinatal loss OR perinatal death OR fetal death OR newborn Death OR stillbirth or pregnancy loss) and FULL-TEXT(parental grief OR bereavement)	259	132	4*
OVID	28.05. 2013	Family support OR psychological support OR psychosocial support or parental grief OR bereavement AND	66	61	10

		Perinatal loss OR perinatal death OR fetal death OR newborn Death OR still-birth or pregnancy loss			
		Manual search			11
		Total			38

\* The relevant by title and/ or abstract articles, even if listed as paid in the database, were searched via Google in other databases, and if listed as free, were counted.

### Appendix 3. The summary of chosen articles

Author(s)	Year	Name	Culture/ background	Major findings
Van, P.	2001	Breaking the silence of African American women: healing after pregnancy loss	African American women	The key coping approaches are turning to religion, trying to find the meaning of the event, live actively. If no one is near to listen or support, women prefer to avoid painful recollection.
DiMarco, M, Menke, E, M. & McNamara, T.	2001	Evaluating a support group	US families	Close circle of friends and family is the most supportive part of environment. Being present and listening is considered as the most supportive actions by parents.
Sanchez, N.A.	2001	Mothers' perceptions of benefits of perinatal loss support offered at a major university hospital	US mothers	Involvement of both parents into process is important. Parents are irritable if health care providers break their promises. Support, personal attention and information supply from nurses is positive. Parents have heightened sensibility to words used by health care providers.
Corbet-Owen,	2001	The health system and emotional care:	White mothers in South	The first required intervention is to validate the event.

C. & Kruger, L.-M.		validating the many meanings of spontaneous pregnancy loss.	Africa	<p>Personalization of care and creating memories are essential interventions for nurses.</p> <p>Mothers want to decide what is good for them. If they have information and can participate in decision, feel empowered.</p> <p>When no death reason is known, mothers are predisposed to self-blaming.</p>
Lundqvist, A., Nilstun, T. & Dykes, A.K.	2002	Both empowered and powerless: mothers' experiences of professional care when their newborn dies.	Sweden, mothers	<p>Less strict rules, personalization of care, being present and giving enough information are prioritized interventions by mothers.</p> <p>Miscommunication leads to isolation, and then to exclusion. Mothers want to be asked about their preferences, needs and wishes.</p>
Hsu, M.T., Tseng, Y.F. & Kuo, L.L.	2002	Transforming loss: Taiwanese women's adaptation to stillbirth.	Taiwan, women	<p>Validation of their status of mothers is a significant point. Therapeutic relations should be formed between a nurse and a mother, so latter can overcome cultural provisions of death conversation avoidance.</p>
Lundqvist, A., Nilstun, T. & Dykes, A.-K.	2003	Neonatal end-of-life care in Sweden: the views of Muslim women.	Sweden, Muslim women	<p>Care should be culturally competent, as well as to consider personal requirements of women.</p> <p>Mothers do not want to stay with dead babies.</p>

				Special rituals should be performed.
Van, P. & Meleis, A.I.	2003	Coping with grief after Involuntary pregnancy loss: perspectives of African American Women	African American women	<p>If family circle supports woman, outer support services are needless.</p> <p>While most women need to discuss the event and to be listened, some women do not want to recollect the loss.</p> <p>Religion is the major source of support; less important are deriving strength from relationship with living children, self-examination and anticipation of a new pregnancy.</p>
Freda, M.C., Devine, K.S. & Semelsberger, C.	2003	The lived experience of miscarriage after infertility	US women	<p>Women, who lost the baby after infertility treatment, tend to separate them from the other women who have lost their babies, since most of them sacrificed their health, time, money to infertility therapy and suffer from double loss.</p> <p>Women have prevalent feeling of guilt, anger and irritation.</p> <p>Such women have a tendency to prefer be alone for some time and also feel isolated even in presence of other people.</p>
Maker, C. & Ogden, J.	2003	The miscarriage experience: More than just a trigger to psychological morbidity?	UK mothers	<p>Self-blame and anger is dominating emotions among mothers; however, frustration becomes weaker as time goes by.</p> <p>Integrating the loss into the life outline proved to be helpful</p>



				for these women.
Kavanaugh, K, Trier, D. & Korzec, M.	2004	Social support following perinatal loss.	US parents (4 African American and 4 Caucasian)	Confirmation of parents' status is important for emotional well-being. Close family and friends circles are the primary source of support. Encouragement and listening are initially required communication activities.
Säflund, K., Sjögren, B. & Wredling, R.	2004	The role of caregivers after a stillbirth views and experiences of parents	Sweden, parents	Creating of memories eases the subsequent mourning. Empathy modifies the message to be heard as encouraging and helping. Time and the way of informing parents should be adapted to receivers' conditions and capability to understand. Time spent with baby, no matter how long it was, seems to be too brief.
Trulsson, O & Rådestad, I.	2004	The silent child--mothers' experiences before, during, and after stillbirth.	Norway, women	Women notify that the nurses should ask about wishes and needs; impersonal care is not welcomed. Communication is a joint process, mothers want to be informed and participate in decisions.
Kavanaugh, K.	2005	Perinatal loss in low-income African Amer-	US, African	The acknowledgement of parent status and personalization

& Hershberger, P.		ican parents: the lived experience	American parents	of care are the leading supportive modes of health care providers. Active lifestyle and planning of new pregnancy named to be effective coping strategies.
Simmons, R.K., Singhb, G., Maconochiea, N., Doylea, P. , & Greena, J.	2006	Experience of miscarriage in the UK: qualitative findings from the national women's health study	UK, women	The recognition of their status as parents is the primary intervention. The careful wording and clear information is appreciated. In respondents' opinions, health care providers should recommend available supportive services.
Armentrout, D.C.	2007	Holding a place: parents' lives following removal of infant life support	13 white, 1 Hispanic, and 1 African American parents	Parents appreciated the possibility to perform parents' activities and to invite friends into hospital to validate their parents' status. Talking with person of similar experience or uncritical listening is helpful for most of parents. Coping strategies vary depending on parents' inclinations and personal preferences.
Modiba, L.& Nolte, A.G.W.	2007	The experiences of mothers who lost a baby during pregnancy	South Africa, African mothers	Lack of information flow, not being present, and a notable difference in attitude when delivering alive or dead at birth baby are negative impressions from mothers experienced perinatal loss.

Bennett, S.M., Litz, B.T., Shi- ra, M.& Ehren- reich, J.T.	2008	An exploratory study of the psychological impact and clinical care of perinatal loss.	“92% of Caucasians, 5% African Americans, 2% Asians, and 1%Latino	Promotion of social bonding is seen as the way of healing. Contradictory result of seeing and holding babies: were seen both as very positive for majority and very negative experiences for a very small fraction of the group. Not the intervention itself, but the positively perceived nurse, supports the best.
Conry, J. & Prinsloo, C.	2008	Mothers’ access to supportive hospital services after the loss of a baby through stillbirth or neonatal death	South Africa, mothers	Some feel that follow up program is important. Mothers want know more about the cause of death and the grieving process. Less limiting hospital rules and more time spent with baby are awaited. Hospital caregivers can support by helping mothers with creation of memories such as footprints, photos)
Gammeltoft, T., Tran, M.H., Nguyen, T.H. & Nguyen, T.T.	2008	Late-term abortion for fetal anomaly: Vietnamese women’s experiences	Vietnam, mothers	Almost all mothers refused seeing the baby. Practices of babies remembrance is not welcomed, as mothers prefer to look into future, not the sorrowful past. Feelings of self-blame and guilt are strong because not information received of possible cause.
Hunt, K., France, E.,	2009	‘My brain couldn’t move from planning a birth to planning a	United Kingdom (UK), parents	Couples feel pressure to take decisions in hurry and with no relevant information.

Ziebland, S., Field, K., & Wyke, S.		funeral': a qualitative study of parents' experiences of decisions after ending a pregnancy for fetal abnormality		Information is given in inappropriate time, which annoyed parents. Parents, in general, are grateful for letting taking photos with some cultural exceptions. Personalization of care and refinement of accepted definitions with parents is needed because not all parents want to name them "baby".
Sejourne, N., Callahan, C. & Chabrol, H.	2010	Support following miscarriage: what women want	French speaking women	Mothers confirmed the necessity of providing support and follow up services and arranging it in a more methodical way; yet noted that support organization and psychologist services were least helpful for them. Working coping strategies were to be engaged in different activities, not connected with perinatal loss, talking with friends and reading information and materials related to loss.
Kuti, O. & Ilesanmi, C.E.	2011	Experiences and needs of Nigerian women after stillbirth	Nigerian women	Most of support comes from spouse and close family. None of women wanted to give name to dead child and less than five per cent took photos. Follow up visits to home are valued.
Branchett, K. &	2012	Neonatal palliative	UK parents	Acknowledgment of parents' status by health care provid-

Stretton, J.		and end of life care: What parents want from professionals		<p>ers is important.</p> <p>Parents depend on nurses in guiding their actions during hospital and after discharge.</p> <p>Parents feel empowerment of given truthful and well-timed information and can participate in the process.</p> <p>Couples glad when nurses behave emphatically, ensure privacy and keep documentation without mistakes.</p>
Sutan, R. & Miskam, H.Z.	2012	Psychosocial impact of perinatal loss among Muslim wom- en	Malaysia, Muslim women	<p>Women experience deficiency in communication and priva- cy while being in hospital.</p> <p>The primary source of support is close family.</p> <p>Religion is the foremost healing approach for Malaysian Muslim women.</p>
Kelley, M.C & Trinidad, S.B.	2012	Silent loss and the clinical encounter: parents' and physi- cians' experiences of stillbirth—a qualitative analysis	US, parents	<p>All parents feel being in isolation, not adequate communi- cation and information supply, not knowing what would happen next and what is usual to feel in such situation, as well as available support services.</p> <p>Parents want to be asked about preferences and needs.</p> <p>Validation of parents' status is a central intervention.</p>
Downe, S., Schmidt,E.,	2013	Bereaved parents' experience of stillbirth in UK hospitals: a	UK, parents	<p>Creation of memories is seen as one of the most positive interventions.</p>

Kingdon, C. & Heazell, A.E.P.		qualitative interview study		Information given should be modified to parents' condition and understanding capacity. Parents prefer to be far from alive babies and mothers-to-come.
Cacciatore, J., Erlandsson, K. & Rådestad, I.	2013	Fatherhood and suffering: a qualitative exploration of Swedish men's experiences of care after the death of a baby	Sweden, fathers.	Validation of fatherhood status and treating baby with respect is initial interventions. Sensitivity in choosing expressions, involvement into process and initiation and help of health care providers to create memories is welcomed by fathers. Deficiency in communication and breach of promises leave negative impression of health care providers.
Mulhivill, A. & Walsh, T.	2013	Pregnancy Loss in Rural Ireland: An Experience of Disenfranchised Grief	Ireland, mothers	Privacy and choice of proper ward are important because women are overpowered with difficult emotions, and realize they have complications in communication with pregnant women and happy mothers. Communication style should be adapted to women condition. Father of the baby provides the most soothing support.

#### Appendix 4. Example of critically appraised article

Author	Hsu, M.T., Tseng, Y.F., Banks, J.M. & Kuo, L.L.	Score
• <b>Abstract and title</b>	Interpretations of stillbirth	4
• <b>Introduction and aims</b>	To explore Taiwanese mothers' interpretations of stillbirth	3
• <b>Methods and data</b>	An interpretive ethnographic approach, interview	4
• <b>Sampling</b>	Purposive sample, n=20, response rate given and reasons for not participating included.	4
• <b>Data analysis</b>	Brief description of analysis process	3
• <b>Ethics</b>	Ethics was mentioned (informed consent and sanction from Ethical Review Executive Committee of Kaohsiung Chung-Ho Medical Center and the National Science Council of Taiwan was obtained), confidentiality kept.	4
• <b>Bias</b>	Bias was discussed	4
• <b>Findings /results</b>	Findings are summarized and correspond to initial aims	4
• <b>Transferability/generalizability</b>	The context and setting of the study is explained satisfactorily. The results coincide with other studies.	4
• <b>Implications and usefulness</b>	Article suggests new ideas for nursing practice	4