

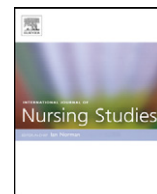


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Fatherhood and suffering: A qualitative exploration of Swedish men's experiences of care after the death of a baby

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ABSTRACT

Background: This study was designed to evaluate fathers' experiences of stillbirth and psychosocial care.

Methods: Data were collected between 27 March 2008 and 1 April 2010 via a questionnaire posted on the homepage of the Swedish National Infant Foundation. The responses to the following open-ended questions were analyzed using content analysis: "Are you grateful today for anything that health care professionals did in connection with the birth of your child?" and "Are you sad, hurt or angry today about something personnel did in connection with the birth of your baby?"

Results: 113/131 (86%) fathers reported feelings of being grateful. Only 22/131 (16%) fathers reported feeling sad, hurt, or angry. Fathers expressed gratitude when health care professionals treated their newborn "with respect and without fear", "with extraordinary reverence", and when their fatherhood was validated by providers. They were also grateful when providers helped them to create memories of their baby. Fathers also reported feeling sad, hurt, or angry when providers were nonchalant and indifferent and when they perceived providers to be uncaring and disrespectful toward their baby.

Conclusion: Bereaved fathers experience overall gratitude for person-centered psychosocial care in the aftermath of stillbirth, particularly when they feel validated as a grieving father and their child is acknowledged with reverence.

Clinical implications: Health care professionals should support fathers by treating the baby who died with respect and dignity and by validating and acknowledging both his grief experiences and his fatherhood just as they would for a grieving mother.

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What is already known about the topic?

- Grieving mothers prefer person-centered care in the aftermath of stillbirth.
- The literature reports differences in mourning outcomes based on gender of parents.
- Fathers emotions are often overlooked in their grief experiences, often relegated to being a caretaker for the

mother. This occurs from family members and from providers. This puts them in a double bind wherein they feel compelled to remain strong and yet be willing to show emotional vulnerability in the aftermath of a baby's death.

What this paper adds

- Most fathers also report feeling grateful for person-centered care provided to them by providers following perinatal death.
- Only a small percentage of fathers (16%), felt negative emotions about the ways in which they were treated by providers following the death of a baby.

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- Fathers feel deep grief upon the death of a baby, and they experience a lack of regard or callousness toward their grief and their babies as disrespectful.
- Conversely, when providers treated the baby with the same “reverence” as a live-born child, men reported feeling validated and experienced gratitude for the compassion and professionalism of providers.

Each of us has his own rhythm of suffering.
–Roland Barthes

1. Introduction

While grief in general has been widely studied in psychological research, much less is known about the ways in which men, as fathers specifically, experience loss, grief, and social support.

Because mothers gestate and give birth, much of the literature on perinatal death has focused on maternal grief and morbidity, while some studies have been comparative along gender lines. Specific to perinatal death, when compared to mothers, fathers consistently report fewer grief symptoms and less anxiety (Barr, 2004), however, trauma symptomatology in the aftermath of a baby's death is a risk identified in the literature for both genders (Badenhorst and Hughes, 2007). Littlefield and Rushton (1986) evaluated the reaction of parents to the death of a child through the perspective of sociobiology. In their study of 263 bereaved parents, they concluded that mothers express more grief than fathers, maternal grandmothers grieved more than maternal grandfathers, and paternal grandmothers grieved more than paternal grandfathers. Mothers seem to have more intense emotional reactions with the exception of avoidance and meaning-making (Wing et al., 2001), and this has implications for grieving fathers.

1.1. Fathers as invisible protectors

Perhaps as a consequence of mothers' tendency toward emotional expression, fathers reported both peripheral and endogenous pressure as protector, feeling neglected in their own experiences of grief. In general, grieving fathers experience a “double bind”: social pressure to remain “strong” as caregivers for their partners while they also felt pressured to be more emotionally expressive. Fathers reported avoidance tendencies, blocking negative thoughts, task centered coping, and solitary grieving, allowing emotional expression only in private settings (Cook, 1988). Cook (1998) recommends a model of father's grief which is not based on an emotioncentric, feminine style.

Yet, this tendency to focus on the feminine expression of grief is apparent in the small body of academic research on fathers and, also, in hospital practices where men often cite feeling that their experiences of loss were overlooked, invisible, or invalidated (Kavanaugh et al., 2004; Lang et al., 2011; Weaver-Hightower, 2011). Fathers report feeling neglected by providers, reporting that others, namely nurses, family, and friends, tended to view the father in a primarily supportive role for the benefit of the mother

(McCreight, 2004). Because they are perceived to have lesser grief than mothers, these perceptions often result in minimal support directed toward fathers or, perhaps, diminished understanding about the ways in which men experience a baby's death. In turn, this may exacerbate already salient relational stressors between partners (Wing et al., 2001).

1.2. Discordant grieving styles

Indeed, gender differences in the expression of grief and thus the perceived need for support, beginning with hospital provider care, may contribute to marital disharmony and discordant grieving. These risks can be better managed with the aid of healthcare providers through early interventions such as naming and holding the baby, psychoeducation, support groups, and rituals that bring parents together toward shared goals of remembering the baby who died (Lang et al., 2011; Wing et al., 2001). Zeanah et al. (1995) found that family support and ego strength were the most salient predictors of symptoms, and in about 25% of the families, fathers expressed more grief than their partners. Additionally, defensiveness was the best predictor of difficulty in coping for fathers.

Yet, some research on paternal grief tells a more nuanced story than merely difference in the expression of grief based on gender. Because the mother endures birth and a physical recovery process, a father's emotional reaction may be delayed due to external demands such as caring for surviving children, hospital protocol, funeral arrangements, and the need to protect his partner (Callan and Murray, 1989). The responsibility to maintain family income may cause some fathers to overwork and become preoccupied with work as a means of distraction from their grief. Additionally, fathers may experience a need to remain strong, so as not to burden their partner with their own distress. And, because some bereaved fathers are reluctant to join a support group and report that peers were not open to helping them grieve (O'Leary and Thorwick, 2006), they may end up bearing much of the burden of their grief alone. As such, fathers also report diminished cognition which may affect their ability to work, as well as emotional states of guilt, shame, anger, and death avoidance (Barr, 2004; Callan and Murray, 1989). In response to these considerations, Callan and Murray (1989) assert the need for doctors to shift roles from providers of medical care to highly person-centered counseling following the death of a child, noting that consistent findings support the idea that grief reactions are influenced by their interactions with parents.

1.3. A father's pain and provider responses

Fathers indeed do suffer after the death of a baby, albeit sometimes expressed differently than mothers. Fathers' expressions of loss after perinatal death can be divided into discrete categories: their visual images and memories of the baby's death, self-blame, identity and/or role confusion, the desire for social recognition and validation of their fatherhood, playing a supportive role to their partners, and their perception of hospital provider's practices

(McCreight, 2004). Using in-depth interviews conducted within five years of the death to address the father's perspective of stillbirth, Worth (1997) found fathers to be preoccupied with their transition into fatherhood and the implications of a stillbirth on their fatherhood. Some expressed a willingness to sacrifice their own life for their child. Fathers reported many moments of affection and attachment behaviors such as counting toes, looking for facial and other physiological similarities, and/or comparing their stillborn child to their living children. However, fathers also reported that the administrative details, often related to final disposition and autopsy forms, felt inappropriate and untimely, often shifting their perception of provider care toward the negative. This can have lasting effects on a man's bereavement trajectory. Like mothers, fathers report that negative hospital care often influenced their grief reactions and processes.

Another significant source of distress for men is the ambiguity of fatherhood when a baby dies (McCreight, 2004). Bereaved men questioned whether or not they should consider themselves fathers, and when they were treated by providers as such, they reported feeling satisfaction and validation. Some reported satisfaction in the opportunity to discuss their experiences and to take the lead in tangible rituals such as funeral services for their child. Similar to other studies, McCreight (2004) found that both parents appreciated the opportunity to interact with their dead child. However, unlike other studies, which have emphasized gender differences in grief expressions men and women, this study found more similarities for both sexes. Similarly, O'Leary and Thorwick (2006) found that fathers felt overlooked by providers' verbal (i.e. asking how the mother is doing) and non-verbal cues. Research is thus mixed and many are asserting that father's grief is not less, rather qualitatively different, from mother's grief (Stinson et al., 1992; Wing et al., 2001), an important point for healthcare providers to recall when considering the ways in which bereaved parents, both mother and father, should be cared for while in the hospital. This applies to the expression of grief, social support, and bonding rituals with the baby who died. However, there exists only a few, small studies which explore the effect of social support and ritual particularly with fathers.

Samuelsson et al. (2001) found that fathers do appreciate an opportunity to actively mourn their child, including holding and seeing the baby and collecting mementos. They also expressed a general feeling of frustration and helplessness while unable to protect their partner from emotional pain. In addition, they felt reliant on providers to make decisions and expressed a general sentiment that their emotional needs were ignored. In a small pilot study of grieving fathers, Aho et al. (2011) found that supportive psychosocial care, peer contact, and resource provision yielded positive outcomes over a control group. This collaborative approach was perceived positively by fathers in the study in helping them cope with their motional experiences.

This study was designed to explore the experiences of grieving fathers in relation to their healthcare providers and the birth and death of their babies. This research focuses on psychosocial care during the first decade of the

21st century, and it is important to note that no significant changes in such practices have occurred during this period in Sweden.

2. Methods

2.1. Study design, data collection and participants

We made information about the study available at the website of the Swedish National Infant Foundation, an organization providing support to parents. A questionnaire was available online at this site. The data were obtained electronically, and inclusion criteria were fathers who had experienced the death of a baby to stillbirth after the 22nd week of gestation at some time from the year 2000 until 1 April 2010. The participating fathers gave their informed consent at the webpage and participated anonymously. The Regional Ethics Committee, Lund, approved the study, Dnr. 467/2006.

2.2. Questionnaire

The web questionnaire was driven by clinical experiences and a thorough review of relevant literature and consisted of 82 items covering demographic information and topics related to the birth of a stillborn baby. These outcomes helped to determine inclusion criteria for analyses of the primary, open-ended questions used for this paper. For example, one question inquired as to whether or not the father present at birth. Another question asked specifically about his contact with the baby. Yet, another asked about the baby's gestational age. The questionnaire took an average of 20 min to complete. The questions posited were both open-ended and multiple choice, and fathers could choose from multiple answers. They were encouraged to write fluently about their experiences with healthcare providers in two open-ended questions. This analysis was conducted on the only two open-ended questions.

2.3. Analysis

Data were derived from the original Excel questionnaire. Qualitative, inductive manifest content analysis was used for analyzing the text from these specific questions: "Are you grateful today for anything that the health care professionals did for you in connection with the birth of your child?" and "Are you sad, hurt or angry today about something personnel did in connection with the birth of your baby?" (Elo and Kyngäs, 2008). Among the fathers who fulfilled the inclusion criteria for this study, there were a total 135 responses to the two questions. The responses for each question were read and re-read several times (i.e. 113 responses to the question about "gratefulness" and 22 responses to the question about being "sad, hurt or angry", for what health care professionals did in connection to the stillbirth). Thereafter, the manifest content of a sentence or a longer paragraph was labeled with one of the codes/statements that emerged inductively during the process of analyses of all text for respective question. The codes/statements were discussed by two of the authors to ensure consistency and thereafter formed into six categories,

Table 1
Statements sorted into categories and number of fathers in each category.^a

Category	Statements
Gratitude	
Providers supported fatherhood <i>n</i> = 104	<i>The really invited me to take part as a father and treated me with consideration.</i> <i>They took the time to pay attention to me alone when I was out in the hallway for a moment.</i>
Confirmation and consideration of the child <i>n</i> = 34	<i>They showed tenderness and used the baby's name.</i>
Preservation of the memory of the baby <i>n</i> = 31	<i>The footprint is worth a lot to us now. The same is true for the little cuddly animal that she had with her during the time we were together in the hospital.</i>
Sad, hurt, or angry	
Being met with nonchalance or coldness <i>n</i> = 12	<i>The physician who delivered the baby was appalling and behaved inhumanely.</i>
Unsympathetic and insensitive <i>n</i> = 9	<i>The physician who reported the death did so in a very cold way.</i>
Disrespect toward the baby <i>n</i> = 6	<i>A staff member who went by the baby without seeing him.</i>

^a One father can be in more than one category.

three for each question. These categories emerged during the process of analysis according to similarities and differences in the text (Table 1).

3. Results

In all, 159 fathers who had lost a child sometime between 1970 and 2010 completed the web questionnaire. Of those, 131 fathers fulfilled the inclusion criteria as they had experienced a stillbirth after the 22nd week of gestation at some time from the year 2000 until 1 April 2010. The majority of the fathers answered the questionnaire within two years after their loss, with 76% experiencing the death of a baby between 2006 and 2010 (*n* = 99). The remaining 24% (*n* = 32) experienced the loss between 2000 and 2005. Almost all fathers (95%) were present during the birth of their baby, all of them saw their child within 30 min after birth, and 102 (78%) held their child. A total of 14% (*n* = 18) fathers did not report feeling grateful for anything that the health care professionals had done in connection with the birth, and 86% (*n* = 113) reported feelings of gratitude. In total, 109 (84%) of fathers did not report feeling sad, hurt, or angry for something personnel did in connection with the birth of their baby. Only 16% of fathers conveyed that they felt sadness, anger, or being hurt by something a provider had done in connection with the birth of their child. There were no significant differences in the data based solely on time since loss.

3.1. Gratefulness for something that the health care professionals did in connection with the birth of the child

Of the 86% of fathers who expressed gratitude for provider care, the dominant recognition was around the degree of provider compassion and professionalism. These statements were often accompanied by descriptions of the providers as “*professional, accustomed to providing help, well prepared, calm, unafraid, considerate, displayed presence of mind and were not stressed, attentive and gave of their time, and prepared*”. Personnel were described as “*empathic, fantastic, supportive, gentle, understanding, wonderful, tender, compassionate, warm, respectful, kind, attentive,*

helpful, understanding, proficient super, good listeners, and willing to help”. An overriding theme was formulated: Gratitude for the compassionate professionalism of providers with the subcategories: (1) supported fatherhood, (2) confirmation of and consideration for the child, and (3) acquisition and preservation of memories related to the loss.

3.2. Health care professionals supported fatherhood

The category “Health care professionals supported fatherhood” consisted of statements from 104 fathers. Health care professionals supported fatherhood by facilitating postmortem rituals such as seeing the birth of baby who died as the birth of a real child, worthy of dignity and respect, and they legitimized his fatherhood as if the baby had been born alive.

They invited me in as father and also thought about me. They took the time to think only of me when I was momentarily in the corridor in their presence (Loss in 2009).

They really were there to help and always available to do so. I was just as pampered as my wife was. The staff made us feel as though we were exactly like all the other couples having a baby (Loss in 2010).

3.3. Confirmation and consideration of the child

The category “Health care confirmation of and consideration for the child” consisted of statements from 34 fathers. Fathers were thankful that health care providers treated their baby as if she or he were alive. This was demonstrated by the positive comments made by the providers about the baby to the parents.

I appreciate that the nurse who was with us at the delivery treated our little girl with respect and without fear (Loss in 2008).

They showed tenderness and used the baby's name (Loss in 2010).

They spoke of him as they might speak about any of the babies. They put a diaper on him (Loss in 2008).

They treated our daughter with extraordinary reverence. (Loss in 2008).

3.4. Preservation of the memory of the baby

The category “Acquisition and preservation of memories related to the loss.” consisted of statements from 31 fathers. Fathers were thankful that health care providers allowed and encouraged memories through hand and foot prints, photographs, and locks of hair.

The footprint is worth a great deal now. The same is true for the little cuddly animal she had with her during our time in the hospital (Loss in 2010).

Footprints and handprints, a lock of hair, a card. That they saw to it that the baby was photographed. We ourselves never thought of this, but the cards are now our most treasured mementos (Loss in 2010).

3.5. Sad, hurt, or angry about something personnel did in connection with the birth

Of the 16% of fathers who conveyed that they felt sadness, anger, or being hurt, the dominant theme stated in their comments was they felt their fatherhood went unrecognized or invalidated with the categories: (1) being met with nonchalance or coldness, (2) unsympathetic and insensitive confirmation of the baby's death, and (3) disrespect toward the baby (Loss in 2010).

3.6. Being met with nonchalance or coldness

The category “Being met with nonchalance or coldness” consisted of statements from 12 fathers. The fathers were sad, hurt, or angry when health care professionals did not recognize and validate them as a father or did not show sensitivity during their traumatic loss.

In contrast with the midwife, the physician we overall had the most contact with did not listen to me. Feels typical, they (caregivers) say that they think it is really important that the fathers take part, but then they completely fail to show any interest, except when they respond with sarcastic remarks or humiliate us (Loss in 2009).

A female physician met me with the attitude that the loss was not as sorrowful for me as for my wife (Loss in 2010).

The first physician was totally cold and said to my wife that she should stop acting like a baby (Loss in 2008).

3.7. Unsympathetic and insensitive confirmation of the baby's death

The category “Unsympathetic and insensitive confirmation of the baby's death” consisted of statements from nine fathers. The fathers were sad, hurt, or angry that

health care providers were insensitive in the death notification process.

The reception we got when we were confronted by the delivery and the staff said that he was dead. A physician showing no feelings, who just left us alone in the room without giving us any answers about what would happen next. We were alone, not knowing if we should go home, remain there, complete the delivery or if an incision was to be made (Loss in 2010).

The staff member who had done the ultrasound examination and said that the baby was dead. They were unbelievably clumsy and insensitive and did not give us any information or guidance. You can go home now and come back tomorrow morning. Goodbye! (Loss in 2010)

3.8. Disrespect toward the baby

The category “Disrespect toward the baby” consisted of statements from six fathers. The fathers were sad, hurt or angry when health care professionals did not treat their baby with respect as a person.

They did not call the baby “baby”, but rather “fetus”, and that was clearly exact but on the wrong side of the “boundary;” for me the baby was a baby and would therefore I would have preferred that the baby had been called that, whatever the correct medical terms were (Loss in 2010).

Some staff member who went by the baby without looking at him (Loss in 2008).

3.9. Summary of the analysis of the replies to the two open questions

Insensitive treatment was the primary reason for fathers perceived transgressions and subsequent psychological distress. Frequently, it was a single individual's behavior that was described as “unfeeling” and lacking in empathy. The majority of the fathers expressed their gratitude for something that the provider had done in connection with the birth of their child. This gratitude primarily had to do with the fact that providers helped fathers *feel* like fathers, acknowledging their parental role for a longed-for baby. They also appreciated when providers treated their stillborn babies with the same dignity and respect as a live-born baby. The result may be summarized in the following quotation by one of the participants:

They treated him as a real baby, smiled at him, complimented his appearance, patted his cheek, and talked about him. They took him rather soon to the photographer so we got a life-long pictorial memory. They gave us hand and footprints. They talked with us and guided us through difficult questions, for example concerning autopsy, about talking with a medical social worker and minister, about how we were going to feel later. We got an information brochure and a book about losing a child. We

were able to borrow a digital camera and we got everything on a CD. I am extremely grateful for all of this. Most of all that the midwife who had the greatest responsibility for taking care of us saw me as a father and talked just as much with me (as with my wife) and about being father of a son (Loss in 2008).

4. Discussion

Consistent with previous research, several men in this study clearly experienced “feeling ignored and unacknowledged as a legitimately grieving” father (Lang et al., 2011, p. 191). Yet, they consistently expressed their gratitude for highly person-centered psychosocial care and when they felt supported and validated in their fatherhood. They were also grateful when providers treated their baby as any live-newborn, helping them to create memories with their baby. Further, when met with perceived nonchalant and detached psychosocial care, and when providers were deemed uncaring and disrespectful toward the baby who died, fathers reported feelings of sadness, hurt, and anger.

Defey (1995) analyzes the particular difficulty facing health care providers when caring for parents experiencing perinatal death. Often times medical providers are insufficiently prepared to deal with death, inciting experiential avoidance. This, in turn, may result in actually avoiding, not only merely the experience, but also the bereaved parents themselves. She attributes perceived transgressions to the medical provider’s own difficulty and discomfort facing the death of a baby. Malacrida (1997) found that parents reported providers as “insensitive” to their needs and that they felt both rushed in their time with the baby and pressured by providers to make important end-of-life decisions.

Mothers and fathers may have more in common than previously thought. Consistent with the findings in this research on fathers, a recent study by Rådestad et al. (2011) found that most mothers who gave birth to a stillborn baby were grateful when the health care providers facilitated postmortem rituals such as holding and seeing the baby, photographs, and locks of hair. Further, health care providers who validated and supported bereaved mothers in their *motherhood*, despite the death of their babies, incited deep feeling of gratitude for the mothers and may help alleviate negative, long-term psychological outcomes (Rådestad et al., 2011). Murray and Callan (1988) indeed found higher self-esteem, lower depression, and improved psychological well-being in bereaved parents associated with satisfactory provider interactions. Satisfaction with hospital interaction was the only predictor of lower depressive symptoms, and higher levels of reported happiness were correlated to the greater amount of time since perinatal death. Cacciatore (2010) suggests that humility, mindfulness, and nuance are immutable aspects of person-centered care likely to benefit *both* mothers and fathers. It is important, thus, to remember that fathers may look to providers to recognize them as such, and health professionals need to be aware of a father’s experience of grief through validation, empathy, and psychosocial care (Worth, 1997).

In the autoethnography, *Waltzing Matilda*, a father’s story about the death of his baby to stillbirth, Weaver-Hightower (2011) sensitively describes his profound sadness and awe:

Her body was not disgusting, as we feared, but instead miraculous, strange and wonderful... Seeing and holding her brought both intense pain and great joy at once. Perhaps this and other stark dualities—the body as beautiful and horrible, simultaneously saying hello and goodbye, giving birth but leaving with empty arms—best define the experience of stillbirth (p. 9).

He goes on to describe the importance of mementos: Matilda’s hair, the yellow comb used for her hair, a small, silver ring “worn only for a few hours”, a cast of her right hand, and more and more “proof” that she existed and of his fatherhood to her (p. 14). He closes the article with Matilda’s legacies: perspective, courage, and other things for which he expresses gratitude. But mostly, it appears, for just “becoming her father” (p. 24).

4.1. Limitations

The web questionnaire completed by the fathers was posted on the homepage of the Swedish National Infant Foundation, and the fathers were thus self-recruited. The anonymity of an Internet questionnaire increased participation rates and gave respondents an opportunity to openly express their feelings and experiences without fear of judgment or reprisal. It is also important to note that Sweden has a long tradition in the provision of psychosocial care, clinical practice, and research in this area. This trend is likely to have influenced the outcomes of this study and may not represent global perspectives on psychosocial care after stillbirth. The results in this study are from a single selected group of fathers from one country and results may be different in countries where maternity care routines and guidelines differ from those in Sweden. Thus, this is a non-generalizable sample. In addition, cultural variation related to death and dying rituals needs to be considered. Still, through the process of careful data collection and qualitative analyses, this study adds to the small but growing body of literature on grieving fathers after the death of a baby or child.

5. Conclusion

Though much more is known about grieving mothers, it seems that in many ways, grieving fathers desire the same degree of psychosocial care as mothers. While most fathers report feeling grateful for person-centered care provided to them by providers following perinatal death, a small percentage of fathers (16%) felt negative emotions about the ways in which they were treated by providers, particularly when they felt invalidated, ignored, and overlooked in the grief experience. More importantly, they resented when providers did not treat their baby with dignity and reverence. Fathers experience deep grief upon the death of a baby, and they perceived a lack of regard or callousness toward their grief and their babies as

disrespectful. Conversely, when providers treated the baby with the same “reverence” as a live-born child, they reported feeling validated and experienced gratitude for the compassion and professionalism of their healthcare providers.

6. Clinical implications

Healthcare providers should support both parents after the stillbirth of a baby. They can focus on validating a grieving man’s fatherhood by treating the stillborn baby with the same respect and dignity as they would a live-born baby. Ways to do this might be through important rituals such as seeing and holding the baby, allowing and encouraging the father to participate in making decisions, using the baby’s name and treating the baby tenderly, and referring to him as a father.

Conflict of interest

None declared.

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Ethical approval

The Regional Ethics Committee, Lund, approved the study, Dnr. 467/2006.

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