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SEXUALITY FOLLOWING THE LOSS OF A CHILD

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*The aim of study was to increase our understanding of sexuality and intimacy following the loss of a child. A questionnaire on intimacy and sexuality was sent to 1,027 members of the 2 major bereavement support organizations for parents who have lost children in Norway. A total of 321 (33%) were returned. In addition, 10 couples were interviewed in depth about their experiences. The final sample (*n = *285) consisted of 169 women (59.3%) and 116 men (40.7%) who represented 175 couples. Parents who were neither married nor cohabitants were excluded, as were nonbiological parents. Around 2/3 of the parents had resumed sexual contact within the first 3 months after their child's death. The activity of about 1/3 had been reduced. Significantly fewer mothers than fathers experienced sexual pleasure and close to 30% of the mothers reported that this had been reduced since the death. Only 11% noted that sexuality as an issue was raised in follow-up conversations. Many parents have only a few sexuality-related problems following a child's death, but a fairly large minority, especially women, experience major problems. There are clear gender differences in reactions and perceptions, often agreed upon by the 2 genders. Men are ready to resume activity in the sexual area much earlier than women. Women suffer much more from grief that in different ways intrudes on the sexual act and they more often perceive sex as somehow being wrong. Men also easily misunderstand women's need for closeness as a wish for sex.*

The pain and anguish experienced by parents who lose a child is reflected in folklore as well as in fiction (Aries, 1981). When a child dies before the parent, the event seems to undermine the order of the universe (Gorer, 1965). Its untimeliness is often accompanied by traumatic circumstances, such as with accidents, Sudden Infant Death Syndrome (SIDS), and stillbirth. A variety of studies done across nations and cultures have shown that it leaves an imprint

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on the majority of parents, increasing the chances for complicated and prolonged grief reactions, making them vulnerable to a range of emotional difficulties (K. Dyregrov, 2003; Keesee, Currier, & Neimeyer, 2008; Rubin & Malkinson, 2001). It has the potential to affect both living siblings and siblings born subsequent to the death, with ensuing familial consequences. In addition to the psychological consequences of such losses (Dijkstra, 2000; K. Dyregrov, 2003), a large epidemiological study from Denmark has shown that mothers who have lost a child (< 18 years) are at an increased mortality risk for many years, highest during the first three years. Men also showed an increased risk, but only early on (Li, Precht, Mortensen, & Olsen, 2003). This study also found sudden losses to be related to a higher mortality rate than expected losses, as was losing an only child. Although many parents learn to live with the loss, it continues to make its presence felt on anniversaries for decades after the fact (A. Dyregrov & Dyregrov, 1999; Lehman, Wortman, & Williams, 1987).

Studies have only to a minor extent focused on how such deaths impact parents' sexual life. Through sexuality, the need for intimacy and pleasure is experienced and nurtured. Sexual satisfaction consistently has been found related to higher marital satisfaction (see Christopher & Sprecher, 2000). Research indicates that a decline in sexual satisfaction over time is related to a greater danger for a breakdown of the relationship (see Christopher & Sprecher, 2000, for an overview). The experience of sexuality thus seems to be associated with the stability of a relationship.

Only one study has specifically focused on sexuality after a child's death (Hagemeister & Rosenblatt, 1997). They studied 24 couples and found that more than half the mothers and a little less than half the fathers had experienced serious problems in the sexual area following the loss (Hagemeister & Rosenblatt, 1997). Women complained about a reduced interest in sex, and men that the sexual contact had been reduced. Almost all had abstained from sexual intercourse for a period after the death, with a more extended period of abstinence when the death was sudden. Although the desire for sex decreased, the results indicated that many had a greater need for physical closeness. Sixteen of the 24 couples in Hagemeister and Rosenblatt's (1997) study had experienced a break or decline in their sexual relationship for a period of time following the death. This break was attributed to

factors such as physical and emotional exhaustion, depression, a sense of numbing, being preoccupied with their grief, or psychological distress about sexual intimacy. Three couples reported adultery, and in six couples one or both partners had cried during intercourse.

Some other studies have acknowledged sexual problems, although sexuality was not a major focus of the study. Schwab (1992) interviewed 20 couples who had lost children due to various causes during the last 4 years before the study. A loss of sexual intimacy was one of several themes brought up. From the men's perspective, women's distancing and lack of response as a sexual partner was experienced as something that took away a source of comfort in connection with their loss. For mothers, their partner's desire for sex could be felt as repulsive and increased their loneliness. Schwab concluded that it appeared as if women more often lost interest in sex as a consequence of their loss, while men retained their sexual needs and only experienced a short break in their sexual interest.

Fish (1986) reported that 60% of bereaved mothers and 40% of bereaved fathers experienced serious sexual distress following a child's death. Women complained of a reduced interest in sex and problems finding pleasure in such activities, whereas men complained that the sexual relationship faded. Lang and Gottlieb (1993) found that mothers who highly appreciated sexual intimacy experienced a stronger longing for their lost child. Fathers who experienced a high level of sexual intimacy 2–4 years after the loss of an infant child experienced less isolation and fear (Lang, Gottlieb, & Amsel, 1996). The same researchers also found that fathers who reported higher levels of sexual intimacy early after the loss experienced more somatisation 2–4 years later. In several of these studies men reported a wish for more sex than women following a child's death (Lang & Gottlieb, 1993; Schwab, 1992).

Johnson (1984–1985) interviewed 14 couples who had lost a child during the previous year. All except two of the couples had refrained from sexual intercourse for a period following the loss. She also reported that when a child died suddenly without any notice, the parents seemed to refrain from having sex longer than following anticipated deaths. Although the sexual desire and contact decreased, there was a greater need for physical closeness (to be held and hugged) without sex. Johnson speculated that the

women's need to verbalize thoughts and feelings were greater than men's, but that men's need for closeness could take other and more physical forms. The author wrote that unfortunately the form of closeness that was comforting for one partner could be a form that the other partner could not tolerate at that particular moment in time.

As previous studies have included few participants or only a few questions about sexuality, there is a need for a broader study in this area. So far most studies have been conducted in North America, and none in Scandinavia. Scandinavia is known for its liberal view on sexuality. Young people have their sexual debut early (in Norway), may have several partners, and often cohabit before marriage (if they marry); marriage is also possible for homosexual couples in Norway. However, sexuality is still a topic that is fairly difficult to bring up in conversation and must still be regarded as a taboo subject. Contraception is easy to obtain, and emergency contraceptives/morning-after pills can be bought without a prescription. Having children is thus often a planned decision, and with the average number of children per family in Norway being 1.9, a great deal of value is placed on the children born.

The aim of this study was to increase our understanding of sexuality and intimacy following the loss of a child, both by including a larger number of participants and by undertaking the first systematic study of this topic outside of the United States. The following research questions were asked: (a) To what extent did couples experience problems in their sexual relationship following the loss of a child? (b) Were there any gender differences in the perceptions of sexuality in the relationships studied?

Method

Subsequent to the reduction of the number of SIDS deaths, the Norwegian SIDS Society has broadened its scope to include parents who have experienced other types of child mortality. Although the percentage of parents who join the organizations that serve bereaved parents is not known, it could be said that many parents belong to the societies. There are, however, few parents with a non-ethnic-Norwegian background in the two organizations, and it is also believed that those with social problems are less inclined to become members.

Based on lists of support members of the two major Norwegian support organizations for bereaved parents from The Norwegian Organisation for Families Who Have Lost a Child and the Norwegian SIDS Society, questionnaires were sent to 1,027 members. Three hundred twenty-one people returned their questionnaires, a response rate of 33% of all possible members. However, this is an uncertain estimate of the response rate, because individuals other than the parents (such as grandparents, friends, etc.) can become support members and records do not indicate loss status.

Out of the 321 individuals, the sample consisted of more women (202; 62.9%) than men (119; 37.1%). Almost all (93%) respondents were married or cohabitants (women: 91%; men: 98%), 4% were divorced (women: 5%; men: 2%), while the rest were living alone or were widows/widowers. As many as 95% stated that their partner was the mother/father of the deceased child. Twenty-seven persons (8.4%) reported a break-up in their relationship after the loss of their child. The women and men represented 211 couples. The couples were represented by one partner only (101; 9 men and 92 women) or by both partners (220; 110 men and 110 women).

Because the aim of this study entails an emphasis on couples and gender issues, 54 were excluded from the sample of these 321 individuals because they were not in the relevant population segment (e.g., not married or cohabitants, with partners who were not father/mother of the child who died). The final sample ($n = 285$) consisted of 169 women (59.3%) and 116 men (40.7%) representing 175 couples. Some of these women had partners who did not contribute to the study (35%). Analyses showed that those women for whom the partner also contributed had a higher level of education and, to a lesser degree, reported that the loss caused a more distanced relationship to the partner. No other statistical differences were found.

The mean age of men was 39.6 years ($SD = 7.2$, range = 31.0), and mean age of women was 37.6 years ($SD = 7.0$, range = 37.0). The mean duration of the relationships was 14.2 years ($SD = 7.2$). Five percent (5.3%) of the group had elementary school educations, 30.3% had attended high school, whereas 64.4% had a higher level of education from the college, academy, or university level. The majority (53.5%) lived in a city, whereas 46.5% lived in rural areas.

A total of 138 persons indicated that they were willing to be interviewed, but only 105 sent back a written consent form. Among these there were 33 for whom one partner either was unwilling to participate or there was no partner. From the remaining 72 participants, 10 couples were drawn based on the following criteria: both partners were willing to be interviewed, parents should be married or cohabitants, they should both be the biological parents of the deceased child, and the death should have taken place within the past 10 years. The interviews took place in January and February of 2006.

Full anonymity was promised for the interviews and no further background information was gathered. Citations have been given in a form that disallows identification. Interviewees have read through all of the citations and approved them. For reasons of confidentiality it will not be possible to track individual couples through the article. Where quotations are taken from interviews, this will be indicated in parenthesis along with the respondent's gender (men [M], women [W]).

Procedure

The Regional Committee for Medical Research Ethics approved the study. The questionnaire along with an information letter from the Center for Crisis Psychology was sent from the parent support organizations to their members in September 2005. The letter was discretely worded, demonstrating respect for the parent's situation, and presented the aim of the study: to increase the knowledge about sexuality and intimacy, knowledge that hopefully could lead to better advice, counseling, and support for parents.

The information letter asked that parents who were willing to be interviewed return a written consent form. A neutral, stamped envelope for returning the questionnaire and the consent form were included. As no name or information that could otherwise indentify the respondent was put on the questionnaire, there was no possibility for sending reminders to non-respondents.

By the interviewees' choice all interviews took place in the couples' homes. The interviews lasted from between 1 hr 45 min to 2 hr 45 min. Four interviews were planned with parents who had experienced SIDS, four following stillbirth, and two following

accidents. In actuality the distribution became 5–3–2, as one couple who had indicated SIDS as the cause of death on their questionnaire had suffered a stillbirth. As the cause of death did not seem to be an important variable regarding the theme of sexuality, no additional couple was included.

Measures

Questionnaire

A questionnaire was constructed for this study based on the few previous studies that have been done in the area (see the introduction). Two couples filled in the questionnaire prior to the study and provided feedback. As they found it easy to understand and fill in, no changes were made.

Questions about the deceased child and their relationship history were included, while the majority of the questions related to intimacy and sexuality and problems in this area, advice they had received, and so on. The questionnaire alternated between questions with fixed categories and open questions that asked for the participants' evaluations and written responses on the subject. They were asked to evaluate sexual activity and pleasure according to the following categories: "increased," "same as before," and "decreased."

Relationship quality was measured on the basis of the following items: "I have been able to communicate with my partner about my feelings," "I am satisfied with the support from my partner," and "I feel understood." These three items showed a Cronbach's alpha at .83 and intercorrelations at the interval .54–.73. In addition, the Dyadic Adjustment Scale was used (Spanier, 1976). Results on the quality of the relationship will be reported separately.

Interview

Qualitative interviews were used to gain a more detailed and in-depth description of the informant's experience of the relationship, as well as an understanding of processes over time. The interview followed a semistructured theme guide. This was built around the same themes as in the questionnaire but allowed the informants to expand, go into more depth, and determine the sequence of

themes. It was deemed important to let the participants experience the interview as a two-way process in which they could actively relate what was important for them, at the same time as the interviewer could reflect together with them about the themes discussed. This creates a collaborative climate that reduces the distance between interviewee and interviewer (Riches & Dawson, 1996).

All interviews were taped and transcribed, and the responses were analyzed to allow both breadth and variation in different experiences and viewpoints. The qualitative material was analyzed using Kvale's (1996) phenomenological mode of analysis, condensing the expressed meanings of the open-ended questions. The condensed material was categorized on dimensions in such a way that repeated evidence of similar descriptions in written statements resulted in the identification of major themes and categories. The same method was used for analyzing the parent's written responses to open questions in the questionnaire, but in addition a quantification of the themes was undertaken.

The 10 couples were interviewed together followed by a short conversation with each of the two partners individually. After three couple interviews the individual conversations were dropped, as they did not provide additional information beyond that of the joint interview.

Statistics

Descriptive statistics (frequency, mean, standard deviation, cross-tabulation with chi-square), reliability analysis (Cronbach's alpha), correlations, and analysis of variance (ANOVA) were computed by SPSS 16. Analyses of couple data may imply dependent observations, and linear-mixed analyses were used for linear-mixed models (two level models) with both fixed and random factors and with possible interactions tested. Restricted maximum likelihood was used for parameter estimation of both fixed effects (*b*-weights), and within- and between-couple random effects, with random effects also transformed to percents of total variation.

Results

Stillbirth was the most common cause of the child's death (39.1%) followed by SIDS (25.5%), other illnesses (24.5%), accidents

(7.3%), and unreported or other causes (3.6%). The mean distance in time since the death was 73.1 months ($SD = 66.1$ months) but varied from 2 months to 28 years. The amount of time since the death was greatest following SIDS (116.4 months), followed by accidents (94.9 months), illness (69.4 months), and stillbirth (47.2 months). The child's mean age at death was 14.4 months ($SD = 34.4$) but varied from 0 months (stillbirth and deaths on the day of birth) to 17 years. Only 8.2% had no children besides the one they had lost, 20.4% had one child, and the majority had two or more children (72.8%). As many as 71.4% reported having had another child following the loss of their child.

What Impact Did the Death Have on Their Sexual Life?

The answers to this open question were categorized in condensed theme groups as shown in Table 1. Each parent could describe several themes. The results showed that the loss had an impact on three fourths of the women and more than 50% of the men. Around a fourth of both genders reported normalization following an initial decline subsequent to the loss. Women more frequently reported disturbing images, thoughts, and feelings that interfered with sex than did men. Almost a fifth of both genders wrote about

TABLE 1 Could You Describe the Impact of the Loss on Your Sex Life? ($n = 220$)

	Women		Men	
Impact	$n = 146$	%	$n = 87$	%
No impact	37	25.3	39	44.8
First a decline, then a normalization	35	23.9	22	25.3
Disturbing images, thoughts, and feelings interfered with sex	32	21.9	6	6.9
Increased activity—important to have another child	31	21.2	11	12.6
Seldom sex, decline in activity	26	17.8	15	17.2
Sex as closeness, comfort, and tension reducer	17	11.6	2	2.3
Exhausted, no energy for sex	16	11.0	2	2.3
Sex out of duty, pressure for sex	4	2.7	7	8.0
First increase in sex, then a decline	4	2.7	3	3.4
Other things more important	3	2.1	2	2.3
Life confirmation, more important	2	1.4	2	2.3

a decline in activity or having sex less frequently than before the loss. Women also wrote somewhat more often than men about increased activity in order to have another child, as well as sex being used for comfort, closeness, and tension reduction. As this is a major focus of the study, qualitative comments will describe how the loss impacted sexuality, giving the numbers greater nuance.[1]

Many men, and a quarter of the women, reported no effect from the loss on sex. In addition, several parents of both genders mentioned a period of little or no sex following the loss and then a gradual normalization: "No effect. Same as before. Had something of a guilty conscience the first few times we had sex, that we could do this instead of thinking of her. Not any longer" (W). The frequency of this category may reflect that for many the death had happened many years back. Parents may have emphasized the normalization more than the problems they experienced initially.

Different aspects of the grief and loss impacted many women. They wrote about not feeling that they deserved anything good, that they were tired and exhausted, and they had difficulties finding any pleasure in life. Their grief took its toll psychologically, and they had no desire for sex. Right after the loss most of them felt they had enough to deal with in just surviving and getting through their daily tasks. Many reported no energy and that grief took their strength away.

> To be grieving takes so much energy that most of the time there is no room for a sex life, not even in my thoughts. It has become better, but still there can be everyday experiences, words or other things related to the grief that disturb my sex life. The need for closeness, however, has increased. (W)

> It was very difficult in the beginning. Life was just about surviving and getting through the day like getting up, eating, showering etc. There was no room for sex in my thoughts. (W)

In one of the interviews a mother said that grief overruled pleasure:

> I think it took so much energy even without my being aware of it, there was no room for anything pleasant, and grief was stronger than pleasure. In a period he [the partner] got his primary needs satisfied, but it was not more than this.

[1]All excerpts have been translated into English from Norwegian by A. Dyregrov.

Several described complicated and mixed feelings, often feelings of guilt and a guilty conscience that emerged in relation to sex. They could not allow themselves to feel pleasure when their child was dead.

> In the first period following the loss, sex was both hurtful and nice, hurtful because of guilt, I was not supposed to feel pleasure when she was dead, and still it was good because of the physical closeness. (W)

In the interviews the guilty conscience, and shame and guilt received further elaboration. In one interview a mother described how information could have alleviated these feelings:

> Actually it would have been ok if somebody had told you early on that the guilt feelings you get, that at least I struggled with initially—my child is dead and that is just awful and I can't enjoy this—are normal, because I felt miserable in the beginning.

Several mothers linked their guilty conscience about having sex to feeling any pleasure at all. They felt that they had no "right" to enjoy anything when their child was dead: "No, I could not feel pleasure with sex when my child was dead. In fact, I felt I should not feel pleasure over anything, as I was a horrible human being." Others described emptiness and a sense of meaninglessness associated with less desire and pleasure. Several, some fathers, associated sex with the place where the child had been born and the sexual act became difficult: "Difficult, especially the first period following the loss. My dead son had come out where I was going in" (M).

The human power of association can lead to difficulties unimaginable for those who have not experienced a dramatic death:

> My sex life has in periods been destroyed because I have images of a dead child in my head and of a partner who is doing mouth-to-mouth resuscitation. It feels unpleasant to be close to a mouth that has been in contact with my dead child. (M)

Increased sexual activity as a consequence of the wish for another child was described by many women and some men: "The aim was to be a mummy and daddy again soon, and then one needed to have sex" (W); "We wanted a pregnancy as soon as possible and that led to a higher activity at certain times before being reduced or normalised again" (M).

But mixed and complex feelings also arose in relation to the wish for another child. Especially women wrote that they had a strong wish for another child, which made them want sex. Sex, however, could be frightening at the same time, because feelings of sadness and a guilty conscience intruded in an act usually associated with pleasure and happiness. Some were also painfully aware of, and feared, that they could create a new child whom they also risked losing. Many, again mostly women, emphasized how physical closeness had become more important, just lying beside each other without necessarily having sex.

Some women pointed out that men's coupling of sex and closeness became problematic. They struggled with the fact that their partner's wish or demand for sex was greater than their own, and sometimes gave in to "console" him: "We had sex some days following the death. Our child was only a few days old when it died so this was also the first sex following the birth. I participated mostly to 'console' my husband" (W).

In the interviews men acknowledged that sex for them could be disconnected from the loss, and function to reduce tension. Some even described its therapeutic function:

> Sex between two people in love is positive and I know that in itself it can be part of the working through of grief. Having sex is one of several factors than can make life easier, to make it possible to look ahead. For our part we became pregnant again, and I stress "we", and that made it possible to think ahead, to think about a future and dare to work through even more. (M)

A decline in or infrequent sex was emphasized by some parents of both genders. It was usually associated with a lack of desire.

> Our sex life has been much worse after the loss. My wife has lost almost all desire for sex. I feel that she only has sex because of a guilty conscience towards me. It has gone from regularly to 1 to 4 times a month. (M)

Some women and men described what could be called having sex out of duty. It became forced, driven by the need to have another child. With this as an overall goal, spontaneity and pleasure disappeared. Instead of satisfaction and coziness, sex became a task: "Tried quickly to get a new child. This led to 'duty' and not pleasure" (M).

In the interviews, some men said that the pressure to perform could interfere with sexual performance. When the sex involved in

creating another child did not succeed in achieving its goal, this period was characterized as an emotional roller coaster where hope and disappointment followed one another.

Resuming of Sexual Activity

The time it took to resume usual sexual activity after the loss can be seen in Table 2. Close to four fifths had resumed sexual contact within the first 3 months. A multilevel model showed no gender difference. The between-couple variation revealed couple clustering (dependency), indicated by a significant amount of between-couple variation $(0.78 = 62.3\%)$ in contrast to the within-couple variation $(0.48 = 37.7\%)$ of the total variation. Thus, men and women within couples are more similar in their responses than individuals from different couples.

Around one fifths of parents after SIDS and accidents resumed their sexual activity at once, while this naturally took more time following stillbirth, and also following illness. In the interviews more than half of the couples reported having sex within the first week after the death, several even before the burial took place. Some commented that they could not get close enough to each other, that they could have crept into each other. The merging with one another in this way was a confirmation of their

TABLE 2 How Long After the Loss Did You Resume Usual Sexual Activity? ($n = 261$)

Resumption of sexual activity	*n*	%
At once	31	11.9
During the first month afterwards	100	35.1
Around 2 to 3 months afterwards	92	32.3
Around 4 to 6 months afterwards	17	6.0
Around 7 to 12 months afterwards	15	5.3
Between 13 and 24 months afterwards	5	1.8
Later than 24 months	1	0.4
Not resumed contact yet	0	0.0
Cannot remember*	24	8.4

*The category "Cannot remember" provided no information regarding the question and was recoded to missing data to ensure a continuous scale.

relationship and that they would continue together. For some this early normalization was followed by guilt.

Change in Sexual Activity

To a question about any change in the frequency of sex after the loss, most parents stated that there had been little change (Table 3). A little less than one third experienced a reduction, and few experienced any increase. Mothers and fathers differed minimally and without statistical significance (analyzed with linear-mixed model). The between-couples variation (47%) demonstrated dependency in data. Just over half of the total variation (53%) was residual (within-couple), showing many differences within couples regarding reported changes in sexual activity.

As could be expected, a statistical relation with the amount of time since the loss was found, with more time being associated with a higher activity level in this three-level scale; activity $= 2.34(b_0) - 0.001(b_1)$; $b_0 =$ intercept, $t = 44.96$, $p < .05$; $b_1 =$ months, $t = -2.02$, $p < .05$.

Through the interviews it became clear that parents first increased their activity because they wanted a new child, and since many succeeded in this, their everyday life with small children became so busy that they had less surplus energy for sex. As many years had elapsed since the loss for many of the respondents, this in itself may have reduced their sexual activity.

Change in Sexual Pleasure

Most parents experienced sexual pleasure at a pre-loss level (Table 4), but significantly more mothers experienced reduced pleasure since the death ($\chi^2 = 9.21$, $p < .01$). More than a quarter

TABLE 3 Assessment of Sexual Activity Following the Loss (%) ($n = 284$)

	Females		Males	
Assessment of sexual activity	*n*	%	*n*	%
Increased since the death	6	3.6	3	2.6
Same level as before	111	65.7	79	68.7
Reduced since the death	52	30.8	33	28.7

TABLE 4 Assessment of Sexual Pleasure After the Death (%) ($n = 282$)

	Mothers		Fathers	
Assessment of sexual pleasure	*n*	%	*n*	%
Increased since the death	10	6.0	8	7.0
Same level as before	114	67.9	93	81.6
Reduced since the loss	44	26.2	13	11.4

of the women experienced reduced pleasure. That is a high number considering that the mean time since the loss was 6.5 years. To a question about whether sexual pleasure at any period had been reduced because of the loss, 73.3% of the mothers and 49.1% of the fathers confirmed this, a statistically significant difference ($\chi^2 = 16.74$, $p < .001$).

Correcting for dependent observations in couples, a two-level analysis showed a significant between-couple variation ($0.11 = 46\%$) and within-couple variation ($0.14 = 54\%$). Men experienced more satisfaction than women ($b_1 = -0.16$, $t = -3.45$, $p < .05$; intercept $= 2.27$, $t = 42.38$, $p < .05$). The amount of time since the loss did not contribute any statistically significant effect ($b_2 = -.001$, $t = 1.82$, $p > .05$).

Causes for Changes in Activity and Pleasure

Table 5 shows the indicated causes for the changes in sexual activity and pleasure. It is evident that mothers and fathers ranked the different causes relatively similarly, even though gender differences in frequency also were evident. It was sadness/depression that was seen as the main cause of the change in sexual pleasure and activity, followed by physical exhaustion (often associated with depression) and being preoccupied with grief. Mothers reported more of these causes than the fathers did.

The between-couple variations in the two-level analyses indicate that for some variables men and women were more similar in their responses within couples than between couples. This was found for physical exhaustion, sadness/depression, feeling of numbing, aversion to physical closeness, guilt when having sex, and the "no change" category. For some variables, more within-couple variations were found (like being preoccupied with

TABLE 5 Causes of Changes in Sexual Activity and Pleasure ($n = 285$)

Causes of change	Mothers		Fathers		Gender diff[a]	$\sigma 2$ in within	% of total between
	n	%	*n*	%			
Physical exhaustion	89	52.7	44	38.3	14.7*	91.3*	8.7
Sadness/Depression	117	69.2	54	46.6	22.2*	86.7*	13.3
Feeling of numbing	27	16.0	11	9.5	6.2	75.2*	24.8*
Preoccupied with grief	53	32.1	23	20.2	10.0*	54.3*	45.7*
Aversion to physical closeness	16	9.5	4	3.4	6.0*	89.2*	10.8
Guilt while having sex	44	26.7	7	6.2	20.0*	83.3*	16.8
Reminder of how the child was made	16	9.5	5	4.3	5.4	81.8*	18.2*
Images of the child entered mind while having sex	27	16.0	3	2.6	13.3*	91.7*	8.3
No change	19	11.2	35	30.2	17.7*	72.7*	27.4*

[a]The gender difference is computed based on fixed effects in mixed two-level models.
*$p < .05$.

grief). When between variance was not statistically significant, the couple status did not contribute to the individual responses.

On open questions as well as in the interviews both mothers and fathers wrote about how the grief interfered with frequency and pleasure related to sex. They mentioned the variations in mood, the heavy emotional strain of the grief period, feeling very tired, and feeling no overall pleasure and initiative in life. More women than men wrote about ambivalent feelings, especially a guilty conscience.

Because of the relatively high prevalence of responses on the physical exhaustion, sadness/depression, and preoccupied with grief variables, these were analyzed with the subjective experience of (a) changes in sexual activity and (b) changes in sexual satisfaction as dependent variables. For the first variable, we found no effect of grief on the dependent variable. However, the dependent variable was predicted by physical exhaustion and sadness/depression. Physical exhaustion was associated with subjective reported reductions in sexual activity ($b = -0.14$, $t = -2.34$, $p < .05$), while sadness/depression was related to a lesser reduction ($b = 0.13$, $t = 2.04$, $p < .05$). The within-couple variance in this model was reduced from 52.8% in a nonconditional model to

48.7%, as more of the individual variation within couples was explained and no couple-level factors were analyzed. Further, a statistical interaction between gender and sadness/depression was found. In this analysis, no main effect of sadness/depression was found, while the gender effect was significant. This indicates that men reported less of a reduction than women, and men with sadness/depression evidenced less of a reduction than women with sadness/depression. A gender-specific cross tabulation confirmed this finding: no relation was found for men ($\chi^2 = 0.83$, $p > .05$), but a statistically significant relation was found for women ($\chi^2 = 4.69$, $p < .05$). A prevalence of sadness/depression is therefore associated with a subjective report of increase/decrease in sexual activity among women but not among men.

Change in sexual satisfaction was predicted by physical exhaustion ($b = -0.12$, $t = -2.12$, $p < .05$). Those who were physically exhausted showed a greater reduction in sexual satisfaction. Another model showed reduced pleasure to be more prevalent among females ($b = -0.29$, $t = -4.31$, $p < .05$) and more sadness experienced among women (main effect of sadness: $b = -0.18$, $t = -4.31$, $p < .05$; interaction effect: $b = 0.33$, $t = 3.06$, $p < .05$).

Some women also found that their own body reminded them of their loss, making pleasure in sex even harder to find. Their body was a bearer of both pain and memories. They could feel intense pain in their body, feel physically exhausted, and sense that their body was against them. These feelings about the body even influenced their self-image, making them feel less attractive:

> I had no child to lay on my breast and felt a strong need to have my husband there, but I also had great difficulties accepting my body because I weighed 10 kilos more than I should and felt very bulky and awful after the birth. In the beginning I could not look at myself, it was hard to accept my body. (W)

> You felt you were not clever and had not succeeded in your task, thinking there was surely something wrong with my body. I struggled with low self-esteem for a long time. I think I still cannot relate to my body. I could not stand my body—it had killed my child. (W)

Was Sexuality Discussed with Health Professionals?

Only about 11% had reported that health professionals raised the issue of intimacy and sexuality following the loss (no gender

difference). Around 69% of both men and women had taken part in a bereavement group, and here 16% stated that these issues had been discussed in the group. Among family and friends even fewer had discussed these themes (7.5%).

Men's and Women's Views of Issues Related to Sexuality

Parents were asked to indicate their agreement with statements about sexuality and intimacy. The agreement percentages are seen in Table 6. Table 6 shows pronounced gender differences. Men wanted sex more often than women. They experienced their partner as becoming more distant and uninterested in sex following the loss. On the other hand, women more often than men experienced frustration because the partner did not understand the need for closeness rather than sex, that it was difficult to achieve closeness because it so easily could be misunderstood as a wish for sex and that they had a greater need for physical closeness. Further, they experienced more often than men that it was not possible to feel anything good when everything was awful, that sex became wrong because it was related to desire, and that sex was physically more painful after death. Sex could also become almost compulsory because both partners wanted another child so much. This was reported by more women than men. Women confirmed the items "Men find sex more comforting than women" and "Different sexual desires can be a source of stress for both partners" more often than men.

Two-level analyses showed relatively high agreement among men and women within couples for the following statements: "For a time sex became almost compulsory because we both wanted another child so much," "Men's desire returns sooner than women's," "Men find sex more 'comforting' than women," "After a child's death both partners need to learn anew the signals of when one wanted to have sex," and "Different sexual desires can be a source of stress for both partners."

It is worth noting that around two thirds acknowledged that sex was a confirmation of life and of what is natural. More than 40% of both genders also confirmed that sex could alleviate tension after a child's death and that men could lose their desire because of women's strong wish for another child. There was no statistically significant between-couple variation in this context,

TABLE 6 Percentage of Mothers' and Fathers' Agreement Statements: Responses Computed with Linear-Mixed Model to Describe Gender Effects, Couple-Within, and -Between Variations (*n* Varies Between 267 and 282)

Statements	Female %	Male %	Gender effect 2-level analysis Δ%[a]	% Variance within couples of total	% Variance between couples of total
Men find sex more "comforting" than women.	54.5	45.0	8.0*	52.2*	47.8*
Sex can alleviate tension after a child's death.	43.8	47.7	3.7	89.9*	10.2
Women who strongly desire a new child can make men lose their desire by pressuring too hard.	46.5	40.0	5.7	64.6*	35.5*
Men's desire returns sooner than women's.	71.0	63.5	6.6	47.0*	53.0*
Women have a guilty conscience about sex more frequently than men.	55.2	46.4	9.0	68.1*	31.9*
Men do not understand that it is difficult to think about sex after the death of one's child.	35.8	25.7	10.0	85.9*	14.1
In a period sex became almost compulsory because we both so much wanted another child.	42.7	29.8	12.1*	42.5*	57.5*
After a child's death both partners need to learn anew the signals of when one wants to have sex.	35.4	34.5	0.2	57.5*	42.5*
The sexual pleasure can never be the same following a child's death.	6.0	7.6	1.7	100.0*	[b]
My partner became distanced and uninterested in sex following the death.	6.1	26.1	20.0*	97.2*	2.8
It is not possible to feel anything good when everything is awful.	49.4	25.5	23.7*	85.6*	14.4

(*Continued*)

TABLE 6 Continued

Statements	Female %	Male %	Gender effect 2-level analysis Δ%[a]	% Variance within couples of total	% Variance between couples of total
Sex becomes wrong because it is related to desire.	29.2	7.9	20.8*	74.0*	26.0*
Sex becomes difficult because of the fear of having another child and losing it.	15.3	18.1	3.0	84.9*	15.1
Differences in sexual desire can be a source of stress for both partners.	86.1	78.1	7.6*	61.8*	38.2*
I think that partners more easily can be unfaithful following a child's death.	16.6	11.4	5.3	76.8*	23.2*
Sex becomes a confirmation of life and what's natural.	66.0	65.8	0.3	86.2*	13.8
Sex was physically more painful after the death.	19.3	6.1	13.3*	87.0*	13.0
I have been frustrated because my partner doesn't understand that I have a need for closeness, not sex.	52.4	16.7	35.5*	96.7*	3.3
It is difficult to achieve closeness because it so easily can be misunderstood as a wish for sex.	54.5	25.9	27.9*	80.7*	19.3
I have a need for much more physical closeness than my partner.	48.2	24.8	23.4*	100.0*	[b]
I want sex much more often than my partner.	11.4	63.8	52.3*	100.0*	[b]

[a]The gender difference in percent is computed based on fixed effects in mixed two-level models when controlling for couple membership.

[b]Not estimated due to there not being a positive definite result in linear-mixed analysis. Analysis was reestimated; all variance was residual and not attributable to couple membership.

*$p < .05$.

indicating no similarity within the couples. For other gender differences and between-couple variation, see Table 6. Given the documented gender differences, parents may find themselves in a terrain that is difficult to navigate.

Discussion

Many parents have only a few sexuality-related problems following a child's death, but a fairly large minority, especially women, experience major problems. There are clear gender differences in reactions and perceptions, often agreed upon by the two genders. Men are ready to resume usual activity in the sexual area much earlier than women. Women suffer much more from grief that in different ways intrudes on the sexual act and they more often perceive sex as somehow being wrong. Their need for closeness is also easily misunderstood by men as a wish for sex. The fact that this still may be a taboo area may influence the parental responses and lead to an underestimation of the problems.

Changes in Sexual Activity and Pleasure

Around four fifths of the parents had resumed sexual contact within the first 3 months after their child's death (84% if one does not count those who do not remember), and about one tenth at once. Although most parents reported sexual activity at the same level as before their loss, around a third reduced their activity. Significantly fewer mothers than fathers experienced sexual pleasure and around 30% of the mothers experienced that pleasure had been reduced since the death. As the mean amount of time that had elapsed since the death was 6.5 years, this is a cause for concern and should be the focus of intervention efforts to help parents, especially mothers.

As in Hagemeister and Rosenblatt's (1997) study, a majority had experienced a break or decrease in their sexual relationship following their loss, and they ascribed their problems to the same factors: physical and emotional exhaustion, sadness and depression, being preoccupied with their loss, and psychological distress at sexual intimacy. Grief was stronger than pleasure. When it came to feelings of guilt about having sex when one's child was dead, images that popped up while having sex, sadness and depression,

being preoccupied with sex, and physical exhaustion, women reported statistically more of such reactions than men. However, with time sexuality was normalized for many. In the written comments on the questionnaires, women reported a stronger influence on their sexual life from the loss than men. When men wrote, they most often wrote that it had had no influence. Grief has many components, whether it be mood swings, feelings of sadness, a lack of energy and tiredness, but also anxiety; anxiety about a new pregnancy and another child who also might not live. The mixed feelings, of a guilty conscience associated with feelings of desire or pleasure, and the difficult images that interfered with sex, explain why many, especially women, had not been able to resume previous levels of pleasure or activity.

It is easy to ascribe the difficulties in sexuality to the loss of the child, but it should be remembered that there is a drop in marital quality within 1 year after the birth of the first child and a decline in sexual activity due to sexual problems experienced postpartum (Pacey, 2004). Poor relationship quality was also associated with less sexual activity and pleasure following the death, but it is not possible to know the causal direction. A reported change in sexual activity was predicted by physical exhaustion for both genders, while sadness/depression was only associated with a change in activity in women. Reduction in sexual pleasure was more often experienced among those who experienced physical exhaustion, among females, and sadness/depression (mostly women). Without having a control group of parents with living children, it is difficult to know whether the problems experienced in the studied group exceed those of "normal" families. Our study also excluded those who had ended their relationship.

The results implied that there was considerable variation within couples when they viewed sexual activity. Most probably this reflects the subjective experience of whether the sexual activity had increased, remained at the same level or decreased. A subjective increase does not necessarily equal an actual increase, but activity can be viewed in relation to one's own standards or expectations from the partner. One partner could interpret the activity as increased, while actually it is at the previous level due to pressure from the other partner who wants to keep the activity at that level. The difference in how they perceive the sexual activity can in turn add to the level of discontent with the activity level.

Women May Struggle with Their Relationship to Their Body

Both in written comments and the interviews it was evident that some women linked the grief to their body, both through physical pain and by developing an image of their body as unattractive and ugly. The women's negative perception of their own body decreased sexual activity and pleasure. This issue has not received focus in previous reports; however, it is not uncommon that perceived and actual changes in the body can have an impact on sexuality in women who give birth (Pacey, 2004). Several women in this study stated that they did not feel "whole," that something had happened to their whole identity and capacity as a woman. They could feel bulky and awful and had problems accepting themselves. The identity changes may to some degree be associated with bodily changes, but also seem to be on a deeper level linked to their inability to produce a child who lived.

Other Issues That Impacted on Intimacy and Sex

When the relationship in itself was not good, it affected sex in a negative way. Many parents, however, very soon engaged in sex to create another child, and a majority had succeeded in this following their loss. In cases where the parents had other children, sexual pleasure and activity could also be negatively influenced by the energy involved in caring for small children. Some parents wrote how it was difficult to know if the decrease in activity and pleasure came as a consequence of a hectic life situation or was caused by the loss.

In written comments many women described how physical closeness more than sex had become central in their relationship, but that men easily misunderstood this as a desire for sex. Men, however, looked at sex as a tension reliever and attributed a therapeutic value to it. Both genders could also feel that sex was a sort of life confirmation. Their confirmation of different statements indicated that men and women differed greatly in their views of different aspects of sexuality, differences that may increase parental distress and miscommunication.

Resuming Sex Early Following a Child's Death

Several of the couples interviewed had sex during the first week after the loss, before the funeral. The questionnaire's categories

did not differentiate sufficiently to capture variations during the first month. These findings indicate that an immediate resumption of sex is not unusual. It can cause self-reproach in parents and a possible conflict between the mother's guilty conscience and the father's early wish for sex, with marital tension as a result. During the interviews couples stated that they thought that if others learned about this they would think there was something seriously wrong with them, in that they could do such a thing. It is therefore important to normalize this and communicate to couples that this is an expression of the need for comfort and closeness, and an escape from the brutal reality they are facing. Although this may not need to hold a central position in information for parents following a child's death, mentioning it can alleviate guilt and self-reproach among those who do have sex shortly after the death.

The Subject of Sex as Taboo

The subject of sex continues to be taboo. Only around 10% had experienced that the subject was raised by health personnel and even less so by friends and family. If a couple is struggling with their sexual relationship, they will receive little information that can benefit them and most likely the subject will not be broached by anyone with the kind of knowledge that might possibly help them. There is an obvious need for health personnel to receive more information about this subject in order for them to be relaxed about raising the issue and discussing any problems in this area with bereaved couples.

Limitations

The calculated response rate was 33%. Feedback from participants through e-mail and interviews indicated that a fairly large, unknown number of support members who had not lost a child also received a questionnaire, as the address lists used did not indicate loss status. The real response rate is therefore believed to be higher. However, the low response rate is equivalent to other studies conducted on bereaved families (Cerel, Fristad, Verducci, Weller, & Weller, 2006; Worden & Silverman, 1996). Although it is an expected and acceptable response rate from a group that has experienced great strain, where no reminders were sent, it is still difficult to know how representative it is.

From research on trauma and sudden death it is known that those who are the worst off usually are those who do not participate (Paykel, 1983; Stroebe & Stroebe, 1989; K. Dyregrov, 2003). The loss of a child is in itself such a tragic event that parents may recoil from the task of filling in questionnaires. When a questionnaire in addition focuses on a sensitive topic like sexuality and intimacy, it may be even more difficult to respond. When intimacy and sexuality is heavily affected, parents may not want further reminders through a questionnaire. It may thus be expected that those who answered the questionnaire may be better off than those who refrain from answering. In addition, as no reminders were sent to potential respondents, one would expect a low response rate.

It is a possibility that one partner can have filled in questionnaires for both partners. However, visual inspection indicated no similar handwriting on the two partner's written answers to open-ended questions.

The fact that no background information is available makes it impossible to compare respondents with nonrespondents. As the focus of the study was cohabitant/married biological parents, the results reflect those who have stayed together as a couple. Those who divorced or changed partners after the loss will probably have struggled more in the relationship area, including intimacy and sex. That so many with a high educational level answered the questionnaire is another indication that those who answered were those who fared best. K. Dyregrov (2003) has shown that bereaved individuals with high education levels evidence less psychological distress than those with low. Those with a high educational level possibly use both professional assistance and their social network better than those with low.

The low response rate makes it more difficult to generalize the results and the conclusions drawn must be viewed in light of this. The low response rate may also reflect that the theme is an intimate one that may be difficult to report on. This should also be kept in mind when examining the answers from those who responded. They may not be as sincere in this area as with less taboo issues. The retrospective nature of the reports, often with years having elapsed since the loss, may threaten the validity of the data. It is possible that they construct meaning post facto to fit with how they would like to view this in retrospect. A longitudinal study of parents would produce more reliable data.

Answering a questionnaire at one point in time several years following their loss (mean of 6.5 years) makes it difficult to capture a process that evolves over time. A longitudinal study that follows parents over time would better capture this process and variation.

Conclusion

Parents' experiences show us that sexuality following a child's death involves few problems for many parents, but may lead to large problems for a fairly large minority, especially women. There are clear gender differences in reactions and perceptions, often agreed upon by the two genders. Men are ready to resume usual activity in the sexual area much earlier than women. Women suffer much more from grief that in different ways intrudes on the sexual act and they more often perceive sex as somehow being wrong. Men also easily misunderstand their need for closeness as a wish for sex. For many, stress and pressure is experienced in relation to a strong wish for another child.

The challenges found in the sexual area demand good communication within a couple and respect for each other's differences, feelings, and needs. However, there is an evident lack of support, counseling, and information in this area in both individual and group follow-up of grieving parents. The provision of verbal and written information would help families through the post-loss period and may lower parental conflict and enable better relational coping. A more structured follow-up of parents who lose a child where the issue of sexuality is included can prevent problems in future bereaved couples.

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