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# Changes in Parents After the Death of a Child from Cancer

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# Abstract

**Context**—Few studies have compared multiple perspectives of changes experienced by parents after a child's death.

**Objectives**—This study used interviews with bereaved parents and siblings to examine changes in parents during the first year after the death of a child from cancer.

**Methods**—Mothers (n = 36), fathers (n = 24), and siblings (n = 39) from 40 families were recruited from three hospitals in the U.S. and Canada 3-12 months post-death (M = 10.7, SD = 3.5). Semi-structured interviews with open-ended questions were conducted in the home with each participating parent and sibling separately. Content analysis identified emerging themes, and frequencies were compared between each paired set of reports (mother versus sibling, father versus sibling, mother versus father).

**Results**—Parents and siblings identified two major categories of change experienced by bereaved parents. These changes occurred in their personal lives (e.g., emotions, perspectives and priorities, physical state, work habits, coping/behaviors, spiritual beliefs, and feeling something is missing) and relationships (e.g., family, others). Ninety-four percent of mothers, 87% of fathers, and 69% of siblings reported parental changes in at least one of these categories. Parents were more likely to report changes in priorities, whereas siblings reported more sadness in parents after the death.

**Conclusion**—Positive and negative changes in parents after the death of a child from cancer occur in both personal and relational domains. Additional research is needed to determine the impact of a child's death on bereaved parents over time and to develop strategies to promote healthy adjustment.

### Keywords

Cancer; parents; bereavement; change

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## Introduction

Each year, over 60,000 children under the age of 20 die in the U.S. and Canada.<sup>1, 2</sup> The death of a child is one of the most painful events a parent may experience. Adjusting to a world without the loved one is a part of the grief process, which may take considerable time and effort.<sup>3, 4</sup> The death of a child is counter to the expected order of life events, and defies basic assumptions about the world. As a result, research has emphasized significant negative effects on adjustment, health outcomes, and social relationships after the death of a child.

Parental grief is prolonged<sup>5-7</sup> and can intensify during significant periods (e.g., holidays), a concept known as "regrief." Bereaved parents routinely score worse on most scales of adjustment, especially internalizing problems, relative to norms and controls.<sup>8-10</sup> Studies have shown that bereaved parents, particularly mothers, are at a higher risk for psychiatric hospitalization than non-bereaved parents.<sup>11</sup> Some parents experience severe anxiety, whereas others have regrets or guilt over not being able to protect their child.<sup>12</sup> Still other parents undergo changes in their basic assumptions, priorities, and perspectives about life.<sup>13</sup> However, emotional ties to the deceased child often continue indefinitely, and negative emotions may persist despite apparent normalcy in other dimensions of functioning.<sup>14</sup>

After the death of a child, risks to parental health include reduced quality of life, physical illness, and even death.<sup>15-20</sup> Some bereaved parents have described physical pain resulting from their grief similar to having been injured or mutilated.<sup>21</sup> The pain has been reported to linger even seven to nine years after the death of a child from cancer.<sup>22</sup> Bowlby<sup>23</sup> found that somatic disturbances like loss of appetite are often coupled with cognitive difficulties of confusion and obsessive thinking.<sup>23</sup> Bereaved individuals who experience extreme loneliness and depressive symptoms may be at risk for suicidal ideation,<sup>24</sup> and mortality rates may be higher among bereaved parents, especially in the first three years after a child's death.<sup>17</sup>

The death of a child, which negatively affects adjustment and physical well-being, may also have profound social implications.<sup>25</sup> Qualitative data suggest families undergo significant change after the death of a child.<sup>26</sup> The home may be joyless as parents and children withdraw into their own grief. One study reported higher family cohesion among bereaved families than controls,<sup>27</sup> but others suggest less cohesion and increased parental and marital strain.<sup>26, 28, 29</sup> Some marriages strengthen, whereas others dissolve.<sup>28, 30</sup> Bereaved parents have reported less marital satisfaction, less sexual intimacy, more frequent thoughts of separation, and higher divorce rates than non-bereaved parents.<sup>31-34</sup> Parents also may be consumed by grief and "overlook" surviving children,<sup>35</sup> or they may become closer and overprotective.<sup>28</sup> Bereaved parents have reported more parenting stress than controls,<sup>28</sup> and bereaved siblings have reported less communication, availability, and support from parents after the death.<sup>35</sup>

Despite the challenges associated with losing a child, there also have been reports of positive outcomes or growth. Multiple benefits related to the loss experience in the form of changes in self-identity and social functioning have been described.<sup>36</sup> Classic studies described a perception of increased compassion and empathy for others, and changes in values and priorities.<sup>37,38</sup> More recent studies have documented growth in parental feelings of competence and strength, and in interpersonal relationships.<sup>39-42</sup> Although work toward designing interventions that encourage personal growth is important,<sup>43, 44</sup> clarifying perceived positive and negative changes from other perspectives is also crucial to understanding parental grief.

Unfortunately, few studies have included multiple perspectives of how parents have been affected by the death of a child. Most research has focused only on the perspective of the

bereaved in describing themselves. We know little about similarities or differences in multiple perspectives of changes in parents after a child's death. Using mixed methods and a multi-site design, we described and compared the frequency and nature of changes in parents as reported by bereaved parents and siblings, on average, within the first year of a child's death from cancer. Thus, the purpose of this study was to 1) examine bereaved parents' perception of changes in themselves after the death of a child from cancer, 2) examine bereaved siblings' perceptions of changes in their parents after the death, and 3) compare parent and sibling responses.

### Methods

This research was part of a longitudinal study of families following the death of a child from cancer. In the larger study, data collection involved visits to bereaved siblings' schools and homes during the first year after the death, followed by another home visit one year later. The aim of the larger study was to reduce the suffering and morbidity of families affected by cancer and the loss of a child through controlled, longitudinal research on the psychosocial outcomes of these families. This paper includes cross-sectional, multiple informant, qualitative data collected from a subset of families at the first home visit across three sites. The first home visit occurred approximately one year after the death.

#### **Participants**

Of 60 eligible and contacted bereaved families, 41 (68%) participated in the home visit. Qualitative data were missing from one family because of a tape recorder malfunction. Participants (n = 99) included 36 mothers, 24 fathers, and 39 siblings. Mothers averaged 40.5 years of age (standard deviation [SD] = 7.4), and 78% (n = 28) were White. The remaining mothers were 8% African American, 6% Asian, and 8% Other. Fathers averaged 43.9 ears of age (SD = 7.8), and 83% (n = 20) were White. Thirteen percent of fathers were African American, with 4% self-identified as Other. Parent educational level ranged from 12-20 years, and averaged 14.5 years (SD = 2.2). Average family socioeconomic status (M = 44.2, SD = 25.1), computed using the revised Duncan's Socioeconomic Index,<sup>45</sup> reflected clerical, sales, and service occupations. Siblings were primarily female (64%, n = 25), White (72%, n = 28), and on average 12.3 years of age (SD = 2.6). Deceased children also averaged 12 years of age (SD = 5.3), with approximately 2.7 years (SD = 2.3) from diagnosis to death. Data were collected six to 19 months (M = 10.7, SD = 3.5) after the death.

# **Procedures and Measures**

Institutional Review Board approval was obtained at the three participating children's hospitals in the U.S. and Canada. Families were sent a letter of introduction from the deceased child's attending oncologist and were then recruited via phone three to 12 months after the child died. Eligible families 1) had at least one bereaved sibling 8-17 years old, 2) were fluent in English, and 3) lived within 100 miles of the hospital. Adopted, half-siblings, and step-siblings were eligible if the sibling had regular, ongoing contact with the child who died. Informed consent and/or assent were obtained from each parent and child, respectively. As part of the larger study, research assistants administered a series of questionnaires and conducted semi-structured interviews that were audio-taped for transcription and coding. For this report, individual interviews included an open-ended question developed by the research team. Parents were asked:

We have talked to many parents who tell us that they have experienced changes as a result of their child's death; others have identified few changes. Some tell us about negative changes, and some have talked about changes in a positive

direction. How would you say you have changed since your child's death? (If needed, probes included: Personally; in your daily activities; how you get along with family, how you get along with friends; at work; how do you see yourself as the same or different from before your child died?)

Siblings were asked:

We have talked to many siblings who tell us their parents have changed since their child's death; others have identified few changes. Some tell us about negative changes, and some have talked about changes in a positive direction. How have your parents and/or family changed since your brother/sister died? (If needed, probes included: What differences do you see – mood, behavior, relationships; at home, at work; with your family, with friends?)

#### Analysis

A qualitative approach was used to analyze data from open-ended questions.<sup>46, 47</sup> A coding scheme was not developed a priori so the researchers could best discover emerging categories within the data.

Four researchers independently analyzed data through content analysis. Content analysis began with immersion, which involved repeatedly reading the transcripts to gain a sense of the data as a whole. Next, researchers chose to first analyze sibling transcripts, followed by parent transcripts. Similar ideas were clustered within excerpted quotes from 15 transcripts, and preliminary categories emerged. The researchers reviewed the suggested coding scheme, extracted quotes, and discussed the rationale for emerging categories. They reexamined data by recoding original transcripts and made mutually agreed upon changes (e.g., editing category names, exploring new categories, combining or dividing categories). Fifteen more transcripts were added, and new codes were adopted when data did not fit an existing category. Memos tracked this decision trail and included questions, possible comparisons, and leads for follow-up.<sup>48</sup> Responses that did not fit into an existing category were identified as "other" and reconsidered each time transcripts were re-coded. This analytic process was repeated until consensus was reached and no new categories emerged. One example of this process was with the category of spiritual beliefs. Originally, spiritual beliefs were seen by two coders as fitting in the category of relationships (e.g., relationship with a higher being). After adding more transcripts and discussing characteristics of participant responses, the analytical process resulted in placing the category of spiritual beliefs as part of personal changes. All data were examined based on the final coding scheme, and narratives for each major category included exemplar quotes. This procedure resulted in parent and sibling descriptions of changes in parents who experienced the death of a child from cancer.

To gain a better understanding of similarities or differences in parental changes reported by mothers, fathers, and siblings, two researchers independently conducted frequency counts of categories of change (kappa = 0.66 to 1.0 across categories). Because reports were not available from siblings, mothers, and fathers within all of the families, McNemar tests were used to compare the frequency of changes between each paired set of reports (mother versus sibling, father versus sibling, mother versus father). A Bonferroni-corrected alpha value of 0.017 (0.05/3) was used to assess statistical significance.

#### Results

Content analysis of parents' and siblings' transcripts resulted in two major themes regarding changes in bereaved parents: 1) personal changes, and 2) changes in relationships. Themes and subthemes within each category are described below. Frequency data (Table 1)

highlighted similarities and differences in changes reported by siblings and parents. The only statistically significant differences among sibling, mother, and father reports were for the themes of priorities (P < 0.005) and sadness (P < 0.05). No siblings reported changes in parental priorities, whereas 10 (28%) mothers and six (24%) fathers described changes in priorities as a result of the child's death. Twelve (31%) siblings reported more sadness in their parents, whereas only six (17%) mothers and no fathers reported this.

#### **Personal Changes**

Sixty-four percent (n = 63) of all participants perceived that bereaved parents experienced personal changes since the death. These changes occurred in parents' (a) emotions, (b) perspectives and priorities, (c) physical state, (d) work habits, (e) coping/behaviors, (f) changes in spiritual beliefs, and (g) feeling something is missing.

**Changes in Emotions**—Forty-four percent (n = 16) of mothers, 17% (n = 4) of fathers, and 31% (n = 12) of siblings reported changes in at least one parent's emotions. These changes included sadness, anxiety, anger, regrets and relief. More participants (18% of all participants; n = 18) described sadness as a parental change in emotions more than any other aspect of this category. Although no fathers reported being sadder, 31% of siblings (n = 12) commented that at least one of their parents was sadder. One bereaved sibling said, "Well... they're sad, you know." Another noted, "Mom, she was very, very sad," and yet another stated, "They cry and stuff." Seventeen percent (n = 6) of mothers reported being sad. One mother shared, "Negative (changes) in terms of just having to deal with it; it's just a constant sadness or struggle that you deal with every day."

Ten percent (n = 6) of mothers and fathers reported they were more anxious after the death, but no siblings reported this. Parents expressed concern about the possibility of another death. One bereaved mom said, "I'm more worried – afraid something will happen to (sibling)." Another said, "I get nervous when (sibling) isn't with me or (husband) isn't with me. ...terrified me that (husband) had some problems with planes he works with...worry about what would happen to them if they lost me." A father shared, "I wonder and worry about (my daughter) more. And (wife)."

Just 5% (n = 5) of participants, including three mothers, one father, and one sibling, expressed anger as a change in parents after the death of a child. The father said, "I am very angry. Irritable with people outside the family – don't give a shit about people out there ... angry with younger people who complain or don't work." A mother shared, "I feel a lot of anger. I feel bitter, cheated." A sibling observed, "He's angry-ish, that guy" while indicating his father.

Two mothers and two fathers acknowledged their regrets. A mother said, "Sometimes I'm just angry that I didn't talk to him or tell him something nice (so) that he would have definitely known there is a heaven," and another parent regretted that she had not "spent more quality time with my kids." A father said, "In some ways, I guess, you feel unable to protect one of your children. So, as a parent you want to be able to protect them, and when something like this happens, you feel like you have somehow failed."

Only two bereaved mothers expressed relief. One said, "Relief – we're relieved. When he died, we could actually start living again, because life had gotten to be so encumbered. It sounds pretty harsh, but it was, you know, and we knew he's better off." The other mother said, "There has been a huge relief for us not to see her hurting anymore."

**Changes in Perspectives**—Forty-seven percent (n = 17) of mothers and 33% (n = 8) of fathers reported changes in this category. However, only one sibling mentioned changes in a parent's life perspective or priorities.

Almost a third of mothers (28%; n = 10) and 25% of fathers (n = 6) commented on a change in life priorities, although no siblings reported this. One mother stated, "I realize how much friends and people mean to you." A father commented on how some things no longer bothered him: "What becomes important changes."

Seventeen percent (n = 6) of mothers and 13% (n = 3) of fathers commented that life was short. One mother shared, "And it makes us realize that life, you know, is too short. And that, it makes us, you know, like think twice about stuff." A father said, "Time is valuable – don't take things for granted. Live for today not looking forward to tomorrow, because you never know."

Equal percentages of mothers and fathers (8%) reported looking on the positive side. A father reported he has "chosen to adopt a glass is half full lifestyle." The sole bereaved sibling who commented in this category observed her parents looking on the positive side: "I think that they have...a better outlook on life too." The mother of this sibling confirmed that observation, saying, "Positive changes in terms of just having a better outlook on life."

**Physical Changes**—Physical changes were noted by only 8% (n = 3) of the mothers. One mother claimed, "I feel more old. Hair gray, eyesight deteriorated. I feel smaller – like I'm not a whole person." Another said, "I've gained weight." None of the fathers or siblings described physical changes.

**Changes in Work**—Seven mothers (19%) and two fathers (8%) discussed changes in work. Four participants described having more work (two mothers, one father, and one sibling), and three mothers described having less work. One mother said, "I started work and just threw myself into work. So now it's like I am a workaholic," A sibling noted, "My dad has been busy with work and everything, and he's been trying to catch up since the past two years ...." Two mothers and one father noted differences in their work. One father said, "I quit my job in December. I was a youth minister, and it was just too much to handle." A mother shared, "I've changed my profession. I've got a degree in Early Childhood Education, and that's in Pre-K through 3rd, which is the same grade he would've been in, and I can't face the children."

**Changes in Coping and Behaviors**—Fifteen percent of participants (n = 8 mothers; n = 4 fathers and n = 3 siblings) described changes in coping strategies and behaviors in response to the question about changes since the death of their children. Some mothers described trying to be strong, and others talked about just getting through it: "I think we're living more day to day now than we were before." A sibling shared, "My mom told me my dad cries every morning when we're not here, and he writes letters to (deceased child). Well, so do I. My mom writes a journal. So, she was going to give it to him whenever he got older, so he'd know what happened."

**Changes in Spiritual Beliefs**—Twelve percent of participants (n = 12) described changes in beliefs about a higher being or their spirituality. Whereas 10% (n = 4 mothers; n = 4 fathers; n = 2 siblings) reported that parents were more spiritual/religious, 2% (n = 1 mother; n = 1 father) felt more distant from a higher being. One mother said, "I think it brought me closer to God than ever before. That's where I find my comfort. He knows what I'm going through and to make it at all possible for me to have a stress free life." A father shared, "Spiritually, I'm more committed to serving. Try to be the kind of person he would

want me to be. Try to be a good person to keep his memory alive. Doing good works – spend days trying to give back for prayers he received." On the other hand, one mother said, "I can't find meaning with that or anything, even my religious belief," and one father admitted "having a hard time with faith, believing in prayer."

**Something Missing**—Twenty-eight percent of mothers (n = 10), 21% of fathers (n = 5) and 5% of siblings (n = 2) described parents feeling something missing in their lives. This change included physical reality of things just being different and loss of self-identity. A father admitted, "Everything is different – everything is changed. Even though the three of us are living here, it's just a huge hole." One mother said, "I don't feel like myself anymore. Life doesn't matter anymore. Thinking about (deceased child) and trying to push myself because of him. No words to describe how I feel. At first I wanted to die ... but I try to think about what I have right now (other child, husband)."

#### **Changes in Relationships**

The death of a child was perceived to have changed bereaved parents' relationships with their family and others. Forty-six percent (n = 46) of participants noted these changes. In families, 26% (n = 26) described improving relationships, and 12% (n = 12) focused on relationships getting worse. In relationships with others, 9% (n = 9) described improvements, and 6% (n = 6) described interactions getting worse.

**Family**—Changes in family relationships were coded as positive or negative in both quality and quantity. Positive changes were fairly equally distributed among siblings (n = 9), mothers (n = 8), and fathers (n = 9), whereas negative changes were seen among seven siblings, four mothers, and one father. A father shared, "I listen to my daughter more and talk about her interests more." A mother commented, "It's changed how we treat each other. We are more respectful, more loving, kiss each other 'bye because you never know. The biggest thing for us is recognizing everybody's feelings." On the negative side, a sibling shared, "It's just been hard to get our family back together ever since she passed away."

**Others**—Positive changes were expressed by nine participants and negative changes by six participants. Mothers described themselves as more patient, more empathic, and more responsive. One mother said, "I am more sympathetic to people. If I see a parent being mean to a child, I just want to stop them and say you know, 'Be thankful you have them.' Better person – more caring, sympathetic." A father said, "I can focus on other people with their dilemmas and their pain. I know I was a recipient of a lot of prayers and lifting up and encouragement and propping up and to be returning the favor...I want to do that."

#### No Changes

Whereas the majority of participants perceived that bereaved parents changed as a result of the death of a child, 6% (n = 2) of mothers and 13% (n = 3) of fathers did not report the change themselves. Thirty-one percent (n = 12) of siblings did not report any changes in their parents. A mother attributed the lack of change to her faith: "No change, because of faith in the resurrection. So, even though we loved (child), we know we'll see him again. That's our belief. So, no it doesn't make a difference, because of the belief we have."

# Discussion

Limited research has examined the frequency and nature of changes experienced by bereaved parents after the death of a child from cancer. This study used mixed methods to identify and assess the frequency of different types of changes in bereaved parents, on average, within the first year of a child's death from the perspective of mothers, fathers, and

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siblings. Consistent with previous studies,<sup>12, 13, 15-20</sup> the majority of family members (83%) perceived that parents experienced changes after the death of a child. Changes included personal changes (emotions, perspectives, physical, work, coping behaviors, spiritual beliefs, and feeling something missing), and changes in relationships (family members and others). However, change attributed to the death of a child was not universally reported for bereaved parents.

A major contribution of this study is that data were obtained from bereaved mothers and fathers themselves, as well as from a surviving child, a relatively uncommon methodological approach. This method allowed us to address commonalities of family members' perspectives, as well as their unique differences. Although differences in reports of parental change were observable across respondents in most categories, statistically significant changes were found only for changes in priorities and perceptions of sadness. A larger sample may be helpful to elucidate additional informant differences across themes. Positive personal changes were reported more frequently by parents, whereas siblings were more cognizant of the negative/observable pain of their parents. Specifically, over 25% of mothers reported changes in their priorities, but no siblings reported these changes in parents. This may reflect parents not sharing changes in priorities directly with siblings, which otherwise would be difficult to observe. Although it is possible that positive and negative changes coexist, negative effects may be more salient to children who have less communication with their grieving parents.<sup>49</sup> Changes in priorities may affect some siblings negatively although the changes may be viewed positively by parents. For example, changes in the parent's spiritual beliefs may be seen as positive changes by the parent, but not necessarily so the sibling. This may account for why siblings reported more sadness in their parents than parents self-reported.

It is also interesting that almost one-third of siblings reported no changes in their parents, whereas few fathers or mothers reported this. This may be explained, in part, by the chronic nature of the child's disease and the anticipatory grief parents may have experienced prior to the death. Many parents of children with cancer report severe grief responses even at the time of diagnosis.<sup>50</sup> Parents may then develop coping strategies to deal with the uncertainty and despair over time.<sup>51</sup> Alternatively, some children, particularly those who are younger, may have genuinely been unaware of changes in their parents. Younger children also may be less able or willing to verbalize observed changes in an interview format.

Taken as a whole, our findings suggest that nearly two-thirds of participants reported that bereaved parents experienced personal changes. Of these, 32% reflected changes in emotions, predominantly increased sadness. This is consistent with research that highlights the prolonged nature of grief<sup>5-7</sup> and the higher risk for internalizing problems<sup>8-10, 52</sup> for some parents. Considering that two-thirds of parents did not report changes in sadness, it is also possible that grief and sadness may ebb and flow rather than remain persistent. Research suggests that depression is episodic and that regrief is a common phenomenon.<sup>5-7</sup> Thus, at any one point in time, some parents may have recently experienced increased sadness or grief, whereas others may have been more stable.

The second most frequent personal change, changes in perspectives, were reported by 26% of participants, most often reflecting changes in parents' priorities. Other work has highlighted similar changes in the beliefs and priorities of bereaved individuals.<sup>13</sup> Interestingly, few parents (only 8% of mothers) spontaneously reported physical changes after their child's death despite a growing literature supporting the physical toll and health risks for bereaved parents.<sup>15-20</sup> It is possible that these physical effects were less salient to parents in the early grief process when emotional changes dominate, or physical effects may emerge later, secondary to persistent negative emotional and social changes over time.

In addition to personal changes, nearly half of participants reported that bereaved parents experienced changes in relationships, most often in family relationships. These changes tended to be positive, such as growing closer and appreciating each other more,<sup>28</sup> but there were also reports of negative effects. Most of the literature has focused on negative effects on social relationships suggesting declines in marital relationships and parenting after a child's death.<sup>26, 28, 29, 31-35</sup> Thus, it is important to also consider the assessment of positive family outcomes in future research.

Other changes of note among bereaved parents included feeling something missing in their lives and changes in coping behavior and spiritual beliefs. The feeling of something missing occurred both in the form of missing the physical presence of the child and experiencing a loss of identity after the death. This has been described previously as the "empty space phenomenon."<sup>22</sup> Changes in coping and spiritual beliefs reflected attempts to manage the ongoing pain of the loss, as well as how to make sense of a seemingly senseless death. This may be related to parent's feeling powerless when faced with the death of a child and subsequent reliance on a superior being. The loss of a child certainly may affect parental perceptions of being a protector and provider for their child.<sup>41</sup> In light of perceived failure in this role, parents may attempt to create meaning through recognition of what is fulfilling and important in life.<sup>53, 54</sup>

Our findings should be considered in light of several limitations. Our sample was primarily White and included bereaved parents and siblings after the death of a child to cancer. This finding may not generalize to more diverse families or individuals bereaved by other means. Data were cross-sectional with relatively little variation in length of time since death, and reports of positive and/or negative aspects of parental change may not persist over time. Interview questions were asked at the end of a long assessment, and responses may have been shorter because of fatigue. Finally, siblings were asked about their perception of changes in their parents and family in general, rather than mothers and fathers specifically, which limited the specificity of the content analysis of their data.

Despite these limitations, this study addressed a gap in the literature by examining similarities and differences in perceptions of parental change reported by bereaved mothers, fathers, and siblings. Other strengths included multiple data collection sites, good recruitment rates that minimized ascertainment bias, and the use of mixed methods. Our findings suggest that health care providers should consider the many changes that occur in families after the death of a child, but realize that change is not universal to all families. Helping bereaved parents and siblings talk about their feelings and the changes they experience can open the door for them to move through the grief process. Families also may gain a sense of normalcy knowing that other families have a continuum of positive and negative responses to loss of a child.

Most studies focus on the pathology of parental bereavement and fail to recognize the human ability to cope with adversity and allow for positive change and growth.<sup>39</sup> More research is needed to provide a balanced understanding of parental bereavement. Future research could include longitudinal studies to examine reports of positive and/or negative aspects of parental change over time. Ideally, this would include attention to factors occurring from the time of the child's diagnosis as antecedents that may affect parental adjustment after the death. Work also should examine the reciprocal nature of family grief and how outcomes vary according to methodological approach (e.g., phone, internet, or face-to-face interview). Overall, studies exploring predictors of positive and negative change in bereaved parents are needed, as well as interviews that promote health adaptation.

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#### Table 1

# Parental Change as Perceived by Mothers, Fathers, and Siblings

	All Participants (N=99)	Mothers (n=36)	Fathers (n=24)	Siblings ( <i>n</i> =39)
Personal Changes	63 (64%)	32 (89%)	15 (63%)	16 (41%)
Emotions	32 (32%)	16 (44%)	4 (17%)	12 (31%)
Sadness	18(18%)	6(17%)	0 <sup>a</sup>	12 (31%) <sup>a</sup>
Anxiety	6 (6%)	5 (14%)	1 (4%)	0
Anger	5 (5%)	3 (8%)	1 (4%)	1(3%)
Regrets	4 (4%)	2 (6%)	2 (8%)	0
Relief	2 (2%)	2 (6%)	0	0
Perspectives	26 (26%)	17 (47%)	8 (33%)	1 (3%)
Priorities	16 (16%)	10 (28%) <sup>b</sup>	6 (25%)	0 <i>b</i>
Life is Short	9 (9%)	6 (17%)	3 (13%)	0
Positive	6 (6%)	3 (8%)	2 (8%)	1 (3%)
Physical	3 (3%)	3 (8%)	0	0
Changes in Work	10 (10%)	7 (19%)	2 (8%)	1 (3%)
Changes in Coping/Behaviors	15 (15%)	8 (22%)	4 (17%)	3 (8%)
Changes in Spiritual Beliefs	12 (12%)	5 (14%)	5 (21%)	2 (5%)
Closer	10 (10%)	4 (11%)	4 (17%)	2 (5%)
More Distant	2 (2%)	1(3%)	1(4%)	0
Something is Missing	17 (17%)	10 (28%)	5 (21%)	2 (5%)
Physical Reality	10 (10%)	5 (14%)	3 (13%)	2 (5%)
Loss of Self-Identity	7 (7%)	5 (14%)	2 (8%)	0
Changes in Relationships	46 (46%)	19 (53%)	14 (58%)	13 (33%)
Family	33 (33%)	11(28%)	9 (38%)	13 (33%)
Positive	26 (26%)	8 (22%)	9 (38%)	9 (23%)
Negative	12 (12%)	4 (11%)	1 (4%)	7 (18%)
Others	15 (15%)	10 (28%)	5 (21%)	0
Positive	9 (9%)	5 (14%)	4 (17%)	0
Negative	6 (6%)	5 (14%)	1 (4%)	0
No Changes Attributed to Death	17 (17%)	2 (6%)	3 (13%)	12 (31%)

<sup>a</sup>Significant at P<0.05.

<sup>b</sup>Significant at P<0.005.