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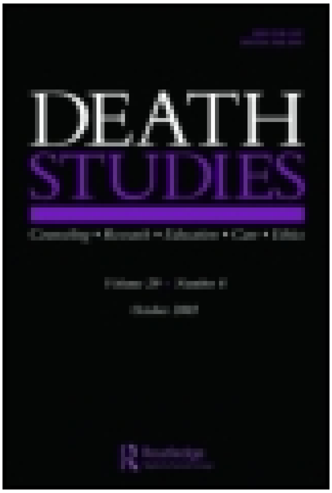

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FATHERS' GRIEF WHEN A DISABLED CHILD DIES

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This qualitative study examines the subjective experience of fathers' grief responses to the death of a child with a disability. Eight fathers were interviewed and completed the Grief Experience Inventory (GEI). GEI results indicated that fathers did not differ significantly from parents who lose a child in other ways. However, subjectively, fathers consistently reported that their bereavement was marked by a "double loss": disability and then death. Consistent with the literature on gender differences in bereavement, fathers reported greater emotional stoicism and used activity, rather than talk or social support, as a primary coping strategy. Clinical implications for professionals working with grieving men or with couples are discussed.

The death of a child is a devastating experience for any parent. The literature indicates that there are variables that affect how the loss of a child is experienced. These variables include the age of the child, circumstances around the death, anticipatory grief preceding the death, and gender of the parents. When a child with a developmental disability dies, this loss may follow months or years of difficult parenting, which may complicate the bereavement process. This study examines the unique experience of fathers who have lost a child with a severe developmental disability. The study uses a semi-structured interview, the Grief Experience Inventory, and the methodology of qualitative research.

There is abundant literature on parenting a child with developmental disabilities (Copley & Bodensteiner, 1987; Fortier & Wanless, 1984;

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Olshansky, 1962; Young, 1977). Similarly there are many studies of bereavement following the loss of a child, and gender differences in grief responses (Drenovsky, 1994; Huntfield, Mourik, Tibboel, & Passchier, 1996; Kavanaugh, 1997; Sanders, 1978). However, little is written about parents' reactions to the two-fold loss: first, learning that your child has a disability, and then losing that child to death.

Milo (1997, in press) examined mothers' responses to the life and death of a child with severe developmental disabilities using both qualitative and quantitative assessments. The mothers' study found that mothers used cognitive coping strategies to identify meaning and benefit in the life and death of their children. They coped with their loss with strategies that helped them re-establish their belief that the world is predictable, meaningful and benevolent. Their experience in parenting and then losing a special needs child was the catalyst for major shifts in their priorities, worldview, and sense of identity. Several mothers in the study reported that, while parenting and then losing a developmentally delayed child was the worst experience of their lives, it was also the most defining experience of their lives—one that they would never wish to give up.

Rooted in clinical experience and literature on men and grief, we assume that a father's response to losing a special needs child will be different than a mother's. Several studies confirm what we intuitively know: men and women in their roles as mothers and fathers have different grieving processes. These differences pertain to their internal timetables, the reported intensity of their grief, and the subsequent marital conflict that may occur at a time that calls for the support of each other.

A number of studies comparing the influence of gender upon grief following the death of a child (regardless of child's age or cause of death) report that mothers grieve more intensely and longer than fathers (Kavanaugh, 1997; Lang & Gottleib, 1993; Moriarity et al., 1996; Schwab, 1996; Thomas & Striegel, 1993, 1995; Zeanah et al., 1995). Vance et al. (1995) found that whereas fathers show briefer and less intense anxiety and depression reactions than mothers, they more often used alcohol to cope following the death of a child. Drenovsky (1994) found that fathers were more likely to feel that someone must be punished for their child's death. Mothers were more likely to feel anger toward their deceased child.

Huntfield et al. (1996) reported one exception to this general trend in gender differences. Using the Perinatal Grief Scale, they found that there were no gender differences in couples who had lost an infant with major congenital anomalies 6 months prior. However, subscales showed that parents do not grieve in the same way or over the same duration.

Schwab (1992) looked closely at the effects of child death and gender-specific patterns of bereavement on the parents' marital relationship. She found that fathers were concerned and frustrated about their wives' grief, whereas wives were angry over their husbands not sharing their grief. This led to a temporary halt in communication, a loss of sexual intimacy, and general irritability between the spouses. The couples withdrew from each other at various points in their bereavement, either because of their own intense bereavement or out of a desire to avoid increasing their spouse's pain. Kavanaugh (1997) supported these findings and found that the fathers who felt concern for their wives coped by keeping busy as opposed to their wives who coped by talking about their loss. Thomas and Striegel (1993) similarly found that fathers grieved for their wives by trying to "hold it together." Perhaps consistent with men's lesser desire to talk about their loss, Murphy et al. (1998) found that fathers who had lost children were less responsive to a 10-week broad-spectrum intervention and showed no immediate benefits of treatment. Kavanaugh (1997) specifically asked subjects why they felt there were gender differences in bereavement when an infant died. The most typical reason the subjects gave was that societal expectations for the typical male role interfered with the father's response to the loss.

Lang and Gottlieb (1993) looked at grief following the death of an infant as a function of marital intimacy. Within the group of fathers, more intense grief responses were associated with lower ratings of emotional, social, sexual, and recreational intimacy with their wives. Fear of separation or divorce was associated with more intense grief for fathers. Zeanah et al. (1995) used the Perinatal Grief Scale to examine the grief reaction 2 months after perinatal loss. For fathers, less ego strength, less social support, and more stressful life events were correlated with significantly higher self-reported grief.

This study was pursued to enhance the research on men's bereavement experience and to serve as a companion piece to the former study of maternal responses to the loss of a child with a developmental disability (Milo, 1997). Six questions guided the research:

1. What is the subjective emotional experience of fathers who have lost a child with developmental disabilities, and how is it unique?

2. How do fathers who have parented a child with a severe developmental disability and then lose that child manage to cope and make sense of their experience?
3. What strategies do they use to cope?
4. What variables may account for individual differences among the fathers?
5. How do fathers' responses differ from mothers' as reported by Milo (1997)?
6. When a child with a developmental disability dies, what can healthcare professionals and specialists in death and dying do to help fathers cope in an optimal way?

Method

Participants: The Fathers

Eight fathers were recruited to participate in the study. Three of the fathers had participated in programs of The National Fathers Network, a support organization for fathers with children with special needs. Three men were recruited by letter because their wives had participated in a similar research project. Two men were referred by those aware of this project. The men, willing to speak about their experience in the context of a study, may not truly represent those who are not yet ready to share their story. Five of the subjects lived within a large, metropolitan area with excellent social and educational services available. Two subjects lived in a small town in an agricultural area and one lived in a rural area. There was diversity in the fathers' ages, socioeconomic status, diagnosis and disabilities of the child, age of the child at death, and period of time since the child's death. Significant in this sample, all of the fathers had similar family structures—all were married with children.

A brief introduction to the fathers and children is below. All names and identifying information have been changed to preserve confidentiality.

Ron's son, Jacob, was born with microcephaly, a seizure disorder, agenesis of the corpus collosum, and lissencephaly, with attendant deafness and blindness. He lived for $7\frac{1}{2}$ months. He was repeatedly hospitalized and died in the hospital. Ron is married and has a 5-year-old daughter. Jacob was his second child. He and his wife have decided to have a third baby.

Peter's first-born daughter, Katie, was born with no noticeable developmental delays. She was diagnosed at about $1\frac{1}{2}$ years with epilepsy and hypomelanosis of Ito, the latter resulting in severe mental disabilities. Katie died on Christmas Eve, when she was $6\frac{1}{2}$ years. She fell off the bed while napping and landed in a position where she could not breathe. Peter is married and has two more daughters, ages 11 and 9.

Rob's first son and second child, Jonathan, was born with developmental delays, seizures, and vision problems. He was not clearly diagnosed, although cerebral palsy was suggested. He lived for 10 months. He was repeatedly hospitalized and died in the hospital. Rob is married and has a teenage daughter, a son, and twins, who were born after Jonathan.

Gary's daughter, Jessica, had multiple severe disabilities. She died at age 16 from complications from chicken pox. Gary is married and has a grown son.

Don's daughter, Diane, was 5 months old when she died. She had lissencephaly, a severe brain disorder. She died in the hospital after being on life support. Don has two other daughters and is married.

Scott's son, Chris, was born with cerebral palsy and severe cataracts. He died when he was $3\frac{1}{2}$. Scott is married and has a five-year-old daughter.

Carl's son, Max, was diagnosed with cerebral palsy, spastic quadriplegia, and seizures. Max was repeatedly hospitalized. He died during the night at age 12. Carl and his wife were on vacation and Max was with a respite provider when he died. Carl is married and has another son.

Brian's daughter, Ann, was severely disabled by anoxia at birth, due to her umbilical cord being around her neck. She died at age 7, while in the care of a respite worker. Brian is married and has two sons who were born after Ann.

Measures

This study integrates qualitative and quantitative measures, a semi-structured, open-ended interview and the Grief Experience Inventory (GEI) respectively. Much of the current research regarding parental loss of a child and adjustment to parenting a child with a disability uses interviews that are later analyzed to determine common themes (Affleck & Tennen, 1991; Helmruth & Steinitz, 1978; Jost & Haase, 1989). An in-depth interview that explores the personal, highly meaningful, and individual experience of fathers is a powerful way of developing an understanding of the phenomenon.

The GEI, while suffering from some psychometric limitations, is one of the few standardized, quantitative measures for bereavement. It was chosen to parallel the Milo (1997) study on mothers. It was used to compare the fathers within our sample, to compare the fathers with the mothers in the Milo study, and to other bereaved parents in the research literature. The GEI is a 135-item self-report inventory used to assess an individual's grief experience through a 12-scale profile. The validity scales include Denial, Atypical Responses, and Social Desirability. The bereavement scales include Despair, Anger, Guilt, Social Isolation, Loss of Control, Rumination, Depersonalization, Somatization, and Death Anxiety. Several populations (including a reference sample of parents whose children died from various causes) have been used to determine the GEI's reliability and validity. The GEI is used to compare the experience of bereavement among bereaved individuals as well as groups (Sanders, Mauger, & Strong, 1978). The GEI scales are expressed as standard T scores with a mean of 50 and a standard deviation of 10. The larger the T score, the greater the intensity of the behavior measured by that scale.

Procedures

Each father was interviewed one time in his home or in a professional office for $1\frac{1}{2}$ to 2 hours. The interviews were audiotaped and transcribed. Each interview began with an open-ended question, allowing the fathers to talk freely about the life and death of their children and ended with more specific questions. Generally, the interview followed the developmental line from the child's birth, the diagnostic process, parenting issues, and then the circumstances and responses to the child's death. An original set of questions was generated from the literature and from the parallel project with mothers who had lost children with disabilities (Milo, 1997, in press). In the qualitative research tradition, questions were added and refined as themes began to emerge from the interviews.

At the close of the initial interview each father was asked to complete and return the GEI. A mean composite score was computed for each of the 12 subscales of the Grief Experience Inventory for the seven fathers who returned the survey. These mean scores were compared with the mean scores of the reference group of bereaved parents. (See Figure 1.) A score was determined to be noticeably different if it was equal to or greater than one standard deviation from the mean for the fathers in the study or the parental reference group.

Similar to the mothers, the fathers reported that they enjoyed the interview. They welcomed the opportunity to talk about their children and their experience. They often asked about the progress of the study and what we were hearing from the other men. Differing from the mothers, they did not resist the use of an objective measurement tool. This was reflected in the return of all but one completed GEI. (When this one was not returned, we tried to contact the participant but were unable to locate him.)

When the themes were developed and consolidated, we invited the subjects to attend a focus group. Four of the eight fathers chose to attend: Ron, Peter, Rob, and Brian. The inability of other fathers to attend was due to geographical distance or a family commitment. We presented what we believed we had heard and asked for their feedback and elaboration. The fathers were intensely engaged with each other during

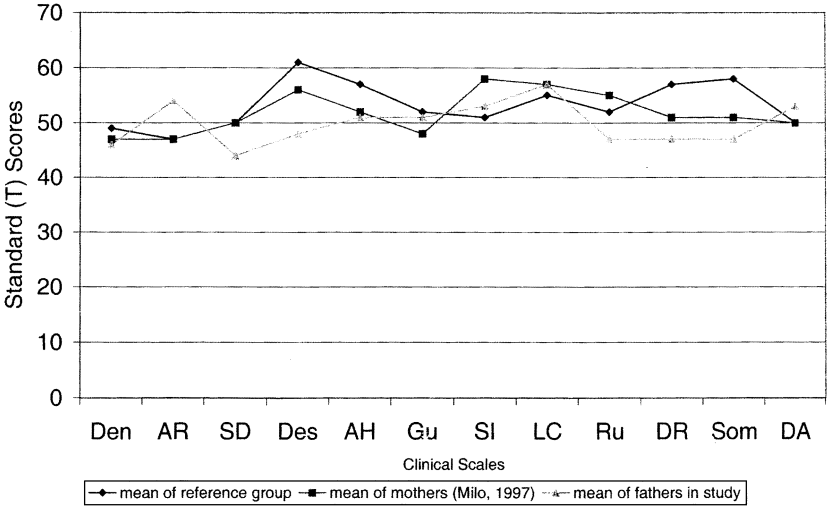

FIGURE 1 Grief Experience Inventory Profiles for Bereaved Fathers and Mothers of Children with Developmental Disabilities and a Reference Group of Bereaved Parents.

discussion. They questioned and challenged each other's perceptions. Each father explicitly stated that he found it was helpful to talk with the others. Each father was given a copy of the first draft of this article and was invited to review it privately and return to us with comments. The last draft was also mailed to participants seeking their review and feedback. The manuscript was refined in response to their suggestions.

Data Analysis

The interviews were audiotaped, transcribed, and analyzed using constant comparative analysis (Glaser & Strauss, 1967) and a synthesis of other procedures outlined by Miles and Hubermand (1984), Strauss and Corbin (1990), and Glesne and Peshkin (1992). The transcripts were divided into meaning units, approximately 4—6 lines each. Codes were derived inductively and then tested by applying them to uncoded protocols. Not all of the original codes survived: Some were collapsed and new ones emerged, overriding the original ones. The final codes emerged from developing and revised a coding system to categorize the themes based on the following: (a) grief responses, (b) recovery and healing processes, (c) changes to the self, world view, and priorities, and (d) perceived gender differences. We looked for relationships among the themes: for example, the connection between the mode of death and the recovery process, the grieving process and spirituality, and the connection between the severity of daily caregiving challenges and the sense of loss and relief.

The fathers' stories were viewed within the research literature's theoretical frameworks of bereavement, parenting a child with a disability, and the psychology of men. We wanted to reach the core issues and gender-based similarities and differences in fathers' grief when a disabled child died. Each author read and coded each transcript independently. Reliability in applying the coding system was assessed and interrater agreement was high. Substantial differences of opinion were resolved through discussion of the transcript data. Recursive text analysis integrated the raw data, ongoing generation of hypotheses and interpretations by discussion between the authors, combined with feedback from the participants. This resulted in further refined data analysis with the goal that, true to the tradition of qualitative research, the stories would speak for themselves and we would be accurate listeners and interpreters.

Results

In analyzing the GEI data, the fathers' mean results were compared with the mean of the reference group of bereaved parents (Sanders et al., 1978) and to the mean of the mothers who had lost children with developmental disabilities (Milo, 1997). (See Figure 1.) The fathers did not differ by more than one standard deviation from either of these two groups on any scale, although there were some slight differences. The fathers, as a whole, scored slightly higher than either of the two comparison groups on Atypical Responses and somewhat lower on Rumination, Depersonalization, and Somatization. Within the fathers' group, there were no clear patterns. This echoed the variability in their narrative responses. The fathers, as a group, gave the impression of less consistency in experience than the group of mothers, who showed high consistency of experience.

There was significant diversity among the fathers' stories and the subsequent reported changes. Despite the diversity, several key areas of focus did emerge even if their reported experience was dissimilar. The differences in experiences did not appear to be related to the severity of diagnosis or how the child died. The fathers more consistently considered their ways of grieving and coping to be reflections of who they already saw themselves to be, rather than attributing enormous personal change to the events surrounding their child's death. Personal change was more related to their child's being born and the subsequent losses related to disability rather than to death. The following themes emerged in the transcripts of the interviews and were revisited in the focus group. Some of the themes were simply validated by the focus group, while others were clarified and some new ones added.

Disability and Death: "A Double Loss"

Several fathers describe the sense of normalcy and anticipation of their child during pregnancy. The world seemed innocent and predictable. There was no reason to expect anything other than a healthy baby and the joys of fatherhood. They described their hopes and dreams. This was especially true for the men who were having their first son. These dreams and hopes for the future were shattered when the men learned of their child's problems. Many of the men described this as a "double loss."

First, the men suffered the "big blow psychologically" when they learned about their child's disability. The time of diagnosis symbolized the initial, metaphorical "death" of the expected healthy child. Second, these fathers then experienced the actual death of their child.

Ron described with melancholy the special things he anticipated and the experience of losing his son twice.

> Seeing fathers with their younger sons: just starting off on journeys into different things, learning experiences, learning to ride a bike, playing catch, baseball, playing golf, tennis, school, whatever, all those new things that are new and fresh and exciting to a kid, things they share with their fathers . . . that I will never share with my son. That was harder than burying him in some respects . . . But that loss occurred almost the first day after we got the finding. . . . I lost that particular future with my son at that point.
>
> At the time of birth, Don describes a foreboding sense of the future: Consciously or subconsciously, there was something wrong with the child . . . I have watched newborn animals and newborn people and this one was different.

The process of diagnosis was not always clear. Some fathers went through a more gradual unfolding over several months or even years to understand the extent of their child's disability or to find a diagnosis. Rob describes the gradual learning as something "that just sends waves of fear through you." While believing he had a healthy baby and enjoying the early period of raising a child, he was also identifying problems at a more gradual pace. "Finding out" was neither marked by a dramatic moment of diagnosis or obvious impairment. The men's response to the diagnosis ranged from, "I was very, very angry," "Why me? Why is this happening to me?," "I went to bed and just cried and cried" to a strong sense that things like this just don't happen to "families like us."

> Why me? Why not somebody else. I mean, there was some irony to it. . . . I was at a tournament and one of the guys I hadn't seen for quite some time had had a child who was just diagnosed, so I was talking and thinking, 'That poor bastard. Thank God my life is charmed and things like this never happen to us!' Two months later Jacob is born and we're going through the same thing he'd gone through.

For the fathers who identified the diagnosis as the moment of most intense grief, the death of their child was a second blow and, although expected, a double loss. Although this did not diminish the pain of their child's death, it allowed time for learning and growth during the period of caring for their child, as suggested by the comment, "We were convinced that it was God preparing us for what was going to happen." Just as one father reached some peace with the diagnosis, his grief was rekindled at the time of his daughter's sudden and unexpected death:

> It took me six years finally before I said, "Gee this is stupid, let Katie be Katie, let me just enjoy her as her dad rather than try to be her therapist, her teacher and stuff. She is going to be this way and accept her." I had just gotten there and she died.

This raises the question of whether knowing that a child's life expectancy is shorter eases a father's pain. Katie was expected to live a full life span, as was Jonathan. Their fathers dealt with an additional element of shock, whereas the other fathers had some ideas, based on diagnosis or illness, that they would have less time with their children alive. When the children were less aware of their environment because of the severity of disability or being a young infant, the men were very direct in stating that they felt their loss was less than the loss of an older or more aware child.

Some of the fathers articulated a sense of relief or freedom when their child died. Two fathers particularly highlighted that aspect of their grief. They would not have to experience their own further difficulty and suffering of raising a child with special needs. Others found relief in the fact that their child would not have to endure a poor quality of life that was a result of discrimination against or lack of services for people with disabilities.

One father described a wonderful sense of freedom:

> Even to this day I can't believe it. I don't have to change diapers any more. I don't have to worry about her any more. I don't have to plan things in advance. I am free now. That still makes me feel a little guilty.

Active Coping: "I Just Got Right In and Got To It"

The fathers' primary strategy for coping and recovery from their grieving was consistent across the circumstances of diagnosis, parenting, at the time of death and bereavement. They took an active approach to coping.

> We didn't know what to think about this problem and at that point I just had to drive around . . . I didn't want to notify the family by phone, I wanted to drive to each location to stay busy and have something to do. And it was hard, I mean, stopping in the course of driving to locations, having to stop beside the road you know, rather than drive through tears.

In response to the disability and the death of their children, fathers wanted to find something to do. They wanted to take action and keep busy with tasks. All of the fathers found something active as a means for coping as the time of diagnosis. These activities included researching medical literature, "becoming the scientist," focusing on work, engaging in sports, as a means of coping with their grief at the time of diagnosis. This also occurred later, at the time of death. This is in contrast to the mothers who had coped primarily by seeking social support and talking about their losses (Kavanaugh, 1997).

At the time of diagnosis, men felt profoundly overwhelmed by their feelings. Fathers coped by staying actively engaged in work and moving into more intense involvement with parenting. Brian reflected on his response to learning about his daughter's problems,

> I guess I just didn't think about it, I just got right in and got to it. My wife did the same thing . . . the issue immediately became to both of us to get in and work as a team and do the best that you can and you make it happen.

When there was no clear activity to pursue, then they experienced a flood of emotion. Rob illustrates the immensity of his feelings when he could not rely on activity,

> I remembered being pretty much overwhelmed by the whole thing . . . my mom and dad came over to help me feed him. I just couldn't do it, I remember I was in tears, and I don't know why, maybe from the standpoint of overwhelmedness.

The future that they had anticipated was now gone. In its place loomed an unpredictable life span with their child that was marked by uncertainty and fear:

> Fear that I think was a kind of lack of control and lack of ability to think . . . Maybe there is something wrong; but what and how can it be fixed . . . just be fixed and done away with because you want your child to be perfect.

Similar active coping strategies were used at the time of death. Each father described with vivid detail the logistics of "making arrangements." This appeared to be an activity that the fathers could engage in to ease emotional pain. Again, the theme emerged of needing and wanting to stay busy. Ron described the irony in needing to saw down a fallen tree in the yard on the morning of his son's funeral. Scott recalled meticulously choosing funeral readings, music, and creating funeral programs and poetry.

It was important to Ron and Don to donate their child's retinas and corneas. This required additional activity that the fathers managed. Although it was not directly stated, indirectly they spoke of this giving their child's life meaning. Each of their children died from profound disability prior to a year old.

Don reported his sense of relief that when given facts, he could move toward a decision and action, as difficult as that decision was:

> I am extremely bitter and always will be. I allowed my innocence and naivete to override my better judgment . . . I said, "You folks (students observing) can leave." They did. He told us what the diagnosis was, what the prognosis was. We cried . . . we supported each other. Then we dried our tears and said, all right, when can we disconnect the child from life support . . . We'll be there. It is ours to do.

Jonathan, Chris, Jacob, and Jessica had numerous hospitalizations. There was enormous anxiety not knowing how a hospital visit would end. While a hospitalization had begun like all the others, there was always the possibility that it could end by "walking out of the hospital with an empty car seat."

When fathers were not present at the time of their child's death, they questioned whether their actions would have saved the child. Although Ann's father was not present at the time of her death, he so deeply trusted the respite worker that he was certain he could have done no better and was not left with lingering anger or guilt ("it was her time"). In contrast, Max's father was left with bitterness that the respite worker may have acted irresponsibly. He reports still feeling bitterness and a lack of resolution about the issue of blame.

Even when a father took appropriate action to prevent his child's death he was left with a feeling that his actions had, in the end, been ineffectual, "Did I do everything I could?" Katie's death was sudden, unexpected, and accompanied by much chaos. Her father administered CPR and medics making resuscitation attempts did not revive her. Peter reported enormous guilt until the medical examiner said, "It just happened, it was completely out of your control." The simple comment "helped lift the burden off my shoulders."

Although fathers were unable to control the occurrence of death, holding, carrying, and attending to their child was an active way for the fathers to continue fathering and claim their child as their own. Several stated how critical it was to them that they, rather than a coroner or medical professional, physically moved their child's body after death. The intimacy of the moment with their dead child was shared in a "kiss on her forehead" or in "holding her for hours just sobbing."

> The coroner was going to go up there and put her in a little bag and I said, "No, no, I am not going to do that. I will go and pick her up and I will carry her out to your vehicle. I am not going to have you put her in a bag and carry her out." We

> did everything together with Ann, we brought her into this world together . . . and we wanted to do it ourselves . . . we washed and dressed her and we cried and laughed . . . Between me carrying Ann down the stairs to the time in the funeral home was the most healing time because again it told me how much you don't know in life and how short life is and how at the blink of an eye it's gone and it's yesterday's news.

Fathers' Isolation: "Select Fraternity"

> When you are burying a child, not many people have gone through that . . . Putting your kid in the ground, I mean, that's a pretty isolated or cocooned experience.

All the men experienced isolation. "People just didn't know how to deal with it." The disability created a sense of a "special club" initially. Now their children's deaths just set them further apart in a "select fraternity." The hurt for many fathers came from the disappointment that they experienced when the friends and family closest to them did not understand. Some men also told stories of extraordinary support from unexpected sources. Four reported that their wives sought counseling, whereas only two fathers reported that they found it helpful. Two fathers told how they could manage their strong emotions in their work and home lives, but while they were alone in their cars "on the bridge the feelings would break through." Rob describes the profound sense of aloneness:

> After they leave you, there you are in your own home and you are the man, you are it, you're in charge, nobody else is going to do it, everything that has to be taken care of for a child like this. I wasn't wishing for help, but you just feel, it's this aloneness.

Relationships with Professionals: "Just Give It To Me Straight"

How the fathers learned about their child's problems was a dominant theme in the stories. Professionals who were straightforward and honest were valued over professionals who tried to protect the parents or protect themselves from the implications of the child's disability. In the focus group, one father stated, "I just wanted to deck him" in response to a doctor's delivery of a prognosis about his child. This response met with enthusiastic agreement and similar emotional experiences from the other fathers.

> I pushed and pushed. The geneticist didn't want to say it . . . I said, "What is the diagnosis going to be here?" She said "Your daughter probably won't ever walk or talk or feed herself, be potty trained or dress herself" . . . I don't remember too much after that except I felt real fuzzy in my head.

All of the fathers described an intense need for the facts of the situation. They wanted doctors to present the facts and medical opinions or belief, even if it was premature or uncertain. They did not seek comfort or want "sugar coating." This makes sense in light of wanting to find something to do or some action to take. The fathers held in high regard the doctors that went the extra mile in telling the details and in listening to the parent's concerns. Ron described his gratitude to a pediatrician who knew how to "ask coded questions" of the specialists in order to reach a sense of the reality of the situation. Don and Peter illustrate the bitterness felt when they could not get clear information or when information was blatantly withheld from the family.

> He knew. They knew. And I was not given the opportunity, nor was my wife given the opportunity to know at a critical point and we were not able to make decisions. You get little bits and pieces over time from the doctors of what the condition really is of the child . . . everybody only knows their little piece and they're not willing to cross the line and say . . . finally, he was good about telling us she is severely damaged, these are the issues at hand, and we don't know.

At least two fathers would have made decisions to not prolong life if they had understood the extent of their children's disabilities. They shared this value with their wives but were met either with a lack of information or direct opposition from medical personnel when confronted with life-prolonging decisions. Ron says, "We decided to allow him to live the course of his life as his body was built to live."

In comparison to the mothers' stories, relationships with professionals were much more central to the fathers' stories. All of the fathers said that they felt very angry and helpless. Anger with the professionals may have served to externalize their sense of frustration and helplessness. The disability and death did not offer easy answers for what to do or what actions to take. Anger at professionals provided some focus to the anger and helplessness of grief. This is consistent with other findings that fathers often report feeling that someone must be "punished" or to blame when their child dies (Drenovsky, 1994).

Role of Father: "Papa Bear," "Ally on the Frontier," Seeking Distance

We asked the fathers to help us understand their daily lives with their children. We wanted to know what it was like from waking in the morning through the middle of the night, caregiving responsibilities. This was partially directed by our curiosity about the emptiness left in their family's life by the child's death when the child required an intense daily caregiving routine. We noticed three themes or models for the father role: protector, ally, or seeking distance from the family and the pain of loss.

We were also curious about the fathers' self-perceptions of their role. All of the men we interviewed were involved in parenting responsibilities. During the focus group, several commented with near reverence about their wives. They described great respect and appreciation for the daily hard work of caring for a disabled child and their wives' abilities to manage that part of family life. Simultaneously, several expressed comfort and satisfaction in the traditional role of provider and protector: "I was her protector and her guardian," "I think it was really enough for me to think that I was trying to take care of my family." Brian described his role as "Papa Bear" for his disabled daughter. Peter saw his daughter as "our whole life . . . everything was Katie."

Gary had a different experience. Rather than protector or provider, he saw himself as "partner." His professional goals changed dramatically as a result of parenting a disabled child. He moved from the academic realm into the activism and advocacy of disability law. He and his daughter were a team:

> She was my ally. I thought about the issue and am I just exploiting her for my own purposes and decided that was not true. It's ok to have a child be your ally on the frontier.

Brian spoke to a different sense of the emotional connection between a seriously disabled child and the parent:

> I believe that parents and children have an interconnection that is God-given and that connection allows the parent to be able to see the needs of the child. If you truly get beyond all the other stuff you can really start looking at the child's eyes and figure out what they are needing.

There was another side to the father–child relationship. Some men describe the distances that they put between themselves and their baby, in order to alleviate the pain of the diagnosis. All of the children in this group had profound disabilities, some with very short life expectancies. Distancing from the babies may have served as a kind of anticipatory grieving. If the father didn't get too attached, the impending early death may hurt less. Some of the children who were older were very difficult, either in the intensity of their need or in their behavior. Carl, whose son would scream inconsolably, illustrates this.

> I always had the feeling that Max didn't like me, that there wasn't a real connection between me and him . . . I always thought at the time that we didn't have a bond, more or less between father and son. What was nice about the father's group is that it forced me to bring Max and spend more time with him and we started to bond a little more. It wasn't just mom that could make him stop crying, could love him and hold him and make him stop crying. I could do that too.

Celebrating and Normalizing the Child: "Let's Have a Walking Party"

Throughout the stories of daily life, a recurrent theme emerged about appreciating the selfhood of the child. No matter how small the gesture, each father identified the features or memories that made his child unique. We were especially interested in this part of their story as it counters parents' perception of public sentiment that the death of a disabled child is somehow less than the death of a healthy child. Regardless of severity of the impairment, every father described the special memories and joys inherent to his child's spirit or personality. For children with severe disabilities and limited ability to respond, the men found the sensitivity of communicating "through her eyes" or viewing his child as the "poet" and "partner" in a spiritual sense of a life together.

> She had a real infectious smile and she would giggle and people would just laugh their head off . . . She liked pretty basic things really: food, music and water . . . She would crawl in and crawl out of a small, inflatable swimming pool we had in our backyard, crawl in and crawl out, lie down for a while and rest and crawl in and out some more. She would just go and sit on the sprinkler in the backyard and play in water for hours.

Katie's family held a "walking party" for her when she took her first steps. Scott appreciated Chris's spirit in how Chris responded to music and to his sister. Carl recalled how he felt that an "intelligent kid" was locked inside his son despite a severe regression following a seizure episode:

> I shaved my beard off and I went in to say "Hi" to Max and he just looked at me and started smiling and almost laughing. It had been almost a year since he had smiled at all. You'd get a little chuckle when his eyes would light up and he would smile. I mean, it was incredible. He had such a nice face.

All of the men reported a desire to normalize their family lives during their child's life and after death, by maintaining their work lives and the siblings' lives. Several fathers described how repeated hospitalizations significantly disrupted their work lives. Many found that work was a welcome relief from the stress of their child's needs. Gary sometimes included his child in his work life by having her present when he spoke on behalf of rights for people with disabilities.

> With Jessica we always pushed the limits of normalization because that was the ideology that was associated with the civil rights movement for people with disabilities and so we always focused on making sure we kept her at home.

Including the disabled child with the rest of the family was a dominant theme, as opposed to protecting the siblings and keeping their activities separate. "We wanted her to experience everything, skibob, sledding, a full life." Sibling relationships were critical avenues for maintaining family stability. All of the fathers saw themselves as protectors of a "normal life" for the siblings. Peter expressed concern in telling how his typical child would pretend that she had "special needs." He expressed appreciation for her special bond with her disabled sister and how "they would sneak out of their bedroom at night to play together in the family room." But he also worried that perhaps special needs had become too much of a focus in his family. The men who had older children perceived their older, typical children's lives as important motivators to continue recovering from grief. Life with their other children was an indicator that "life moves forward" even when "you feel everything should just stop."

Stability of Identity and Worldview: Hunters and Ministers

The fathers' stories were told with two distinct styles. These two distinct styles correlated with the language and metaphors the fathers used and the activities they used to cope. One group spoke more of the solitude and stoicism with which they experienced their grief. The other group spoke more of the community that supported them and helped to create a more public meaning of their child's life and death. The first group used the metaphor of a "hunter" and the second group used the word, "ministry."

Fathers who used the metaphor of "hunting" told their stories with a directness that was almost scientific or clinical in its coolness. Don held his handcarved bow and described his orientation to life:

> Life may be a precious thing, but life is renewable resource. There is a point where one can fully or substantially enjoy life and there is a point at which one can not. For an animal that is the point at which it needs to be terminated . . . She was born with a degenerative disease, she died.

Ron summed it up as, "Life is a crapshoot." While it is possible to misread such directness as cold or unfeeling, the hunter's style coupled directness with a reverence for and hidden intimacy with the spirit of the animal. When their children died, this group of men went about making arrangements to the tone of "it's all logistics," just doing what needed to be done. But their own deep pain was private and reserved for solitude:

> We went to a remote cliff, a craggy little point . . . took the bag out, ran my hands in it (the ashes) and looked at it . . . it was snowing and wind blowing and we just threw it. We made sure there was nothing left in the bag because I have a thing about that, letting everything escape from the soul.

These fathers who grieved as "hunters" did not articulate significant personal or spiritual changes but said that their experiences had reinforced their more fatalistic views of life. Ron says

> You are born and you spend however long you are in the world like a pinball, bouncing off different things, different decisions, and somewhere along the line, or call it a spaceship traveling through space, sooner or later you are going to hit a meteorite and you are going to blow up. Life is a series of meteorites going by.

These fathers identified themselves as "cynical." However, in the interactions between the men and the interviewer (and wife or child present during the interview), it was clear that a deep tenderness and sensitivity lurked beneath the surface of cynicism. These fathers, in particular, identified realism, a gritty honesty, and adventure as strong values in raising their living children. When asked, "How has this impacted your spirituality?" these fathers said they did not believe in that. They perceived personal changes as related more to life phases than any particular event.

The fathers who used the metaphor of "ministry" described their grieving as more emotionally expressive with a community. This public aspect of grieving brought comfort, whereas hunters found public expressions and community more irritating than helpful. Comfort in community was experienced by a strong investment in the funeral details. For example, Scott and his family designed a musical tape recording of their son's favorite music. The funeral rituals gave expression to their religious faith and meaning to their child's life. This group of men included those who also went on to become advocates or spoke of wanting to be in "ministry" to others who had gone through what they had. This group was active in the Fathers' Network, law, or their church.

These fathers, whose grief evolved toward a sense of "ministry," commented more frequently about their personal changes. Brian stated, "She made me who I am as a father." Peter reflected on significant personal changes:

> I am more compassionate . . . more reflective. She has made me understand the simple things in life: water, food, and music. That's it . . . She has made me think with my heart, not with my head. So what if it doesn't make sense. It makes sense in your heart . . . Life is what you make it.

The fathers whose grief evolved toward "ministry" expressed more similar changes to the mothers in worldview and priorities: "life is short," "others' expectations and opinions are unimportant," and "be kind." Brian says that his daughter "made us grow tenfold." He learned "that people are a strange breed" when he heard rude comments regarding his daughter's disability and death that implied that her death was somehow less than another child's. Peter described a "richness" to his personality and inner emotional life that he now attributes to the experience of his daughter's disability and death.

The men's spirituality was, in general, more reinforced rather than radically altered. The fathers who reported no shift in spirituality also reported that they had no sense of spirituality or faith prior to theirchild's birth and death. When spirituality was an important aspect prior to the child's death, it remained important. Two men felt that the birth and death of their disabled child was a part of "God's plan" for their family, "I had faith that God has a plan for us, and that's just fine." They reported finding enormous relief and comfort in their faith. Rob said, "I have a strong faith, I believe in God, I believe in Christ, and I believe He is taking good care of us and Jonathan." Their views on spirituality were strong prior to their child and were reinforced by the comfort that they found. One father who had been involved in civil rights prior to the birth of his child continued to focus his life work toward disability rights, specifically.

He cited his religious beliefs as the foundation for his work prior to his child, and following the birth and death of his child.

Only one father reported experiencing a significant shift in his spirituality. Peter experienced a shift from believing that "what happens is God's will" to:

> Your life happens, God is there, you have many choices in life and he is there to help you. But when bad things happen it is not because God wanted it that way. It's because sometimes bad things just happen.

Gender Impact on Marriage: "I Didn't Grieve Less, Just Differently"

Research literature of the death of a child has recently shifted away from concluding that the death of a child increases a couple's chances of divorcing (Lang & Gottlieb, 1993; Rando, 1983). This study supports the more current findings (Schwab, 1996) that many marriages remain strong. These fathers reported that their marriages were strong prior to their children's deaths and that the death contributed to making them more deeply committed to each other. It is important to note that this group is self-selected and does not include some of the father's responses noted in Milo (1997). Initially, two fathers stated it had significantly strained their marriages, but they came through the difficult period by acknowledging that they and their wives were grieving in different ways. It seems most likely that this group result was due to the self-selection process of participating in the study. Fathers who had divorced were difficult to recruit to be participants.

One of the themes that emerged in the focus group that was not evident in the interviews was the extent to which the men grieved for their wives. Five fathers stated that they felt the loss of their child was much harder on their wives than on themselves. They attributed this partially to the closeness that exists when the mother does the primary daily tasks and to a belief that there was an inherently closer relationship between mother and child. The men's focus on grieving "for" their wives is an angle that warrants further examination and holds significant clinical implications, particularly for marital therapists.

During the focus group there was a vigorous discussion about the roles and responsibilities of husband and wife. When the majority of the group reported idealizing their wives, Ron articulated his feeling of isolation when being the "at-home" parent for his child. He reported that he struggled with expected gender stereotypes and that he would escape into work and his wife would carry the emotional response to the death. He stated that he felt he had shouldered the emotional process of the family, resulting in a severe depression and lengthy recovery process. He encountered a lack of acknowledgment by helping professionals that, because he was a man, he would experience the grief so profoundly.

The other at-home father specifically stated in written commentary that he also did not share idealized feelings toward his wife. He described being deeply affected by his daughter's death and feeling a sense of responsibility. He had, unknowingly, exposed her to a virus that ultimately caused her death. He acknowledged feeling responsible, as opposed to feeling excessively guilty. Overall, guilt was a less prevalent experience among fathers than among mothers.

During the focus group, we also discussed research findings that men grieve "less." These fathers adamantly rejected this notion. They felt they had grieved significantly differently than their wives. It is significant that the fathers, with the exception of Ron, rarely expressed feeling discounted or ignored in their grief. Given the paucity of literature on men's bereavement, we expected that a culturally based disregard for men's grief would be a stronger factor in their experience. One father wished that his child had had a stronger impact on him, that he "envied my wife's sense of ministry" following the death. However, he also noted that one of the lasting impacts of his son's life was in "protecting me from a worldlier lifestyle." Three fathers expressed difficulty with the idea of having more children because "maybe there's feelings so buried that I would be afraid to rekindle the pain of that much love." Three fathers had children following the death of their child.

Healing: "I'll Never Forget"

Regardless of coping style, the fathers did not want their children to be forgotten. Several fathers said that their feelings of grief don't change over time, but that the emotional intensity decreases over time.

> Our big fear was we don't want to ever forget him, we don't want his immediacy to fade, we don't want to forget the details about him. Maybe it's callous, not callous, but an inevitable consequence of life that as you go on, old feelings are replaced by new feelings. Then you might encounter something that brings everything to the surface.

Some of the things that "bring it to the surface" are seeing fathers with sons, seeing a girl in a wheelchair, music or movies, and recalling special moments. All of the fathers reported enjoying being able to talk over memories for the purposes of this research. It is one of the ways in which their children are remembered.

All of the fathers had special memorials to their children. Several expressed a fear that the memory of their child would be lost, and "that dead is not forgotten." This seemed to be related to disability, as if the public would remember a disabled child less. Some fathers described rituals such as birthday cards, hanging Christmas stockings, and visits to the cemetery as ways of keeping their child's spirit alive. Gary described how very much alive Jessica remains as a "silent partner" in his work. Peter stated that he really wanted us to know that, "I really miss my daughter a whole lot." Katie has a star named after her.

During the focus group, Ron spontaneously raised this question with the other men: How do you remember now? The men moved from the stories of disability and death toward how they view emotional health and peace in the present. There was a wide range of experiences: Mother's and Father's Day cards, taking balloons to the grave on birthdays, and continuing to bake birthday cakes. Some families maintained these rituals just following the death and some continue them into the present. Each family had settled into rituals of remembrance that felt comfortable to them.

All of the fathers reported having reached a place of peace, despite struggles with bitterness, anger, and depression. Simultaneously, all expressed moving back into those intense feelings of grief at times. Healing had many faces. Some found healing by maintaining connections with the community of fathers of children with special needs or by social activism and advocacy in the disability community. Simply talking about their children was reported as healing by several fathers. For others, healing was found in the solitude of hunting or playing golf. One father said his sense of healing in the present is illustrated by a quotation posted on his family refrigerator: "I'll never forget but that doesn't mean that I always have to remember."

Discussion

> Give sorrow words. The grief that does not speak; knits up the o'erwrought heart and bids it break. (Shakespeare, *MacBeth*)

All of the fathers who participated in this study felt that their loss was different than other fathers who survive the death of a child. The roots of these differences lay in the initial losses related to disability preceding the loss of death. We concluded that there were four common themes about fathers who lose a child with special needs: (a) fathers use an action orientation for coping with painful feelings and to prevent feelings from overwhelming them; (b) fathers experience deep feelings of isolation, based first on the child's disability, then on losing the child through death; (c) fathers reported that the object of their grief was often seeing their wives in pain and acknowledged significant differences in grieving that they perceived to be based in gender differences; and (d) fathers reported consistency in self-identity and world view that influenced their ways of grieving and healing, unlike the mothers who reported significant changes in identity and world view.

Research on families with children with special needs indicates that the more a father is involved in the healthcare of his child, the higher the level of family functioning, resilience, and marital satisfaction (Frey, Fewell, & Vadasy, 1989). Professionals need to help dispel the myth that men grieve less for their children by inviting men into conversations regarding their children's disability, death, and their own subsequent bereavement periods. Acknowledging the differences in the ways that mothers and fathers grieve the loss of a child with special needs at diagnosis and at the time of death has significant implications for clinical practice, social policy, and future research.

Clinical implications for professionals charged with the care for children with special needs include facilitating and maintaining a connection to the father by providing straightforward information, inviting questions and discussion, and acknowledging the difficulty of the situation. Fathers did feel that their grief and isolation were different from other fathers who had lost a child. Discussion groups targeted specifically at this population may be very helpful. The fathers reported that they enjoyed the opportunity to meet each other in this study, even if they had never participated in a support group during their bereavement. Several fathers indicated a desire to stay connected to each other and often inquired about the experiences of other fathers during the interviews.

For therapists and counselors, eliciting the stories of grief from men must include an open invitation to all ways of coping that are not self-destructive. The fathers had many stories to tell, but there was an undercurrent of concern that they would be judged by professionals that they were not really grieving if they chose not to talk about it. The popular idea of a step-by-step grieving process caused concern for some men who felt that were weren't grieving "properly." Maintaining respect for an action orientation toward healing challenges the bias of the counseling disciplines toward "talking it out." Many of the men did not feel the need to talk about their experience, simultaneously they all reported enjoying talking in the study. Perhaps this was because it was not framed as "therapeutic" but as an active research project that was of use to other families and professionals. The project itself was an action to take toward continued healing, helping others, and honoring their child's life.

Because their children's disabilities demanded overwhelming daily tasks, the fathers felt an increased need for time as a couple. Public funding and trained providers for respite care was (and continues to be) a critical support for optimal family adjustment. Fathers used their workplace as a means of respite both pre- and post-death. Granting equitable opportunities for mothers and fathers to make use of family medical leave and bereavement leave is an important part of allowing time for healing. It also protects marriages from the strain of individuals distancing from each other when they are in such need of each other. Social policy relevant to family leave, respite funding, and clinical training of medical professionals would benefit by considering the emotional needs of fathers.

Research questions that have been raised by this study include taking a closer look at gender differences, particularly as men are increasingly primary caregivers or equal partners in parenting. Could it be that previously reported gender differences are more socially constructed than based in the reality of the men's emotional experience? As the research on men and grief expands, it would be interesting to conduct a cross-generation inquiry of men's experience of grief: How is it different or similar to their fathers' experiences? This would illuminate men's emotional experience in light of the social changes toward increased tolerance of disability and differences and movement toward a greater permission for men to articulate their stories of pain as an aspect of their lives. The psychologically minded solution of "talking it out" may be grounded in differences across generations. Did the men who had a model of open emotional expression with words have higher levels of optimal adjustment following bereavement?

Research with couples should continue with regard to the real and perceived impact of gender differences of grief. The concept of "grieving for my wife" warrants further illumination. Is this a displacement of the husband's feelings or a distinct, additional loss that he experiences? Discerning the elements of a marriage that help it withstand enormous grief and stress may clarify the path for marriage therapists working with bereaved couples. Research on couples that identifies specific strategies to enhance individual coping, maintain optimal levels of connection and distance, and allow for communication that contains intense feelings associated with grief, will inform effective clinical practice. Mental health professionals and healthcare providers can help families identify these issues proactively and anticipate difficulties that may lie ahead. Anticipation, preparation, and active engagement decreased feelings of helplessness and empowered men in their role of father.

In general, there was a lack of social support for the fathers. This can be addressed by continued efforts by professionals to include fathers in the care of their children, including at the time of death. The fathers' stories tell us that the deepest moments of pain, intimacy, and healing were found when fathers were full participants during the life and death of their children. As professionals, we must honor those moments and continue to be receptive and empathic to the broad range of men's grief experiences.

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