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Decision-making of Czech mothers about contact with their baby after perinatal loss

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ABSTRACT

Introduction: The objective is to describe the experience of Czech mothers in terms of decision-making about visual and physical contact with a baby after perinatal loss, and also to explore the effect of this experience on the intensity of the mothers' grief after perinatal loss.

Methods: A mixed method design using qualitative data from 18 in-depth interviews was used in the Czech Republic, as well as mixed qualitative and quantitative data from an internet based questionnaire. A total of 100 questionnaires were analyzed using "Interventions after Perinatal Loss" and the Czech version of "the Perinatal Grief Scale".

Results: The decision making of women after perinatal loss over contact with their deceased baby is influenced by internal factors (the need of a woman to get to know her child, concerns and fear of contact) and external factors (emotional support for the woman, professional information and interventions of the midwife or doctor). Internal factors are often conflicting and the social environment has the decisive say. The research has proven that a mother's independent decision about contact with a baby after perinatal loss has significant impact on the intensity of her grief. The grief of mothers who decided independently and who were sure about their decision was statistically significantly less intense than in mothers for whom the decision had been made by medical staff.

Conclusion: The results of our research reflect the professional uncertainty of Czech midwives taking care of mothers after perinatal loss. This is demonstrated in a majority of cases by a paternalistic approach to communication.

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Introduction

Perinatal loss (the death of a foetus in the uterus after 22 gestational weeks, and the early death of a neonate within

7 days of birth) affects about 400 parents in the Czech Republic annually. Death is in contrast to birth and yet they meet on this occasion. Parents lose not only their baby but also part of their future, their dreams and plans. Nowadays, parents develop a very close relationship with

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the foetus early on in pregnancy; they communicate with it, they can see it in ultrasound images and they prepare a place for it in the family. In the majority of cases the loss is accompanied by an intense mourning process. It is only recently that the practice of parents saying farewell to a baby through visual or tactile contact has been seen in the Czech Republic. This research is focused on the process of Czech mothers' decision-making about contact with a baby after perinatal loss.

The first reference to the psychological effects of perinatal loss on parents in scientific literature in the Czech Republic comes from the 1972 textbook *Porodnictví* (Obstetrics). In the chapter that deals with the death of a foetus in the course of pregnancy and during birth, Kotásek states: "Never show the mother her stillborn baby! Inform her gently that the foetus is not alive and postpone the explanation of the cause" [1]. Technological development resulted in the specification and development of diagnostic and therapeutic methods. However, the dehumanization of the healthcare professional–patient relationship occurred together with the medicalization of grief. By pushing death out of view, society placed an excessive pressure on the surviving relatives to cope with the situation in a very short time. In the second half of the twentieth century, mothers in the Czech Republic were made to deny their grief and replace the loss by having another baby. Mothers rarely had the opportunity to see their babies. Instead, stillborn babies "disappeared" to minimize psychological trauma.

Currently, perinatal mortality in the Czech Republic remains low. In 2013, according to the Czech Statistical Office, the stillbirth rate was 3.4 per mile, and the total perinatal mortality was 4.4 per mile [2]. However, the Czech Republic is still coming to terms with the previous practice of insufficient psychological and social care for mothers who sustained perinatal loss.

The objective of our study was to determine the following: which factors influenced the mothers' decision-making about visual or tactile contact with a baby following perinatal loss? Is the intensity of grief found in mothers after perinatal loss influenced by the decision about contact with a baby?

Material and methods

Design

The research part is based on the phase model combining sequential methods. The research strategy used is both qualitative and quantitative. A qualitative method is used to better understand the process of mothers' decision-making about their contact with a baby after perinatal loss, and then a quantitative method is used for assessing the influence this decision-making has on the intensity of the grief in mothers who sustained perinatal loss. This model led to strategies which do not attach different importance to individual types of research.

Participants

The research was carried out between 2011 and 2014. At first, the manager of the *Prázdná kolébka* (Empty Cradle,

a self-help group for parents who have lost their baby) was approached with a request for assistance. In January 2011, a letter was sent via this organization by e-mail to mothers who experienced perinatal loss in the Czech Republic, with a request for participation in the qualitative research in the form of an interview. Gradually, 18 mothers from the Czech Republic with experience of perinatal loss were acquired for cooperation. 11 of them agreed to a face-to-face interview and 7 agreed to an asynchronous e-mail interview.

The selection of the sample for the quantitative research was based on the principle of voluntariness and availability. The research survey was repeated in January 2012, 2013 and 2014. An invitation to participate in the quantitative research was published on the project "*Prázdná kolébka*" website, and a cover letter with links to the questionnaires on the Internet was also sent. Considering the relatively small basic sample and the sensitive topic, only the following criteria for the selection of the sample were selected: they had to be female, have experience with perinatal loss in the Czech Republic, it had to be a maximum of 5 years after their perinatal loss, and they had to be of Czech nationality. A total of 100 mothers duly completed the questionnaires.

Data collection

For the collection of qualitative data, several different methods were used which enabled a great deal of empirical material to be acquired. This concerned a semi-structured face-to-face interview, an asynchronous e-mail interview, and freely provided statements of participants in a questionnaire-based survey. The material acquired included textual information with a total of 554 thousand characters.

Two questionnaires were used for the collection of quantitative data. One of the questionnaires was a Czech version of the Perinatal Grief Scale (CzSVPGS). The Perinatal Grief Scale refers to a questionnaire recommended in a number of countries for finding the intensity of grief in mothers/parents who have sustained perinatal loss [3]. The CzSVPGS as a single-factor scale was used where all 33 items of the original scale are preserved. The reliability of the research tool determined by Cronbach's alpha coefficient ($\alpha = 0.9545$) indicates a high reliability [4]. The CzSVPGS includes 33 items assessed by the respondents on a 5-degree Likert-type scale that is limited by the following statements: *I completely agree* through to *I completely disagree*, with a neutral centre point (*I do not know*). The total score on the CzSVPGS ranges from 33 to 165 points. A higher score indicates a higher intensity of grief. Values above 91 points represent potential psychiatric morbidity.

The other questionnaire was titled *Interventions after Perinatal Loss*, which was based on a thorough study of professional references concerning the provision of psychological interventions to mothers sustaining perinatal loss by a midwife in the healthcare establishment. In addition to socio-demographic questions, the questionnaire contained questions focused on the offer of saying farewell to a baby (11 questions). These concerned the mother's contact with a baby, decision-making about it, feelings related to this type of contact and acquiring mementos

of the baby. An open answer from this questionnaire was included in the qualitative data.

Data analysis

The acquired qualitative data was subjected to content analysis. The data was organized and sorted using the ATLAS.ti software application. Data from the questionnaire-based survey was statistically processed. The distribution of the CzSVPGS values and a normality test were carried out. The normality prerequisite was not fulfilled and therefore the Wilcoxon non-parametric test was used. In addition, a chi-squared test was used, and in the case where the prerequisites for its use were not fulfilled the evaluation was executed using the Fisher's exact test. The statistical tests were evaluated at the significance level of 5% ($\alpha = 0.05$). The Stata v.13 software application was used for data processing.

Results

Characteristics of the research sample

In-depth interviews were held with 18 mothers from various cities in the Czech Republic who were in the 28–40 years age group ($M = 31.7$). 11 mothers had secondary education, and 7 mothers had a university education. Two respondents were single but lived with a partner, the others were married. One respondent was pregnant again at the time the research was conducted. The time elapsed since perinatal loss varied from 1 month to 10 years with the respondents ($M = 2.2$ years).

The questionnaires were completed by 100 mothers from the Czech Republic in the age group of 23–45 years ($M = 33.2$). There were a total of 78 mothers who experienced a stillbirth and 22 mothers who had an experience with the early death of a neonate. The basic characteristics of the sample are presented in Table 1.

Forty four mothers who saw or held their baby after perinatal loss participated in the research. Only four respondents stated that the ritual was carried out on the basis of a recommendation of or with the support of the medical staff. On the other hand, five mothers stated that they saw the baby even though they were discouraged or forbidden to do so by the medical staff. Our sample included 36 mothers who felt the need to get to know their baby and wanted to see/hold it. On the other hand, 56 respondents did not see their baby after perinatal loss. Of these, only 13 mothers decided not to see it on their own, eight mothers did not feel they had support from the medical staff and did not have enough courage to see it, and 33 mothers did not see their baby after perinatal loss because they were not offered or recommended to do so by the medical staff.

The intensity of grief in mothers after perinatal loss is measured by the Perinatal Grief Scale (CzSVPGS). The basic statistical data acquired from the values measured using the CzSVPGS scale is provided in Table 2.

Table 1 – The characteristics of the sample (N = 100)

Item		N	%
Age	18–20	0	0
	21–30	26	26
	31–40	71	71
	41–45	3	3
Education level	Basic	0	0
	Secondary	4	4
	High School	49	49
	University	47	47
Marital status	Single	12	12
	Married	67	67
	Divorced	8	8
Number of children	0	64	64
	1	28	28
	2	8	8
Gravidity (at the time of the research)	YES	12	12
	NO	88	88
Perinatal loss (22 w.g. to 7 days after birth)	Stillbirth	78	78
	Early neonatal death	22	22
Years after the loss	1 month – 1 year	46	46
	1–2 years	20	20
	2–3 years	16	16
	3–4 years	5	5
	4–5 years	13	13
Contact with the dead baby	Did not see	56	56
	Only saw	15	15
	Saw and held	29	29
Who decided on contact	She did, was certain	49	49
	She did, lacked courage	8	8
	Medical staff	37	37
	Close person	2	2
	Not stated	4	4
Mementos	Does have	28	28
	Does not have	72	72

Table 2 – Intensity of grief in mothers who experienced perinatal loss in the Czech Republic (CzSVPGS values)

	Number	Median	Mean	SD	Min	Max
CzSVPGS values	100	87	88.8	27.7	41	154

Mothers' decision-making about visual or tactile contact with a baby after perinatal loss

During the analysis of qualitative data the factors that influenced the mothers' decision-making process about contact with the baby after perinatal loss were identified. The factors were divided into external and internal. The links between these selected factors and the data is identified in the text by italics. In addition to the respondent's identification, the bracket following a reference also contains information about whether the mother had either visual or tactile contact with her baby or not. The mothers' statements were dominated by two powerful internal factors:

1. The mother's desire or need to get to know her baby and to know what it looked like, to fulfil the nature of

maternity, to recognize the existence of the baby and to establish a relationship with it (bonding).

If I do not have the baby, I would at least like to see it (E, contact YES). *I couldn't not see my own baby!* (P, contact YES). *I could not live without at least knowing what my baby looked like, or without saying goodbye...* (from questionnaire, contact YES). *I know nothing about it* (the baby), *which is terrible...* (M, contact NO). *The feeling that I was a terrible mother was even worse because I did not want to see her...* (W, contact NO).

2. Worries and fears about contact with a baby after perinatal loss, or, where applicable, worrying about meeting death “face-to-face”.

I did not want to, I said I was worried... (L, contact YES). *If somebody had told me that it* (the baby) *looked as if it were sleeping, I would have loved to have seen and held it* (from questionnaire, contact NO). *I lacked courage and I said: it will not be a nice sight* (V, contact NO). *The doctor asked me whether we would like to see her and logically I got alarmed* (P, contact YES). *I was terribly worried at the time that it would have an illness that would be visible. If I couldn't have her at home, I wanted to imagine what she would be like* (W, contact NO).

The internal need and desire of the mother to get to know her baby was sometimes suppressed in the first phase of mourning due to fears and worries about meeting death. Both feelings are absolutely natural and understandable but often in conflict with one another. The mother's decision-making process is also influenced by external factors.

Three powerful external factors were analyzed:

- A) Emotional support from a close social environment (mostly the partner, family).

This factor played a supporting role and only directly influenced the mother's decision in the case of Ms. L. The respondents accentuated the possibility of sharing emotions, ideas and decision-making with someone close.

My husband told me that there was nothing to worry about as she is beautiful (L, contact YES). *My husband was there with me. At first, I did not want him to be there but I must say that it was the strongest feeling that we have ever experienced... together. Although it was not good... it connected us firmly* (R, contact YES). *We embraced one another and cried, and that is a moment I will never forget. He supported me so much and I respect him for that* (V, contact NO).

- B) Information about the options for saying farewell to a stillborn baby was available, the advantages and disadvantages a specific decision can bring, the possibility to discuss the mother's feelings and opinions.

So I asked her questions and we talked about it... it helped me... (J, contact YES). *Thanks to the approach of the medical staff I really changed my mind during birth, from the feeling that I did not want to see my baby to definitely yes, I want to say goodbye* (from questionnaire, contact YES). *I am sorry that I was not given any information* (from

questionnaire, contact NO). *When I look back, I think that somebody should have come and told us: 'I understand your reaction, but try to think about it, the practice is as follows'... I still feel that it was a mistake that we did not see her* (I, contact NO).

Sufficient information or a lack of information on the option to say farewell often had a strong impact on the mothers' decision about visual or tactile contact with the baby after perinatal loss. If the mothers understood that the medical staff failed to provide them with sufficient information, their feelings included anger, sorrow, blame and inferiority.

- C) Intervention of the medical staff and their attitude to the ritual of saying farewell to a dead baby expressed verbally as well as non-verbally.

Her words: It is terrible, don't look', were not of any consolation for me (from questionnaire, contact NO). *A nurse took my baby boy away with such a look of disgust that I was afraid to ask whether I could see him* (from questionnaire, contact NO). *When the midwife asked me before, I told her 'no', and she replied that it was perhaps better as I would have seen him for the rest of my life* (from questionnaire, contact NO). *He was shaking his head the whole time in disagreement and I became scared that the baby might not be so beautiful* (I, contact NO). *The medical staff at the University Hospital... they were absolutely professional, a young nurse was holding my hand all the time, she took a photo of me and the baby and took a footprint and a handprint for me* (from questionnaire, contact YES).

Often the interventions by medical staff not only had a direct influence on the mothers' decision, but also on the mothers' satisfaction with their decision.

Impact of the decision about contact with a baby on the intensity of the mothers' grief after perinatal loss

The following hypothesis was tested: the intensity of grief (the CzSVPGS values) in mothers who decided about the interventions (not to see/to see/to hold the baby) will be lower than in mothers who had the impression that the medical staff decided about the intervention. The evaluation of the hypothesis included mothers who decided independently about their contact with their baby after perinatal loss and who stated in the Interventions after Perinatal Loss questionnaire: “*I was sure that I wanted/did not want to see the baby*” (N = 49), as well as mothers who felt that their decision was influenced by the medical staff: “*I was not offered to see the baby*”; “*I was not sure but I was aware of the pressure from the medical staff to do/not to do so*”; “*I was not sure but the medical staff recommended I did not see the baby*” (N = 37). It was essential to identify who made the decision, rather than the outcome of the decision. In the cases where mothers decided about contact (not to see/to see/to hold the baby) with the baby on their own, the intensity of their grief was statistically significantly ($p = 0.002$) lower than in mothers who did not make the

decision and in those for whom the decision was made by the medical staff on their behalf.

In addition, we also tried to find a relationship between the resulting contact and the person who decided on it. We discovered that the mothers who made the decision on their own decided in 73.5% (36/49) of cases to see their baby. In the cases where the decision was made by the medical staff, only 10.8% (4/37) of mothers saw their baby. A statistically significant difference in the final contact depending on who made the decision ($p < 0.001$) has been discovered.

It was also discovered that there is a relationship between the resulting contact and the feeling that the mothers stated (*they are glad or they regret that they were/were not in contact with their baby*). A total of 91% (42/46) of the mothers who had “a good feeling” saw their baby. A total of 96% (52/54) of the mothers who regret/did not know/did not answer, did not see their baby after perinatal loss. A statistically significant relationship between the resulting contact and the feeling ($p < 0.001$) was discovered. The mean value of the intensity of grief in mothers who had contact with their baby was lower than in mothers who did not say farewell to their baby, but a statistically significant difference was not discovered ($p = 0.397$).

Discussion

The results of the research of the ritual of saying farewell through visual or tactile contact with a baby after perinatal loss in the Czech Republic differ greatly from those presented by specialists from the English speaking countries or Scandinavia. In our research, 56% of mothers did not see their baby after perinatal loss, while in the research carried out in foreign countries 5–9% of mothers did not see their stillborn baby [5, 6, 7]. A statistically significant difference in the final contact depending on who made the decision about this ritual was discovered. If the mothers decided on their own, they preferred contact with the baby after perinatal loss. If the decision was made by medical staff on behalf of the mothers, no contact between the mother and the baby occurred in the majority of cases. Czech midwives and physicians in general do not support bonding between a baby and its mother after perinatal loss. On the contrary, they are supporters of an evasive strategy which is not generally regarded as beneficial. In addition, the persistent influence of the paternalistic approach of healthcare professionals in the Czech public health sector is obvious. When deciding about contact with a baby after perinatal loss, in 37% of cases the mothers felt it was the decision of the medical staff (in the majority of cases this concerned the fact that they were not offered or recommended the option to see their baby). Koopmans et al. state that with mothers who lack the support of the medical staff during physical contact with their stillborn baby there is a four times lower probability that they will see their baby or will hold it, compared to mothers who win the support of the medical staff [8].

According to the testimonies of women in our qualitative research, after perinatal loss, mothers are sensitive

to the behaviour of the medical personnel. They observe the verbal as well as non-verbal indications, which influences not only decision-making about visual and tactile contact between the mother and the baby, but also their satisfaction with this decision for the grieving process that follows. The research conducted by Cacciatori et al. [5] has proven a relationship between the psychological condition of mothers and the conduct of the medical staff in the case of a stillbirth, or, where applicable, in the way in which they were offered the ritual of saying farewell to a stillborn baby at the time of perinatal loss. It has been discovered that in mothers who noticed that it was not just their decision to see their baby, the occurrence of symptoms of depression is lower. Apparently, the verbal as well as non-verbal signals that healthcare professionals send out influence the mother's attitude and her perception of the situation. If the medical staff react in a way in which seeing and holding a stillborn baby is the same as seeing and holding a live baby after birth, the mother's attitude and reaction is positive. In relation to the evaluation of care after a stillbirth, Rådestad et al. [9] discovered that the mothers were glad to be encouraged to see, hold and spend some time with their baby. Rådestad and Christoffersen [10] recommend not wasting the first 30 minutes after a stillbirth and actively offering contact to the parents.

In the Czech Republic, the paternalistic approach of healthcare professionals is firmly rooted [11, 12]. The dominant position of healthcare professionals in relation to the patient allows the medical staff to decide what will be disclosed to parents and how to support them. It is not possible to assume what will be the best solution for any given mother or parents, or what will help them and what will be important for them [13, 14, 15]. In 2013, the Cochrane database published an overview of the support provided to mothers, fathers and families after perinatal loss. In this the following is stated: “*Despite a lack of empirical evidence, research and opinion papers published on this topic generally agree that holding and seeing a stillborn baby is valuable for most, but not all women, and that staff should hence be mindful and sensitive to the individual needs and wishes of each family*” [8].

When interpreting the results of our study we should keep in mind the limitations caused by the method of choosing the research sample and a low number of participants in the research. The sample represented a highly selective group of women who suffered perinatal loss. All of the women participated on a voluntary basis; women who were extremely traumatized by the loss may have not been represented in the sample. We are aware that the grief and its intensity are influenced by a range of personal, relational and situational factors. However, co-decision about the care and active involvement of clients in nursing care is one of the essential rights of patients! Only a free and informed choice is the right solution in the case of offering the ritual of saying farewell to a baby after perinatal loss in the Czech Republic.

The option of an informed choice and an independent decision is one of the instruments available to the mother to regain personal control in cases of perinatal loss. The fact that the mothers could decide about the situation gave them a feeling of confidence that their life is, at least

partly, in their hands. Mothers must be provided with the opportunity, space, time and information to be able to take advantage of any choice.

Conclusion

The results of the research in the Czech Republic reflect the frequently occurring uncertainty of midwives taking care of a mother after perinatal loss, which is manifested in the majority of cases by a paternalistic approach to communication, a low level of psychological support, inappropriately chosen verbal or non-verbal communication, and little or even no help in collecting memories of the baby. We recommend paying more attention to the education of midwives in caring for women after perinatal loss, the life-long education of healthcare professionals, and more research in the Czech Republic. Midwives and doctors need to receive information about best practices and proven methods of high-quality healthcare, which they can apply in order to respect the values and attitudes of the patients (women and their families).

Conflict of interest

The authors declare that no conflict of interest exists.

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