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# Both Empowered and Powerless: Mothers' Experiences of Professional Care When Their Newborn Dies

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**ABSTRACT:** **Background:** *The death of a newborn is a complex and tragic situation, the uncertain and stressful nature of which places emotional burdens on the parents. The aim of this study was to examine and illuminate mothers' experiences and perceptions of the care given to them at neonatal clinics while facing the threat and the reality of losing their baby.* **Method:** *Interviews were performed, in the form of conversations, with 16 mothers approximately 2 years after the death of their newborns. The interviews were analyzed using a hermeneutic phenomenological method.* **Results:** *The primary themes identified were feeling empowered and feeling powerless. Three related themes to feeling empowered were a sense of nearness—supporting confidence; a sense of encouragement—supporting self-esteem; and a sense of empathy—supporting comfort. Three related themes to feeling powerless were a sense of distance—leading to strength or adjustment; a sense of violation—leading to helplessness and despondency; and a sense of disconnection—leading to insecurity and discouragement. All mothers felt both empowered and powerless. When experiencing empowering care, they had a feeling of encountering benevolence, with respect to their individual desires. Experiencing competent care without humane treatment made them feel powerless, and they were neither respected as a mother nor a person.* **Conclusions:** *Feelings of empowerment emerged when the health care professionals not only saw the mother as an individual but also “saw through the mothers' eyes” and “felt with the mothers' feelings.” Feelings of powerlessness emerged when the similarity in the lifeworld (i.e., the world of lived experiences) differed, and the perspectives of the mothers and the health care professionals did not correspond. (BIRTH 29:3 September 2002)*

Losing a newborn is highly stressful for all those involved, especially the mother. Communication between the health care professionals and the parents is often difficult, partly because the mothers have ambivalent feelings toward their suffering and dying newborn (1). Some mothers avoided developing a mother-child relationship in the belief that their grief would be more difficult to bear if they did. In such

situations the health care professionals may experience a personal failure because they cannot make the mothers touch or hold their dying and dead newborn (1).

Many hospitals have therefore developed perinatal bereavement programs, which help the staff to inform, counsel, and support the parents. The aim is to facilitate the parent's grief process when losing a fetus (<26 wk) or a newborn (1–8). Such programs were used as a starting point to develop a questionnaire, “The Perinatal Grief Scale,” which was used by Lasker and Toedter to rate the degree of satisfaction with professional care received by 158 women and 56 husbands or partners (9). The most appreciated intervention among the neonatal loss group was for the parents to touch or hold their baby while he or she was still alive. Taking photographs was not as

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important to the early fetal loss group (< 26 wk) as it was to the other groups (> 27 wk).

Kavanaugh performed a study of 5 mothers and 3 of their husbands (10). All had experienced the death of a newborn weighing less than 500 g at birth. The parents were very sensitive concerning the way the physician explained the likelihood of their newborn's survival. They experienced that holding their newborn at the actual time of death was painful and made them feel helpless. Schlomann and Fister interviewed 4 parents, all of whom had been in a situation involving critically ill and dying newborns (11). The parents said that they needed the staff to embrace both their experiences and the critically ill newborn. In another semistructured qualitative study involving 9 mothers, carried out during and just after the dying and death of their newborn, the importance concerning the time, skills, and resources required to provide individual care was demonstrated. Seven women appreciated the opportunity to hold and bath their baby and all wanted time to talk about the situation (12). The preceding studies, all performed in the United States, produced valuable findings, but a limited number of parents (8, 4, and 9, respectively) were interviewed. A small number of informants are appropriate in qualitative studies when the focus is on the knowledge of the lifeworld (i.e., the world of lived experiences) of mothers. Therefore, the aim of this study was to focus further on and illuminate mothers' lived experiences of the professional care they had received while facing the threat and the reality of losing their baby.

### Method

Mothers who gave birth to a baby who died within 2 weeks of delivery at any of 3 hospitals in the south of Sweden during 1997 and 1998 were eligible for the study. The participants were identified with the help of the chief physicians and the National Swedish Board of Health and Welfare. Mothers with stillborn babies, those who had miscarriages, and those whose addresses were unknown were excluded. The remaining 21 mothers were invited to participate in the study by a letter that informed them about the purpose of the study, that their participation was voluntary, and that all the information they gave would be treated confidentially. Three mothers had unlisted telephone numbers and were therefore requested in the letter to call the author (AL). None of them called. Of the remaining 18 contacted by telephone, one did not want to participate and another was too busy at the time of the study. Thus the study sample comprised 16 mothers (M.1–M.16).

Both the interviews and the analysis were inspired by van Maanen (13). The first author (AL) interviewed the mothers for a period of 60 to 90 minutes between 14 and 32 months (mean 22 months) after the death of their baby. The interviews were audiotaped either in the mother's home (6 mothers), in a secluded room in one of the hospitals (1 mother), or at the department of nursing (9 mothers), all according to the respective mother's wish. The women were invited to narrate their experiences and thoughts in the interview. During the dialog, the interviewer intervened with questions such as, "What do you mean? Can you explain in more detail?" van Maanen describes his method as "a philosophy of the individual that we pursue against the background of an understanding of the evasive character of... the *whole*, the *communal*, or the *social*" (13, p 7). It "aims at gaining a deeper understanding of the nature or meaning of everyday experiences" (p 9). However, as emphasized by Hall, the researcher should not follow the method "like a recipe" (14).

All interviews were transcribed verbatim (by AL) and analyzed to identify their meaning. To gain a complete sense of the proceedings, each author read all of the interviews. The first author (AL) analyzed each single sentence by asking: what does this sentence reveal about the experience(s) being described? Significant statements were clarified and organized into broad topical areas. The next step was a process called "free writing," responding to the question: what is it that the mothers want others to know about their experiences? The purpose was to permit the emergence of themes more sensitive to their experiences (15,16). In this way clusters of themes were identified. To increase credibility, the other authors (AKD, TN) also read the themes and compared them with some interview texts. Agreement among the authors was reached. Finally, a summary of each theme and a description of the experiences were sent to 5 mothers for validation. These mothers were selected to represent the heterogeneity of the sample. In their answers, they all recognized that their own experiences were reflected in the summary, signifying validation of the findings. No indication of misunderstandings was evident.

Ethical approval and permission to undertake the study was obtained from the Research Ethics Committee of the Medical Faculty, Lund University, Sweden.

### Results

Of the 16 mothers, 10 were primiparous and 6 multiparous; 3 of the former and 2 of the latter had given birth to twins. Of the 21 babies, 18 had died. All

mothers were Swedish citizens and spoke fluent Swedish. Their educational level varied; 4 women had 9 years of compulsory education, 4 had senior high education, and 8 had university education. Their ages varied between 20 and 37 years, and all were married or lived together with the father of their child. Ten deliveries ended with emergency cesarean section, and 6 were vaginal deliveries. Three women had complications during pregnancy, and 3 were informed that their baby showed malformation discovered during an ultrasound examination. Eight infants had malformations, 6 were preterm, 3 died from complications at delivery, and 1 died from sudden infant death syndrome; they lived between 15 minutes and two weeks (mean = 5.6 days). The gestational age ranged from 23 to 41 weeks' gestation.

Two primary themes were identified from the interviews: feeling empowered and feeling powerless. All mothers related both types of experiences. They were in an emotional turmoil, feeling difficulties in interpreting the care they were receiving and the reality they were going through.

Related themes to feeling empowered were a sense of nearness—supporting confidence; a sense of encouragement—supporting self-esteem; and a sense of empathy—supporting comfort. All mothers believed that the health care professionals were on their side. They experienced benevolence and acceptance, which gave them an increased sense of control. A primary nurse and often a physician attended all mothers. These health care professionals mostly treated the mothers with empathy expressed as nearness, that is, having sympathetic insight as to how the mothers felt and exhibiting a warm and human approach. They also individualized the care of both baby and mother by being keenly aware of each mother's unexpressed needs.

Related themes to feeling powerless were a sense of distance—leading to strength or adjustment; a sense of violation—leading to helplessness and despondency; and a sense of disconnection—leading to insecurity and discouragement. The experience of feeling powerless included a sense of not being respected either as a person or as a mother. All the mothers sometimes had a sense of lack of dialog between them and the health care professionals. This instilled a feeling of loneliness and a sense of not being in control. Their experience was that the health care professionals were not engaged in the individual mother or her situation, but rather, treated her from their own aspect.

#### *Feeling Empowered*

*A sense of nearness—supporting confidence.* The mothers' experience of nearness to the health care

professionals occurred when the latter attended to the mothers without being asked and instilled a feeling in them of both involvement and listening. When informed about the baby's incurable disease, feelings of despair and feebleness occurred. Information about the disease and the threat of death before birth or soon after giving birth to a living baby was given to the mothers gradually as the examination of the baby proceeded. The information was experienced as objective and clear, but at the same time it instilled confidence. The decision to start or withhold treatment was experienced as being left to the parents, especially when the baby had a heart malformation. These mothers did not want to be responsible for the decision. However, according to the mothers, the physicians avoided making the decision, since the results of treatment were uncertain. The mothers were finally able to make the decision themselves because of the careful approach of the physician when informing them. None of the mothers regretted their choice later.

The physician weighed the pros and cons of the treatment, but in some way one could perceive something in the way he expressed himself.... I found him as a very, very good physician; he really was. He gave us time and explained.... Maybe in the way as he explained it there was more that was negative.... The decision we came to was ours.... We had the firm feeling that we made the right decision and we haven't changed our opinion. (M.8)

It was frightening for the mothers to see the inanimate baby in the incubator, and the little body connected to a lot of equipment, in the neonatal intensive care unit. Most frightening was when the baby was preterm and the mother had never seen a preterm baby before. The mothers experienced a feeling of nearness toward the nurses and sympathy from them for the ambivalent feelings the mothers had toward their baby. The nurses showed sympathy by allowing time to talk and sometimes by holding the mother's hand, often without saying anything, and this gave her the courage to touch her baby. External actions were experienced as strengthening the mother's confidence. The father was given the opportunity to stay in the same room with the mother; and the ban on visitors was cancelled. The parents were asked whether they wanted to give their baby a name, and a ceremony with candles and flowers was arranged. Even if the mothers had declined photography, the nurses nevertheless took photographs during the procedure. Later, all but one of the mothers were pleased with the photos.

*A sense of encouragement—supporting self-esteem.* Being confronted with the fact that the baby was going to die (because ventilation was to be withdrawn or death was imminent) made the mothers dissociate

themselves from their baby. One mother did not want to go into the baby's room any more. Another developed breathing problems. All (but possibly one) mothers felt at the bottom of their hearts that they wanted to hold their still living baby, but they did not have the courage, fearing that they would come too close to their baby. The mothers' experience was that the health care professionals encouraged them to change their minds by helping them to see the situation from the baby's perspective. They were given time, which made them feel that the staff was attentive toward them. One mother was very happy that a nurse had told her that she had done well by giving so much attention to her twins. Even persuasion by the staff was found to be supportive.

We didn't want to go in and look at the baby afterwards [being informed that the baby was dying], but they persuaded us. We went in there.... I had a wish at heart but was scared. I didn't want to believe that it was not my baby anymore. But then they said that he could feel us being there.... I tried to see something positive in...to have him a short while more. He must have felt that we were there stroking his cheeks and holding his hands. When we got the information, our whole world collapsed. Then there was a feeling, a wish that we also would die. Nothing more to live for...could almost not eat. It tasted like paper. They persuaded us. And we ate. We allowed ourselves to be persuaded. It was a very good way of helping us. (M.1)

*A sense of empathy—supporting comfort.* Being confronted with the death and dying of their baby was strange. The mothers put their confidence in the health care professionals. Their security, increased by the empathetic actions of the staff, encouraged them throughout the dying process. When hearing that it was not unusual for babies to die in the arms of the mother, their first feeling was that this would be impossible. The practical guidance given by the health care professionals was experienced as being tactful both with respect to the baby's well-being and confirming their sensitivity toward the mother's needs and wishes. Deciding about the time of death, the same or the next day, was left to the parents. They could stay with the baby as long as they wished, and afterward the staff would bring the baby back at any time if the parents requested. It was also possible for the mothers to see their baby after autopsy or organ donation.

Our baby wouldn't survive.... Often they [the babies] would fall asleep with the mother or father [the physician had said]. My first reaction was, I can't go through with this. But then, I thought he would recognize my heartbeats. Of course he will be in my arms.... We had to give him a name. We didn't want to baptize.... I had not wanted my baby to have a borrowed christening robe [crying]. The nurse had prepared a small bunch of flowers that we have dried and now keep in a book. She hadn't lit the candles, but we had candles. They

had taken away almost all [the equipment from the baby's body]. My husband and I named him, and then we withdrew the ventilator. First the nurse put him beside his twin sister [to say good-bye] and then directly in my arms. There he quickly fell asleep. After a while we felt that we had said good-bye to him. Later on we heard that the reflective breathing had gone on for a long while, and the nurse had had him in her arms, which was so good to hear [crying]. Then, the day after they asked if we wanted to look at him again. (M.7)

Siblings of the dead baby were welcomed at the hospital. The first reaction from the mothers was that they wanted the siblings to see the dead baby. However, since the mothers were overwhelmed by their own grief, they felt uneasy about bringing the siblings to the hospital, but all went well. The mothers observed that the staff diverted the siblings' attention from the situation. The staff played with the siblings and let them participate in things like helping to make breakfast for the family.

After the baby's death the mothers were vulnerable. They experienced the health care professionals and social workers as being sympathetically engaged in and affected by the baby's death.

Saving as many memories as possible helped most of the mothers in their grief. They were encouraged to keep just the items they wished to keep.

And the physician came into our room...his eyes were filled with tears. ... It didn't matter that he was crying. No quite the reverse, he was very good. (M.9)

We knew nothing about dying and death. We had very good help from all of the staff, with the burial and announcements in the newspaper and all. When you are too tired to go on any longer, they take care. They ask [questions], come with ideas, your own brain stands still when you are sitting there. (M.16)

### *Feeling Powerless*

*A sense of distance—leading to strength or adjustment.* A sense of distance leading to *strength* occurred when the health care professionals in the women's clinic refused to allow the mothers, especially after cesarean section, to visit the baby in the neonatal intensive care unit. The staff said that the visit could wait until the following day. Three mothers experienced this treatment as if the staff dissociated from them and lacked empathy for their situation. At that moment the treatment gave the mothers strength. Instead of obeying, they disregarded the policy and asked their husbands to obtain a wheelchair to take them to the neonatal intensive care unit. In one case, when a mother went to the unit to visit her baby for the first time, she was informed that her baby had been transferred to the university hospital, causing her considerable distress.

Sometimes the mothers experienced the health care professionals as being unwilling to see things from their perspective. Seeing their premature baby in the neonatal intensive care unit for the first time instilled feelings of ambivalence in the mothers for their baby. One mother said that the baby was more like a nestling. The mothers were urged to touch the baby, but did so only after repeated urging from the nurses. This created unpleasant feelings due to the fear that the baby was so fragile.

...and we should touch him, but he was frightened when I touched him.... I was so insecure... He shivered. And one felt insufficient; one couldn't do anything. (M.6)

The health care professionals expressed the opinion that it was important for the mothers to hold the baby in their arms during the dying process.

It was like that... they insisted on doing it [holding the baby when dying], that it was normal to want to hold the baby. I must be exceptional, because I did not want to do it. ... They didn't respect my position; I had feelings of guilt... but hardly a bad conscience for not holding him. But I stood up for myself. ... I mean, one has no possibility to sit down and analyze, should I hold him now, because I will feel better later on. One is not interested in such things. In this situation it is the feelings you have in that moment that are important. What comes later on, you will handle later on. There is as much grief just in the moment that you can't think of more than that.... If you have not gone through such a situation yourself, you can't understand. Even if it is your work, it is quite another thing. I do really think the staff have to be more sensitive. ... (M.3)

One mother had not been informed about withdrawal of life support and was "accused" of not being cooperative in the decision concerning the time for withdrawal.

As I see it, the physician who was responsible for the care of our baby was much too interested in the machines. And he made decisions that I now know he had no right to force us to follow. He had no right to force me to withdraw the ventilator... I felt that I had no say in the matter concerning my baby. (M.16)

The physicians emphasized that it was they who had the right to decide about withdrawing life support. Their decision was determined by the moment at which they believed the suffering of the baby was too great. Some mothers said that they did not want life-sustaining treatment, but they were not given the time to explain their reasons. A sense of guilt was experienced and a feeling of not being respected as the mother of the baby or as a person. They only silently *adjusted* to the professional decision.

I wanted them to withdraw [life support]. But the physicians didn't want to do so.... They didn't respect me. They said that they would not go on longer than they considered

correct, or if the baby was suffering or so.... It is my experience that when one as a parent says no, then that it is... They [the physicians] who are deciding.... It wasn't right to go on, he was so small, he will never have a dignified life. I felt that they rode roughshod over me... it is not easy to go against physicians, and then you feel that you are quite small.... There were about five to six men standing around the incubator (crying). (M.6)

*A sense of violation—leading to helplessness and despondency.* A feeling of not being taken into account and the lack of confidence in the health care professionals was experienced. For instance, one mother noted that information about the state of her baby was withheld from her. Another mother, who had not been informed, felt violated when she overheard nurses talking to each other, saying that their baby was brain dead.

The mothers felt despondent if the health care professionals did not confirm the mothers' experiences of having had contact with their baby. For instance, one mother told the physician that the value on the monitoring instrument increased when she held her baby's hand, but the physician answered that this did not depend on her action, but on the sensitivity of the instrument. Being congratulated by the nurse for having given birth to such a fine baby was painful under the circumstances. Still, the mothers were understanding about such behavior.

I don't think you can congratulate, even more, ask, "How are you?" or "Look here!"...It was almost as if it was thrown at me what is she saying? Don't congratulate me! He was lying there. Only by looking at him you would have understood that congratulations were not appropriate. However, she [the nurse] didn't mean to be unkind. It was certainly just thoughtlessness. (M.12)

The mothers' helplessness became apparent when their decisions were questioned. For instance, when one hospital chaplain, after the mother had consented to let the baby die, wanted to discuss the decision with the mother from a religious viewpoint. This also happened when the social workers were perceived as unsympathetic and uninvolved and when the nurses informed the relatives about the baby's death. After consenting to an autopsy, one mother misunderstood the expression "pathology ward." She thought that they brought the baby to the cold storage room, but the staff referred to the place where the autopsies were performed. The mother could not, to her great regret, see her baby anymore. Despondency was experienced in some situations: for example, when the question of an autopsy or organ donation was raised only a short while after the baby's death. Still, the mothers generally had a tolerant attitude toward the health care professionals.

Our last wishes were that we would be left alone when the ventilator was withdrawn. ... But the physician came and asked, with a smile on his lips, about an organ donation. It was frustrating. ... Our last moments together with the baby, and he could not wait. ... I think that he was nervous about asking us, and people who are nervous often smile when they find the situation unpleasant. (M.2)

*A sense of disconnection—leading to insecurity and discouragement.* The mothers kept their thoughts to themselves when they felt disconnected from the staff. During the interview the mothers often said that they had wanted to be more “guided.” The care process was frightening and intimidating due to all the machines and tubes that surrounded the baby. The health care professionals were very busy operating the technical care, and asked the mothers to tell them when they wanted to hold and to give care to their baby. But the mothers rarely volunteered to do so, although in fact they longed to.

The staff told me to ask them when I wanted to hold them [the twins], then they would help me, as there were many wires and tubes. ... But even if they said I could. ...it is very seldom (crying) one asks for it. I know that they don't mean to be unkind. They believe that the mother will ask for help, but you don't ask because you don't want to disturb the staff. (M.10)

The feeling of disconnection caused the mothers to feel insecure because they were worried about their lack of concern for their baby. They needed confirmation from the health care professionals that they met the staff's unexpressed expectations, but at the same time did not want the staff to decide for them.

I had bad feelings or a bad conscience the whole time, when I left the baby and went home. The gnawing anxiety was always there. But no one understood.... Maybe they did not want to say yes or no. They always said, “do what you feel is right.”...But I didn't want them to say that I should have stayed in the hospital all the time (laughing), but be a little more definite— “of course you shall go home if you want to.” (M.6)

Sometimes attention was given only to the critically ill baby, and the mothers were left feeling ignored. The mothers also had problems in handling their grief later, when some felt that they had received too little information about the treatment that had been given to their baby. They would have liked someone from the staff to sit down with them afterward and explain the medical details and nursing care reports to them.

I only remember that there were a lot of doctors and other staff, almost ten persons in the room who all at once fell upon him. And we felt a little outside; we didn't know what was happening.... There was no one to talk to us. Some support would have been comforting, just at that moment. Only being there. (M.2)

## Discussion

During the interview, the mothers were often sad, but they communicated their experiences with a sense of gratitude because of the interest in their grief. In this study the mothers' narratives contained many detailed observations about the care, revealing how they recalled their experiences, and this is what matters to the mothers. These memories are valuable to the staff.

We believe that most memories are accurate, since the mothers were personally involved. This assumption is in agreement with the findings of Githens et al (17), who compared 102 mothers' recall with their recall with their medical records concerning the birth of their child. They found that a recall period of 4 to 6 years did not appear to be a disadvantage in an event such as risk factors prior to birth, prenatal care, problems at the labor and birth, and also problems during the first postpartum weeks. There was 89 percent agreement between the telephone-interviewed women's responses and their charts. Ujda and Bendiksen (18) found similar results among 40 parents who had experienced pregnancy losses within the past 4 years. What the care professionals had said and done to them at the time of their loss was remembered very deeply. Even Simkin (19), who compared 20 women's long-term memories about their first birth experiences directly after delivery and after 20 years, found a great consistency. Moos and Schaefer (20) stated that mothers have to establish the personal meaning of the events. An example of this reasoning is that sometimes the words spoken by health care professionals can take on more importance for the listener than the speaker could possibly imagine.

The difficulties of the method used in this study were especially to remain optimally open and flexible during the analysis. To increase credibility, the second and third authors read the results section, and then used the themes to assess their presence or absence in the interview transcripts. Five mothers also validated the study.

The empowering care with which the mothers were confronted is in accordance with the theory presented by Paterson and Zderad (21). They emphasize the intersubjective relationship between the health care professionals and the mother, in which each could be the originator of human acts and responses. The interaction became an action that went both ways between the persons involved, conveying courage. Our findings concerning empowering care are also, to some extent, congruent with the study from Magnusson et al, in which 14 neonatal nurses described their experiences of their role in working with critically ill babies and their parents in the neonatal intensive care unit (22). The nurses emphasized the responsibilities

of establishing an effective relationship with the parents. They would give them time, listen to and interpret even what the parents did not say, be at hand, and be close.

The mothers in our study experienced that the care could also make them powerless. Paterson and Zderad (21) described this as a phenomenon occurring when the health care professionals do not focus on the whole person but only on some limited aspect. For instance, in our study, being treated as an object made the mothers keep their thoughts to themselves. They also felt violated as a person and as a mother. Although they gained a great deal from the experts' knowledge, neglecting the mothers' thoughts cannot be justified. Through an open dialog it is possible to make an action plan that is acceptable to both the mothers and the medical experts (23). Assuming that among the foremost ethical principles in health care are nonmaleficence (to do no harm) and beneficence (to do good), care that is experienced as giving a feeling of powerlessness represents an ethical as well as a professional problem in care practice. Despite the experience of feeling violated by health care professionals, the mothers made excuses for them. Similar forgiving behavior is reported from Halldórsdóttir and Hamrin (24) in a phenomenological study about the care experienced by 9 cancer patients. Although all the mothers in our study made excuses for the staff, receiving such care is a traumatic experience.

In terms of generalizing the findings, our study has at least two limitations. First, the method used can only be generalized with reference to the type of experiences identified, not the frequencies. Thus, we believe that feeling both empowered and powerless will be found in other studies. The mothers were sometimes provoked to be inventive when they encountered perceived violation. For instance, 3 mothers visited the neonatal intensive care unit, despite being prohibited by the staff. When they experienced empowering care, they tolerated both persuasion and coercion, feeling that the health care professionals really cared for the individual mother's desires. When they experienced competent professional care without humane treatment, however, they felt powerless.

Second, the mothers interviewed were all Swedish. Thus women with other ethnic backgrounds might very well have different experiences related to the themes identified and discussed in this article. For instance, 2 mothers "stood up for themselves" and did not hold their baby during the dying process. To hold the baby while he or she is dying appears to be the routine in Sweden. Lundqvist and Nilstun (2) reported that the nurses experienced a personal

failure if they were unable to persuade the mothers to hold their dying baby. Whether or not such reluctance is more common among mothers from other cultures requires more empirical studies (25). Thus, an examination of the relevance of the parents' ethnic background to the formulation of guidelines needs to be explored further.

## Conclusions

All mothers experienced feelings of both empowerment and powerlessness when losing their baby. Feelings of empowerment emerged when the health care professionals not only recognized the individual mother but also "saw through the mothers' eyes" and "felt with the mothers' feelings." Feelings of powerlessness emerged when the similarity of the parties' lifeworld (i.e., the world of lived experiences) differed and the perspectives of the mothers and the health care professionals did not correspond.

To provide meaningful support, professional care of bereaved mothers includes an awareness of how they experience the world when their newborn dies. The mothers want to have their lived experiences understood and accepted. Thus, health care professionals should identify the mother's desires and be open for and react to their discomfort, impart a sense of solidarity to them, and cooperate with them through verbal guidance and practical handling. From an ethical point of view it is important to strengthen the mothers' autonomy. The challenge to health care professionals is to make empathy possible by encountering the mothers in their actual and lived experiences.

## References

1. Robinson M, Baker L, Nackerud L. The relationship of attachment theory and perinatal loss. *Death Studies* 1999;23: 257-270.
2. Lundqvist A, Nilstun T. Neonatal death and parents' grief. *Scand J Caring Sci* 1998;12:246-250.
3. Cohen L, Zilkha S, Middleton J, O'Donohue N. Perinatal mortality: Assisting parental affirmation. *Am J Orthopsychiatry* 1978;48:727-731.
4. Kellner KR, Kirkley-Best E, Chesborough S, et al. Perinatal mortality counselling program for families who experience a stillbirth. *Death Educ* 1981;5:29-35.
5. Lake M, Knuppel RA, Murphy J, Johnson TM. The role of a grief support team following stillbirth. *Am J Obstet Gynecol* 1983;146:877-881.
6. Harmon RJ, Glick AD, Siegel RE. Neonatal loss in the intensive care nursery: Effects on maternal grieving and a program for intervention. *J Am Acad Child Psychiatry* 1984; 23:68-71.
7. Carr D, Knupp SF. Grief and perinatal loss: A community hospital approach to support. *J Obstet Gynecol Neonatal Nurs* 1985;19:130-139.

8. Kohner N, Henley A. *Miscarriage, Stillbirth and Neonatal Death: Guidelines for Professionals*. London: Stillbirth and Neonatal Death Society (SANDS), 1995.
9. Lasker JN, Toedter LJ. Satisfaction with hospital care and interventions after pregnancy loss. *Death Studies* 1994;18:41–64.
10. Kavanaugh K. Parents' experience surrounding the death of a newborn whose birth is at the margin of viability. *J Obstet Gynecol Neonatal Nurs* 1997;1(26):43–51.
11. Schlomann P, Fister S. Parental perspectives related to decision-making and neonatal death. *Pediatr Nurs* 1995;21:243–248.
12. Skene C. Individualised bereavement care. *Pediatr Nurs* 1998/99;(10):13–16.
13. Van Maanen M. *Researching Lived Experience*. 2nd ed. London, Canada: Althouse Press, 1997.
14. Hall EOC. Phenomenological methodologies in the service of health. In: Fridlund B, Hilding C, eds. *Qualitative Research Methods in the Service of Health*. Lund, Sweden: Studentlitteratur, 2000:26–46.
15. Swanson-Kauffman KM. A combined qualitative methodology for nursing research. *Adv Nurs Sci* 1986;8(3):58–69.
16. Swanson-Kauffman KM, Schonwald E. Phenomenology. In: Sarter B, ed. *Paths to Knowledge: Innovative Research Methods for Nursing*. New York: National League for Nursing, 1988:97–105.
17. Githens PB, Glass CA, Sloan FA, Entman SS. Maternal recall and medical records: An examination of events during pregnancy, childbirth, and early infancy. *Birth* 1993;20:136–141.
18. Ujda RM, Bendiksen R. Health care provider support and grief after perinatal loss: A qualitative study. *Illness Crises Loss* 2000;8:265–285.
19. Simkin P. Just another day in a woman's life? Part II: Nature and consistency of women's long-term memories of their first birth experiences. *Birth* 1992;19:64–81.
20. Moos RH, Schaefer JA. The crises of physical illness. In: Moos RH, ed. *Coping with Physical Illness: New Perspectives*. New York: Plenum, 1984:3–21.
21. Paterson JG, Zderad LT. *Humanistic Nursing*. 2nd ed. New York: National League for Nursing, 1988.
22. Magnusson G, Tedesand S, Dahlberg K. Att vara behövd som sjuksköterska på en neonatalavdelning (Being needed as a nurse in a neonatal unit.) *Vård i Norden* 1998;18(2):31–36.
23. Berg M, Dahlberg K. A phenomenological study of women's experiences of complicated childbirth. *Midwifery* 1998;14:23–29.
24. Halldórsdóttir S, Hamrin E. Experiencing existential changes: The lived experiences of having cancer. *Cancer Nurs* 1996;19(1):29–36.
25. Herbert MP. Perinatal bereavement in its cultural context. *Death Studies* 1998;22:61–78.