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A Qualitative Study of Advice from Bereaved Parents and Siblings

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Abstract

Despite a growing bereavement literature, relatively little is known about what families find helpful after a child's death and how best to assist them during the grieving process. This qualitative study explored advice from 40 families (65 parents, 39 siblings) of children died who cancer 6–19 months earlier. Content analysis emphasized the individual nature of grief and revealed advice that fit into three temporal categories: before the death, soon after, and long-term. Findings are discussed in the context of contemporary theory and provide insight into the development and timing of grief interventions.

Keywords

family bereavement; grief; parental grief; qualitative; pediatric cancer deaths

In the United States and Canada, nearly 60,000 children under the age of 20 die each year (Heron, 2007; Statistics Canada, 2007). The death of a child is one of the most painful and profound losses a family may experience, yet the impact of this trauma on siblings and parents has received limited attention relative to research on other types of loss (e.g., death of spouse or parent). Previous studies have largely focused on psychosocial adjustment, suggesting that bereaved parents are at higher risk for disruptions in family relationships, such as marital and parent-child (Lehman, Lang, Wortman, & Sorenson, 1989; Oliver, 1999; Rogers, Floyd, Seltzer, Greenberg, & Hong, 2008); internalizing difficulties including depression, anxiety, guilt, and post-traumatic stress symptoms (Hazzard, Weston, & Gutterres, 1992; Kricbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Miles & Demi, 1992; Murphy et al., 1999; Rogers et al., 2008); and health problems or mortality (Li, Precht, Mortensen, & Olsen, 2003; Rogers et al., 2008). Bereaved siblings appear to be at risk for a wide range of both internalizing and externalizing problems. They have reported

feelings of sadness, anxiety, guilt, and isolation from peers (Davies, 1991; Fanos & G, 1991; Hogan & Greenfield, 1991; Martinson & Campos, 1991) and have been rated by both parents and teachers as significantly lower in social competence, higher in social withdrawal, and higher in aggression than standardized norms or control groups (Birenbaum, Robinson, Phillips, Stewart, & McCown, 1989; Hutton & Bradley, 1994; McCown & Davies, 1995; Silverman, Baker, Cait, & Boerner, 2003).

Although parents and siblings may experience significant grief and adjustment difficulties that can endure for years after the child's death, much of our knowledge about what may be helpful for bereaved families comes from research involving the death of an adult. A few qualitative studies have been conducted on perceptions of helpful resources and advice from parents or siblings after a child has died. For example, in a study of early parental adjustment after the death of a child from cancer, parents noted the importance of: maintaining a relationship with the deceased child (i.e., continuing bonds); relying on significant others, family, and friends for stability and support; and keeping busy by focusing on both old and new routines (Barrera et al., 2007; Barrera et al., 2009). Adolescents whose siblings died up to five years earlier reported that: stress-reducing activities, personal belief systems/religion, support from parents, extended family, and friends, organized peer support groups and professional support (e.g., psychologists and ministers), and time were most helpful in coping with the death of their brother or sister (Hogan & DeSantis, 1994). Another study indicated that adolescents who lost a sibling to cancer seven to nine years earlier spoke positively of: spending time with their sibling prior to his or her death; sharing the death experience with others; recalling memories of their sibling; and relying on family for emotional support (Martinson & Campos, 1991). These siblings advised other siblings to: obtain information about the sibling's illness, make the most of time together, balance personal and family needs, stay optimistic, and recognize and enjoy the good times.

Many bereavement interventions have been based on such qualitative findings and contemporary theories, focused on coping, sense or meaning making, and continuing bonds with the deceased. Considering that many individuals do not utilize formal grief interventions, these theories may also provide guidance on informal strategies that may be helpful during the grief process. For example, stress and coping theories emphasize the importance of cognitive appraisals of threat and controllability in relation to available coping resources (Lazarus & Folkman, 1984). Coping, which has been defined as conscious, volitional efforts to regulate responses to stress (Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001), involves either engagement or disengagement with the stressor or resulting emotions (Compas, Champion, & Reeslund, 2005). Within the domain of engagement coping, "primary control coping" aims to change the stressor or one's emotional response, while "secondary control coping" involves efforts to adapt to the stressor or one's emotional response. Secondary control strategies, such as positive reframing and cognitive restructuring, have been found particularly effective in response to uncontrollable events, such as the death of a family member (Benson, Compas, Layne, Saltzman, Steinberg, & Pynoos, 2009; Compas et al., 2001; Folkman, 2001).

Folkman (2001) suggested that positive reappraisal processes may redirect individuals to focus on positive meaning (i.e., meaning-based coping) when initial coping strategies fail and to re-engage in efforts to cope with persistent stress, such as grief. Secondary control and/or meaning-based strategies may be helpful in mastering the adaptive tasks of bereavement, such as coping with existential issues, role and identity crises, and making sense of the death. For example, recent studies have found that parents who were unable to make sense of their child's illness or death had more severe grief symptoms and adjustment

difficulties relative to parents who were able to find some meaning (Keesee, Currier, & Neimeyer, 2008; Murphy, Johnson, & Lohan, 2003; Wu et al., 2008).

Continuing bonds may also be important. This theory suggests that bereaved individuals develop and maintain a spiritual connection or ongoing attachment with the deceased through activities such as keeping belongings, creating legacies, or viewing their loved one as a guardian angel (Klass, Silverman, & Nickman, 1996). These strategies allow the bereaved to maintain a “sense of presence” with the deceased in the absence of physical contact and are consistent with the common belief that loved ones will be reunited in the afterlife (Hogan & DeSantis, 1996). According to Klass and colleagues (1996), these connections can provide comfort, ease the transition from the past to the future, and facilitate coping strategies for both adults and children. However, continuing bonds have also been associated with more grief symptoms and adjustment difficulties (Boelen, Stroebe, Schut, & Zijerveld, 2006; Hogan & DeSantis, 1994; Neimeyer, Baldwin, & Gillies, 2006; Normand, Silverman, & Nickman, 1996), which suggests that the role and impact of maintaining connections with the deceased is complex for some individuals.

Despite increased attention to these contemporary theories, empirical approaches to intervention have been limited. Bereaved children and parents have been offered a host of interventions ranging from peer counseling, support groups, weekend retreats, and group, individual, and family therapy (Webb, 1993) conducted by a wide range of providers (e.g., public health and social service organizations, hospice programs, psychologists; (Rolls & Payne, 2003). Despite attempts to develop, deliver, and evaluate effective interventions for bereaved parents and children, interventions may be underutilized, and their efficacy has been debated (Larson & Hoyt, 2007; Neimeyer, 2000). One meta-analysis (Neimeyer, 2000) concluded that such interventions are typically ineffective, and perhaps even harmful, to bereaved individuals, while another reported that grief interventions are as likely to be as effective, or even more effective than, psychotherapy in general (Allumbaugh & Hoyt, 1999). Two meta-analytic reviews of bereavement interventions with children suggested that interventions provided in a time-sensitive manner to “high risk” children (i.e., those already showing signs of difficulty) may be beneficial (Currier, Holland, & Neimeyer, 2007; Rosner, Kruse, & Hagl, 2010). However, it has been argued that drawing conclusions from these meta-analyses is premature considering the poor quality of intervention research (e.g., lack of controls or long-term evaluation) and methodological differences across studies that make direct comparisons difficult (Schut, Stroebe, van den Bout, & Terheggen, 2001).

Thus, despite growth in the bereavement literature, relatively little is known about what bereaved siblings and parents perceive as helpful to them and how to effectively assist families following the death of a child (Kazak & Noll, 2004). While qualitative studies have contributed to our knowledge of bereaved families, they have been limited by convenience samples, single site designs, retrospective reports up to nine years after the death, and the absence of data from both parents and siblings. In addition, the bulk of the literature focuses on bereaved spouses and parentally-bereaved children, while the death of a child has received much less attention. The early state of research in this area, then, supports the continued use of qualitative methods to inform future quantitative work, as well as more prospective strategies to obtain information from multiple informants, including fathers and children.

The aim of the current study was to develop a better understanding of what bereaved families would advise others to do in the same situation. Qualitative interviews were conducted with bereaved siblings, mothers, and fathers on average within the first year of a child’s death from cancer. This study is unique in its inclusion of multiple sites and family members, as well as improved recruitment rates relative to previous studies. Through

systematic analysis of subjective and experiential data, family members' advice to others was categorized based on thematic content. These data may inform future intervention research and enhance the ability of healthcare providers to effectively and appropriately support bereaved families.

Method

This research was part of an ongoing longitudinal study of families following the death of a child from cancer. Data collection in the larger study involved visits to bereaved siblings' schools and homes, on average, within one year after the death, followed by another home visit in the second year post-death. This paper includes cross-sectional, qualitative data collected from an initial subset of families at the first home visit.

Participants

At recruitment, eligible families: (a) had a bereaved sibling 8–17 years old, (b) were fluent in English, and (c) lived within 100 miles of the hospital. Adopted, half-siblings, and step-siblings were eligible if the parent reported that regular ongoing contact had occurred between the sibling and the child who had died. One eligible sibling was randomly selected to participate from each family. Of 60 eligible bereaved families who were located, 41 (68%) participated in the home visit. Qualitative data were missing from one family due to tape recording malfunction, and one sibling was too upset to participate in the interview portion of the study. Thus, participants ($N = 99$) included 36 mothers, 24 fathers, and 39 siblings. Mothers averaged 40.5 years of age ($SD = 7.4$), and 78% ($n = 28$) were White. Fathers were about 43.9 years of age ($SD = 7.8$), and 83% ($n = 20$) were White. Parent educational level averaged 14.5 years ($SD = 2.2$). Average family socioeconomic status ($M = 44.2$, $SD = 25.1$) reflected clerical, sales, and service occupations on the Revised Duncan Total Socioeconomic Index (TSEI), a contemporary indicator of SES that is sensitive to changes in occupational prestige (Nakao & Treas, 1992). Siblings were primarily female (64%, $n = 25$), White (72%, $n = 28$), and an average of 12.3 years of age ($SD = 2.6$). Deceased children also averaged 12 years of age ($SD = 5.3$) at the time of death, with approximately 2.7 years ($SD = 2.3$) from time of cancer diagnosis until death. Data collection occurred at about 10.4 months ($SD = 3.5$) post-loss, ranging from 6–19 months after the child's death.

Procedures and Measures

Institutional Review Board approval was obtained at each of the three participating children's hospitals in the United States and Canada. Families were sent a letter of introduction from the child's attending physician and recruited by phone 3–12 months after their child died. Informed consent was obtained from each participating parent at the beginning of the visit, and assent was obtained from participating children. As part of the larger study's home assessment, research assistants administered a series of questionnaires and conducted semi-structured interviews. Individual interviews with open-ended questions were conducted one-on-one with each participating family member. Participant responses were audio-taped for later transcription and coding. Data reported in this paper were derived from answers to one of the interview questions:

“If you could offer one bit of advice to other families/kids who have lost a child/brother/sister, what would you say?”

Analysis

Three researchers independently analyzed the data through content analysis, a qualitative approach for analyzing data from open-ended questions (Hickey & Kipping, 1996;

LoBiondo-Wood & Haber, 2006). For complete coding procedural details, please refer to Foster et al. (2009). In short, researchers repeatedly read the transcripts to gain a holistic sense of the data. Similar ideas were clustered from 15 transcripts, and preliminary categories emerged. The researchers reviewed the initial coding scheme, extracted quotes, and regularly discussed the rationale for emerging categories. Data were re-examined by recoding original transcripts and making mutually agreed upon changes (e.g., editing category names, exploring new categories, combining and dividing categories). Fifteen new transcripts were added to the coding scheme, and new codes were adopted when data did not fit into an existing category. Responses that did not fit into an existing category were identified as “other” and reconsidered each time transcripts were recoded. Memos containing questions, possible comparisons, and leads for follow-up (Strauss & Corbin, 1990) were kept throughout the coding process. Researchers repeated this analysis process until they reached consensus, and no new categories emerged (i.e., saturation). Parent transcripts were coded in their entirety first, followed by the transcripts of siblings.

Findings

After content analysis, nine major themes emerged from the data that represented a range of advice provided by family members who have lost a child to cancer. One theme (i.e., the individual nature of grief) was conceptually unique from all others and therefore merited discussion as a separate entity. The eight remaining themes fit into three overarching temporal categories: (a) advice focused on the time *before* a child has died, (b) advice focused on the time soon *after* a child has died, and (c) advice focused on the extended future as more time passes from the child’s death. Similarities and differences across informants (i.e., mothers, fathers, siblings) are indicated below. Of note, several parents could not provide an answer, as they simply did not know what would be helpful. With prompting, some parents ultimately were able to provide some advice, while others were still unable to do so. One mother, for example, simply stated, “There are no words.”

The Individual Nature of Grief

One of the most frequent themes that emerged from the data was the idea that the experience of grief and the bereavement process are highly individual and likely to vary from person to person. A majority of parents recognized that having expectations about how one should grieve may be misguided, as each situation—and each person— is unique. One mother explained, “Everyone is so different, and it’s just so personal...what works for me may not work for the next mom. And it’s okay to feel this way or that way or to not feel a certain way.” Another mother echoed a similar sentiment, “Losing a child, the way you handle it is personal. Even if I could advise you, to feel the way I feel, if it’s not for you, it’s not for you.” A father qualified his response with a similar precaution, stating, “Well, I can say what’s worked for me. I wouldn’t presume to offer advice though because I know how personal it is.” Only a few siblings expressed similar notions, with one adolescent explaining, “This question always gets me ‘cause people always ask me this. I don’t know what advice I’d give to anybody because it really depends on what happens.”

Parents also advised that because grief is individual, there should be no expectations about how one should or should not feel, and acceptance of personal experiences was encouraged. One mother stated, “There is no right way. There is no book that tells you how to do this, and so go with your instincts.” A father explained, “I don’t have expectations of feelings. How I feel is how I feel and that’s okay. I don’t think I need to be somewhere else in this process. Where I’m at is fine; this is just fine.” Another father advised, “Just give yourself all the breaks you can. No expectations. Don’t do anything you don’t want to do. Don’t talk to anybody you don’t want to. Indulge yourself. Indulge it.”

Advice for Before the Child's Death

Many parents, but no siblings, offered advice to other families for the time leading up to and directly prior to the child's death.

No regrets—Bereaved parents spoke of doing what they felt needed to be done, or not done, for their child so that they were not left with regrets. One mother stated simply “If I didn't feel comfortable doing something, I didn't do it...this is my child”. Another said, “I guess I truly felt I had exhausted all of our earthly, worldly, doctorly, medically options and so I could feel confident.” A father shared, “Try not to have any regrets in your efforts to save your child. Get a second opinion if you want. Don't hold back.”

A key part of not having regrets appeared to be spending time with their child and cherishing the time their child had left. One mother stated, “You just spend as much time as you can with them. Love ‘em and hug ‘em.” One father put it simply, “Live everyday like it's going to be the last with your kid.” Another father shared:

You know, so many people put things off. They say I'm going to do that some other time. We just tried to do all those things when we were able. You know, we tried to experience and have him experience as much as he could in the time we had.

No second guessing—Several parents advised families to avoid second guessing themselves and the decisions they made during the time of treatment. Recognizing the potential for complicated feelings of guilt, one mother stated, “You just have to realize that you did things at the time because that's what you thought was best at the time. You can't keep questioning yourself and saying, ‘I should have done this, I should have done that.’” A father explained:

It's just going to take time to maybe understand that you didn't do anything wrong. Based on what you know at the time, you make that decision and it's not, it's not wrong. You haven't done anything wrong, but it takes time.

Advice for Soon after the Child's Death

Many parents and siblings focused their advice on what they found helpful after the child died, citing social support, self-expression, faith/religion, and memories as keys to managing their grief.

Relying on social support—The most frequent advice offered by parents and siblings was to rely on various sources of support for comfort after the loss of a child. Family members discussed the importance of reaching out to their families, friends, and church communities. One father reported, “Without family and church family and a lot of friends, I don't see how we would've survived it. It would be almost impossible to survive something that way if you were alone. It was comforting to have others who were always right beside you to help you and cover for you and give you reprieve from routines.” Interestingly, fathers, more often than mothers, spoke about relying on their spouses for support. One father explained, “I was blessed to have a beautiful spouse...When I was up or if she was ever down it always worked that I was up and vice versa.” Another shared, “I have a spouse and companion that you wanted to share that with, to weather that with, to lean on. Hopefully, I comforted her too...We wanted to be there to console one another no matter what.”

In contrast to fathers, mothers discussed the support they received from close friends. One mother put it simply, “Talking to my friends is what pulled me through,” while another explained further:

The friends you do have that you can keep close to you, that you have someone to share your emotions, who’s still very willing to let you talk about your child and they feel comfortable talking about your child, sharing memories. I think it’s important to have someone that you can really just express your emotions with.

Several mothers advised others to try to make specific connections with other parents who have gone through similar experiences. One stated, “I just became friends with someone who lost a 12-year-old also to leukemia, and we just became friends,” and another advised, “Talk to other people who have been there.”

Siblings also focused on family as support. One sibling stated:

Just, always remember that your family will be there for you, and no matter what your situation is, whether you’re so sick, or you’re completely fine without any problems... your family will always be there for you. No matter what...through thick or thin.

Only a few parents and siblings provided advice about seeking support from professionals. One mother suggested, “If you need help for it, go to a counselor and talk,” and a father, recognizing that seeking help can be an added challenge for men, stated, “Get help if you need it. I think there’s a pride in men, especially that we can fix things.” One adolescent sibling explained:

We’re all human. We all have feelings, emotions, and to not be afraid to let go of your emotions to someone, but if you can’t control your emotions, you got to. There’s always hope, especially if it’s still at (treatment center). You guys always have a counselor they can talk to, and I suggest that they speak to them, because they can be really helpful, and even though they may not think they need help to cope with their problems, I suggest they speak with someone, like a professional, to get professional help and advice.

Parents recognized the importance of seeking out and relying on various social supports but also discussed the inherent difficulty in doing so. One mom noted:

It’s great to have a few confidants that will share your grief because it’s hard, but I do think people distance themselves from you because it is so uncomfortable talking about death, especially when it’s the death of a child. So I would say we’ve lost friends who were never able to embrace our grief.

Several parents advised others that even though it may be uncomfortable, “You need to be willing to accept help.” One mother stated:

Learn to be a gracious recipient. It’s okay to take, because people want to give and so, you know, we had done previously for others, and we have sent them the same thing, but it is kind of hard at first to say, “Ok.” But I would, I would. That would be a recommendation. Make sure that, you know, you open your mind to that.

Talking about it—Parents and siblings alike noted the importance of being open and honest with one’s feelings and finding an outlet to express them, no matter how difficult that may be. Two mothers stated, “Don’t hold it inside” and “Talk about it. Don’t keep it to yourselves.” Similarly, one father suggested, “Not to hold it in, not to be afraid to share your feelings with people,” and another advised:

Talk about it. It doesn't bother me. I mean, I talk about it to strangers. Whenever. It makes other people feel more uncomfortable than it does me. You know, but it helps me cope with it. So, I just continue to talk about it when I want."

Siblings had similar advice, stating, "Talk about it because if you bottle it up inside it's gonna end up worse," and "Talk to people, and be honest about how you feel so they can actually help you."

Some families suggested other avenues of self-expression that they found helpful, including the use of email, internet blogs, and websites devoted to their children. One parent stated, "I think communication is real important. I think that email update I wrote was very, very important. In fact, I still do that. It just has been very therapeutic." Another shared:

It helped me to write some things of when (child) was sick. I kept a blog of it. After he died, it wasn't like I kept it up, but on significant events, I would write about those. I think those writings helped me, so I think writing is a good thing.

One sibling suggested recreational activities as a means of expression, advising others to "get in a lot of other activities, like football, to get your anger out. Cause if you're on defense, you can just hit 'em as hard as you can."

Finding comfort in faith and religion—Nearly all families made reference to their faith and/or their religion as being helpful in coping with the death of a child. Many parents discussed finding comfort in the tenets of their faith, their belief in the afterlife, and their acceptance of a larger plan. One mother stated, "She's in a better place now; she's our angel. When someone dies, it's the best gift of life." Similarly, another advised "Never lose your faith, like in God. God takes them to a better place, and they're not suffering anymore." Several parents found comfort in their belief that they will see their child again. One mother shared her thoughts about God's plan:

For me, just knowing God is in everything and that he has a bigger plan than my eyes can see. My life from this perspective is like I am looking through a fencepost that has a knothole in it. I can't see the big picture on the other side, but the big picture is better than what I can see through the knothole.

Similarly, siblings often relied on their faith/belief system as comfort for their grief. One sibling stated, "I would tell them that they shouldn't worry that much...because someday we'll meet them, and we'll see them, and we'll all just be together." Another agreed, "I'd tell them not to worry about it. You know, God wanted 'em, and one day you'll see them again. And just not to be sad anymore." Another elaborated on his belief:

When you pass away, there's not really anything to be afraid of because surely they've put a good message for you and that when you pass away, they'll be the ones that, it's your reward to see them again. So when you go up to heaven, look forward that somebody was gonna greet you.

Some families suggested specific religious practices/rituals as means of coping. One mother advised others "to pray consistently, to ask for God's wisdom and God's comfort, cause he will comfort those who cry out to him," and another stated:

It's not easy to lose a child, but with what we believe in, it sometimes helps me. So, what I will advise is for them to read the Bible because the Bible is very kind, very helpful and that will also help us overcome our grief.

A sibling expressed a similar sentiment, stating, "I'd say that they might need to keep up their strength, and they need to pray a lot, like be more faithful to God and like just read the Bible a lot and stuff."

Continuing bonds—Families advised others to never forget the child who died and, more specifically, to keep reminders of them and find ways to continue bonds with the deceased child. Memories appeared particularly valuable, as one mother advised others “to always keep the memory of their child in their heart.” One father stated simply, “Never forget them,” and another suggested, “Remember all the good things and the bad things. Just, try to keep your child in your thoughts as much as possible.” One parent warned, “Sometimes people want you to forget but I don’t ever want to; it’s strength to me.” Two separate siblings agreed, “Just try to remember the good memories that they had with their brother or sister,” and “Just keep them in your heart.”

Many parents described specific strategies for or encouraged keeping tangible reminders of the deceased child, like one mother who stated, “I still visit her gravesite and put flowers on her gravesite. You know, I honor her around the house, got flowers all around her pictures,” and a father who noted, “We keep pictures around and keep his stuff around.” One mother specifically advised others, “Don’t get rid of their things, because you will hate that one day...How can you cope without their stuff? You need to be able to hold it to get through.” One sibling suggested that others “could [deal with the death] if they could find a way to remember her, like a special little thing or something that their brother or sister did for them. And somehow do something so that it could make sense.”

Advice for the Future

Parents and siblings also provided advice for other families as they look toward the future and the life they have yet to live.

Finding acceptance—Many families spoke of the importance of acceptance. One father suggested, “Accept things and don’t worry about the past. You can’t change the past. Just learn how to let it go,” and a mother noted, “It’s really hard to accept, but you have to accept it.” A sibling agreed, “It’s very painful at first, but once you like get used to it, you realize you really have to accept it. You have to accept it as it is.” Another sibling made a distinction: “Well, I don’t think you really ever get over it. But it just keeps getting easier. So, even though it seems really hard at the moment it just gets easier and easier as you go to accept it.”

Going on with life—Embedded in the process of acceptance was the notion of continuing to live one’s life. Fathers, more frequently than mothers, expressed this sentiment, saying “don’t stop, don’t stop living. Go on, and you know they are there. They are there with you,” “I feel like, that she would want me to go on with life and take care of her brothers and sisters and make sure I do the things I needed to for them and take care of her mom of course,” and “We’re not looking back, we’re looking forward, and we feel that’s what he would want us to do.”

Cherishing every moment and living for the now—With their child’s death as painful evidence that life can be short, families advised others to cherish every moment they have, to focus on the present, and to live life to its fullest. Mothers and fathers alike advised, “Value every minute you have,” “Enjoy every second you have because ...you just don’t know,” and “Appreciate things.” One father made his advice more specific, stating, “If they have other kids, just spend more time with them. Take each day, day by day, and let them be kids.” One mother offered this advice:

You just got to live for the now. You can’t get bogged down with stuff. You can’t get bogged down with schedules. You can’t get bogged down with chores. The people in your life are what is important. It’s not the stuff. It’s not dust. It’s not vacuuming the floor. It’s not the Christmas ornaments still out on January 11. That

stuff will all happen whenever you have time. And if you're stressing over that stuff, what good is that? You've got to enjoy every minute that you have, you know, kind of like pick and chose your battles, you know. Don't die on the hills. Wait for the mountains.

Discussion

Content analysis of qualitative interviews with parents and siblings who lost a child to cancer revealed a wide range of advice to other families facing the death of a child. Results from this study are unique given the inclusion of multiple sites and improved recruitment rates relative to previous studies. Interviews also were conducted more proximal to the child's death than previous studies and included mothers, fathers, and siblings. Findings, then, provide insight into what may be helpful for individual family members near the first year of a child's death. Overall, there was consistency with previous studies identifying specific coping strategies, such as seeking support from family and friends, relying on personal belief systems/religion, and continuing bonds with the deceased child, as helpful following the death (Barrera et al., 2009; Hogan & DeSantis, 1992; Martinson & Campos, 1991). Prominent themes were consistent across sites and highlighted the individual and temporal nature of grief. However, some notable differences were found over time and across family members. Siblings offered more concrete strategies relative to parents, and mothers suggested the use of more external sources of support relative to fathers.

Many parents' first reaction to the advice question was to assert the individual nature of grief and to clarify that any advice they gave may not be universal. Parents stressed that they felt comfortable only describing what they found helpful and that they could not presume to know whether those strategies would be useful for others. Grief was viewed as an intensely personal experience and an individual journey for parents both across and within families. It follows that parents qualified their advice as situation-specific. Parents cautioned that expectations for how one "should" feel or act were not helpful, because there is no 'right' way to grieve. Recognition of grief as a private experience and an individual process is an important consideration in the creation of intervention efforts. Interventions that are 'one-size-fits-all' may not be perceived as useful as those that are tailored to a particular individual in a particular set of circumstances.

Themes that emerged from families' advice clustered into larger categories representing advice for before the child died, for immediately after the child died, and for further into the future. This temporal distinction highlights the idea that what may be helpful for families is not just situation-specific, but also time-dependent as grief is an ongoing process in the life of a parent whose child has died (Arnold, Gemma, & Cushman, 2005; Schut et al., 2001). Thus, support provided to families should differ according to where they are in the grief process (Arnold et al., 2005). Encouraging parents to advocate for themselves with healthcare professionals regarding spending time with their child and family decision making may be beneficial prior to a child's death, while promoting early acceptance may be misguided and premature. Determining the optimal timing of different components of interventions has been a challenge in bereavement research, particularly given the sometimes prolonged nature of grief or episodes of "re-grief" that may occur much later (Schut et al., 2001). Additional research is needed to more fully understand the trajectories and patterns of grief in relation to what may be perceived as helpful to bereaved individuals over the course of their experience (Bonanno, Boerner, & Wortman, 2008; Barrera et al., 2007).

Advice offered by families appeared to fit several current theories of coping, sense or meaning making, and continuing bonds. Advice from parents in our study suggested that

engagement coping activities, both primary (e.g., seeking social support, emotional expression) and secondary types (e.g., cognitive restructuring, acceptance), may be considered most helpful during the grieving process. This is consistent with research on effective stress responses, as these types of strategies generally have been associated with better adjustment (Compas et al., 2001; Skinner, Edge, Altman, & Sherwood, 2003). Interestingly, disengagement coping strategies (e.g., wishful thinking, denial) were not reported, possibly because they are not often associated with long-term, adaptive outcomes (Compas et al., 2001; Skinner et al., 2003) or alternatively, because individuals that primarily relied on disengagement were less likely to participate in the study.

Reports from both parents and siblings in our study demonstrated that secondary control and/or meaning-based strategies may be helpful in mastering the adaptive tasks of bereavement, such as coping with existential issues, role and identity crises, and making sense of the loss. Families appeared to use religious and spiritual beliefs as a framework for making sense of their loss and finding meaning in both their life and that of the deceased (Folkman, 2001; Hays & Hendrix, 2008). Although some studies have found that meaning-making is associated with better adjustment in response to a child's illness or death (Keesee et al., 2008; Murphy et al., 2003; Wu et al., 2008), much less is known about this process in bereaved children (Balk & Hogan, 1995; McCarthy, 2009). Thus, future research should continue to examine the role of spirituality and meaning-making in bereaved children.

A majority of parents and siblings stressed the importance of maintaining a connection with the deceased child, whether through keeping personal possessions, actively reflecting on memories, talking to the deceased, visiting the gravesite, or honoring them in the home via pictures or other representations of the child. This advice is consistent with continuing bonds theory (Klass, Silverman, & Nickman, 1996), suggesting that these connections can provide comfort and facilitate coping for both adults and children. There has been controversy about the adaptive role of continuing bonds in bereaved adults, with some research finding associations with greater grief symptoms and adjustment difficulties (Boelen et al., 2006; Hogan & DeSantis, 1994; Normand, et al., 1996), particularly when individuals are unable to make sense of the loss (Neimeyer et al., 2006). In this study, however, parents and siblings generally suggested engaging in the types of volitional or purposeful bonds that have been identified as having comforting effects (Foster et al., 2009).

Differences among reports that emerged during content analysis continued to highlight the individual nature of grief and suggested interventions be tailored not just to a particular family but to each individual within that family. Siblings, who largely focused their advice on the time immediately after the child's death, offered concrete strategies for dealing with grief (e.g., talk to somebody, keep memories close, read the bible) and rarely discussed more conceptual/existential issues noted by their parents (e.g., grief is individual, no regrets, cherish every moment). This restricted range of advice is not unexpected, given developmental differences in children's cognitive abilities. Concrete and active strategies for dealing with grief may be better suited for siblings, particularly those who are younger at the time of the death, than talk-therapy that requires introspection and abstraction. Another notable difference emerged between mothers and fathers with respect to social support, as fathers reported receiving comfort largely from their spouses, and mothers more often identified close friends and family as primary supports. This gender difference is consistent with literature that identifies women's social relationships as more involved and more intimate than those of men and that across age groups, women are more likely to self-disclose private feelings and problems to others (Fehr, 1996; Reisman, 1990). Effective interventions, then, may look different for men and women.

Our findings should be considered within the context of several limitations. Because the sample was limited to bereaved families who lost a child to cancer, advice may not generalize to those whose children have died from other causes (e.g., accidental death, homicide, suicide). In addition, families were interviewed within the first year after the child's death. Because the experience of parents and siblings may evolve over time, it is important to follow families over time and examine how advice changes as well. In terms of sampling, approximately one-third of eligible families declined participation, which could have introduced a self-selection bias, and our sample was largely White. Thus, future research with a more diverse sample is needed. Due to the nature of the interview question, little is known about what bereaved parents and siblings perceive as unhelpful before and after the death of a child. A companion study exploring what families would advise against is needed to ensure that interventions are not just effective for families, but also not likely to cause harm. Finally, evaluating the impact of length of time in treatment and whether or not the patient received hospice and/or palliative care are important considerations for future quantitative work.

Despite these limitations, findings from this study contribute to our understanding of what bereaved families find helpful after the loss of a child and therefore provide some insight into how to create and deliver effective and timely interventions. Future research should focus on identifying individual trajectories of grief for family members after the loss of a child and on incorporating primary and secondary engagement coping strategies into interventions that are tailored for bereaved mothers, fathers, and siblings. Mental health providers working with bereaved families should appreciate that grief is an individual process and that each family member may experience and cope with loss in qualitatively different ways. Furthermore, emphasis should be placed on the notion that there is no "right" way to grieve, and support should focus on the individuals within a given family, as mothers, fathers, and siblings appear to have different perceptions of what is helpful during the grieving process.

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