Women's experiences with perinatal loss of a child

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Abstract

Introduction: Perinatal death is an extremely sensitive area in a parents' life since it is considered to be the most painful of losses. From health care professionals it requires expert and compassionate treatment that will help parents in the process of coping with the loss of a child. Health care professionals should be able to listen and to be receptive to parents' needs and not become insensitive to their grief. The purpose of the research was to gain insight into the experiences of women in Slovenian maternity hospitals who have experienced the loss of a child in the perinatal period. *Methods:* A quantitative research approach was based on an online survey convenience sample of women (n = 114) who have experienced the loss of a child in the perinatal period. Women were previously requested to participate via online forums and groups where they also get a link to the online survey. The survey was conducted from January to June 2015. The data were analyzed using basic descriptive statistics. *Results:* The results showed that the majority of women which have experienced perinatal loss of a child, wants to talk about their experience. Health care professionals have been mostly empathic, respectful and supportive to them in the treatment. Despite the fact that health care professionals are sensitive to the needs and aspirations of women and respect their feelings, their professional behavior in emotionally demanding situations was more reserved, which is against the wishes and women's needs. This is sometimes due to the way of working, which allows and encourages more rigid professional behavior. *Discussion and conclusions:* In the area of perinatal palliative care there is the need to further improve understanding of the needs of grieving parents among health care professionals and additionally trainings to work with bereaved parents. It is also necessary to overcome the shortcomings in the system of treatment to be more supportive to grieving parents.

Keywords: perinatal death, needs of grieving mothers, health care professionals, help

Death in old age is more widely recognized, but when death and loss relate to the opposite extreme of age, we are quite uncertain (Mander, 1994). No one expects his child to die before him - we see the death of the child as something that should not have happened and is against natural laws (Globevnik Velikonja, 1997; 2000).

Stillbirth is defined as the birth of a child after the 22nd week of pregnancy, when child has no signs of life, and at the age of weighing at least 500 grams or the length of his body at least 25 centimeters (Statistical Office of the Republic of Slovenia, n. d.). Barfield (2011) adds that during the perinatal death we also count all live births, who died in the first 7 days of life.

The health care of a deceased newborn should be directed to the whole family, and requires health professionals to individually address the physical, emotional, social and spiritual needs of the mother and child or family from the beginning of the delivery process to the adaptation of the entire family (Skoberne, 1991). In this point, Globevnik Velikonja (1999) adds that the real needs of mourning parents depend on their individual feelings, personality and circumstances of the child's death, but nevertheless they all deserve to be treated with the utmost sensibility. The field of pediatric palliative nursing in Slovenia is an extremely poorly explored area, therefore, we wanted to gain insight into the experience, feelings and emotions by women who experienced a loss of a child in a perinatal period. Thus, on the basis of their personal experience, we would highlight and emphasize the advantages or disadvantages of treatment by healthcare professionals.

Methods

The research was based on a quantitative research approach. The convenient sample included women ($n = 114$) who experienced a child's loss in the perinatal period. The data were collected using an online survey questionnaire from January to June 2015. The question sets in questionnaire were related to the display and expression of respect, empathy and emotions, respect for decision-making, needs and wishes of mothers, respectful communication, information, providing psychological assistance, and about respecting the spiritual or cultural needs of mothers by healthcare professionals. Replies were processed using basic descriptive statistics.

Results

Most women (76%) who experienced a child's loss in a perinatal period wanted to talk about their experiences and would like to speak today. They needed a conversation and it was helpful for them, but many did not dare to ask them or wanted to ask them about it.

The results of the research showed that the healthcare professionals were relatively respectful in relation to women, since they largely ensured intimacy of the moment (68%), took into account the needs for respectful, discerning and empathic communication and respected the feelings of women (76%), met the need for 'being listened to' at least sometimes (78%) and for psychological assistance (50%), providing information related to child's death (50%). In a large proportion (97%), professionals also respected the decisions of the mothers (e.g., about the way of treatment, the place of burial), but in many cases (58%), mothers were also required to make decisions immediately after their birth (e.g., about the name of the child, the manner of burial etc.).

The need for information was largely neglected: information about treatment after discharge from hospital (31%), about possible consequences requiring immediate action (28%), and written information was not provided (42%).

In the area of emotional support for women, there were bigger deficits in the respondents' responses. The professionals did not meet the needs and fulfilled the wishes of women's own choice of the department where they would be accommodated (86%). Most (54%) were not able to spend the first night in the hospital with a partner, as well as not to coexist with him throughout the hospitalization (61%). They also did not have the opportunity to say goodbye to the deceased child after 12 hours (82%). In most cases, they were not encouraged to choose the child's name (80%), or to see the dead child (57%), to cradle it (56%), or to collect memories of the child (53%). The lack of emotional support also shows the answers about receiving attention by healthcare professionals always or sometimes (78%), yet in most cases (73%) they felt alone with their own pain. Comforting touches and time from healthcare professionals received slightly more than half women (56%).

In meeting the spiritual, religious and cultural needs about the method of childbirth, care or burial, 54% women did not have specific desires, however in 24% answers showed that treatment of this area has not been respected. Many of them also received inappropriate 'comforting' comments from professionals related to the youngness of women and to the possibility of subsequent pregnancy or to already pre-existing children. According to the majority of respondents (78%), these comments were well-intentioned, but completely unnecessary.

Discussion

This research shows that in the future more attention should be paid to the needs and desires of women who lost their child in the perinatal period. Many deficits in treatment have been shown in the consideration of women's wishes and needs, as well as in informing, in showing compassion and emotional support, and in the sphere of spiritual, religious and cultural needs of women. According to Cehner et al. (2005), healthcare professionals should be more aware

of the needs of the grieving woman and family so that they can approach in a more integrated and individual way.

Although healthcare professionals were relatively respectful in relation to women and also respected women's decisions, they sometimes also required from women to make decisions right after birth. This, in contrast to Skoberne (1991), argues that the mother must not be required to make a decision immediately after the child's death. If the mother is not prepared yet for taking decisions in a postmortem. Therefore, in no way mother should be forced to make decisions in the maternity ward, if she is not prepared yet.

The respondents also received too little attention. Healthcare professionals were not available when they needed help, which also led to bad events. If healthcare professionals do not know how to approach a mournful family, they prefer to withdraw or to comfort in an inappropriate way (Globevnik Velikonja, 1997). Grieving parents can be assisted in a better way by those who can give them the opportunity to speak about the loss and recognize that their child existed.

Therefore, healthcare professionals should avoid rigid professional behavior, they should be friendly and honest, and if they feel sad, they should not be ashamed of crying with grieving parents (Skoberne, 1991). The respondents also missed a warm and comforting word and respectful communication; on the contrary, some were receiving inappropriate remarks. Skoberne (1997) points out that affected parents can be alert and sensitive to every spoken word of healthcare professionals; they attach great importance to it, which obliges healthcare professionals to be more accountable for what they say (Skoberne, 1997). It is also important to take into account the individual wishes of a woman, e.g., the choice of department she will be accommodated. The least that healthcare professionals can do is to offer the woman the option of choosing a post delivery period accommodation or to encourage her to decide to stay in a private room at the maternity ward where the whole family will benefit from quality health care. It is necessary to take into account the women's desire to go to a department that is isolated from the child's crying and other mothers (Skoberne, 1997).

Informing women is also problematic area. Women missed the acquaintance, help and encouragement in collecting memories of the child, which is according to Globevnik Velikonja (1999; 2000) very important because these objects serve as evidence of a child's life and offer parents the opportunity to mourn. Since memories of the child all that remains, each one is valuable. The situation is similar with the encouragement of giving a name to the child, cradling a child and to say goodbye to deceased child. Skoberne (1997) points out that the healthcare professionals should encourage parents (but not force them) to choose the name of the child, even if it is stillborn or die shortly after birth, to see it and cradle it, to say goodbye, give him their things, take photos, healthcare professionals take photos, or other impressions to have memories.

High deficits in treatment are also reflected in the emotional support of women. Skoberne (1997) states that, in general, the best assistance to parents at that time is genuine contact, based on the compassion, understanding and receptivity of an individual, thus emphasizes:

„We should not be afraid to ask them what they feel and whether they want to talk about their distress. Above all, let's listen to them. Even our silent presence or touch can be encouraging enough to encourage parents to express grief or help them regulate conflicting feelings they are experiencing“ (Skoberne, 1991, p. 72).

Although the research has shown that the spiritual, religious or cultural needs of women are not taken into account, it is necessary to think of what the Globevnik Velikonja (1999; 2000) emphasizes that some ritual like baptising the child before death may mean a great deal for parents, so we have to allow them to do so.

In Slovenia, the Solzice Association has already changed many things in the field of treatment after perinatal loss of a child. Training in Slovenian maternity hospitals should become a constant practice in order to make healthcare professionals better trained in dealing with women in case of perinatal death. New findings based on researching perinatal child loss experiences are so necessary, especially in relation to the Slovenian space Slovenian area.

Conclusions

Although the loss of a child in a perinatal period is more and more common, this topic is still a major taboo. In Slovenia, this is a little researched area, and further research are needed. It would also be interesting to compare the treatment methods in Slovenian maternity hospitals with the aim of transferring good practices. There is also a need for improvements in the educational programs themselves, which at this moment perhaps do not offer knowledge in a way that would prepare future healthcare professionals for coping and proper handling of such cases. It would be necessary to integrate and to cooperate with associations helping grieving parents. This can be an important source of information and awareness for healthcare professionals of what are needs that grieving parents have at the time of a child loss. Informal forms of education and lifelong learning as seminars, professional meetings are also welcome. At the same time, personal involvement and responsibility of each individual healthcare professional is also necessary. Healthcare professionals are the first who have an opportunity to create a memory of a lost child, thus enabling a woman and her family to mourn through the mourning process. Therefore, women who have lost a child in a perinatal period should be listened and helped in a personalized and individualized way.

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