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Benefit Finding in Fathers of Childhood Cancer Survivors: A Retrospective Pilot Study

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Abstract

There is a growing literature examining positive outcomes following traumatic experiences. Although the diagnosis of a child with cancer poses extraordinary challenges for the family, awareness is growing that such a life-changing event can be a catalyst for positive growth. The current mixed-method study investigated benefit finding in fathers (N=25) of childhood cancer survivors. Benefit finding included positive changes resulting from adversity. Participants completed a benefit finding measure and an interview describing their experience and benefits from the challenges faced during their child's cancer journey. Findings indicated that fathers endorsed high levels of benefit finding ($M=4.1$ out of 5) specifically in: personal growth, spiritual change, and relationships with others. Our study extends the literature by examining how their child's cancer journey contributed to specific domains of paternal benefit finding. These results support the use of a positive psychology framework for understanding effects of a child's cancer diagnosis on caregivers.

Keywords

Childhood Cancer; Fathers; Benefit Finding

Over the past several years a trauma framework has been used to understand and treat post-treatment psychological adjustment difficulties experienced by childhood cancer survivors

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and their families (Kazak, Kassam-Adams, Schneider, Zelikovsky, Alderfer, & Rourke, 2006; Stuber, Kazak, Meeske, & Barakat, 1998). Childhood cancer is viewed as a life-threatening medical event, with survivors and their families at risk for developing posttraumatic stress disorder (PTSD). Clinical rates of PTSD among parents of childhood cancer survivors are modest but variable, ranging from 10–25%, and are typically higher for mothers than for fathers (Brown, Madan-Swain, & Lambert, 2003; Kazak, Alderfer, Rourke, Simms, Streisand, & Grossman, 2004). However, significantly higher rates of posttraumatic symptoms have been reported in both childhood cancer survivors and their parents (Kazak et al., 2004), particularly when compared to normal peers (Barakat, Kazak, Meadows, Casey, Meeske, & Stuber, 1997).

Although the diagnosis of a child with cancer poses extraordinary practical and emotional challenges for the family and may lead to increased distress, awareness is growing that such a life-changing event can be a potential catalyst for growth and positive change. These positive changes have been conceptualized in several ways. For example, posttraumatic growth has been defined as “the extent to which survivors of traumatic events perceive personal benefits, including changes in perceptions of self, relationships with others, and philosophy of life, accruing from their attempts to cope with trauma and its aftermath” (p. 458; Tedeschi & Calhoun, 1996). Generally, this term is used to describe any *positive changes* or *benefit* when presented with trauma or adversity. Adversity challenges the individual’s worldview and growth results from striving to make meaning of the experience. After experiencing a traumatic event growth may occur through active cognitive processes in at least five domains: (1) personal strength; (2) new possibilities; (3) relating to others; (4) appreciation of life; and (5) spiritual change (Tedeschi & Calhoun, 1996; Calhoun & Tedeschi, 2006). In this manuscript, we use the term *benefit finding* to refer to any perceived positive changes, posttraumatic growth, or benefit from having a child who survived cancer.

Constructs of benefit finding related to a wide range of traumatic events including life threatening illness has been studied across a variety of populations and settings, although mainly in the adult literature. Findings from studies focusing on adult cancer patients and survivors (e.g., breast cancer survivors; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2009) indicate that despite stressors many adult cancer patients and survivors report positive gains including a deepened sense of purpose, closer relationship with family and friends, and a deeper spiritual life (Carver & Antoni, 2004).

More recently, Phipps and colleagues examined benefit finding in children with cancer (Phipps, Long, & Ogden, 2007). Studies of benefit finding in children diagnosed with cancer and childhood cancer survivors are generally consistent with those found in the adult literature. Typically adolescent survivors report experiencing at least one benefit from their cancer experience, and on average report additional positive changes including positive changes in how they think about life and how they treat others (Barakat, Alderfer, & Kazak, 2006). Older youth find more benefit in being diagnosed with cancer than younger children (Currier, Hermes, & Phipps, 2009).

There is some suggestion that parents of children with chronic illness experience lasting benefit from the experience as well. Hungerbuehler, Vollrath, and Landolt (2011) reported that parents of youth with chronic illness show a moderate degree of growth after their child’s diagnosis. Barakat and colleagues (2006) have reported specifically on benefit finding in parents of childhood cancer survivors. In their sample of over one hundred mothers and fathers of adolescent cancer survivors, they found benefit finding in 90% of mothers and 80% of fathers. Areas of reported positive changes were generally consistent for mothers, fathers and adolescent survivors and included changes in how they perceived life and treating other people better. Michel, Taylor, Absolom, and Eiser (2009) reported

that parental benefit finding was positively related to how much they felt their child's prior cancer diagnosis and treatment impacted their lives.

To date only one quantitative study has examined paternal benefit finding from having their child survive cancer (Barakat et al., 2006). Although quantitative research is helpful in examining overall levels of benefit finding, qualitative narrative is necessary to better understand how individuals derived benefit from a traumatic event and the resultant domains of growth. In order to address this limitation in the literature we conducted a retrospective mixed method pilot study to examine benefit finding in fathers of childhood cancer survivors.

Method

Participants

Participants were identified from a survivor database at the University of Alabama at Birmingham (UAB), Division of Pediatric Hematology and Oncology at Children's Hospital. Participants included 25 fathers of childhood cancer survivors. All survivors were younger than 18 years old and resided at home. Tables 1 and 2 list the demographic and medical information for the childhood cancer survivors and their fathers. At the time of diagnosis, 22 of the participating fathers were married, 2 were single and primary caregivers, and one was divorced. At the time of the actual study, no changes in marital status were noted with the exception of two fathers.

Inclusion criteria included: 1) child completed cancer treatment between one and ten years previously; 2) father is English speaking; and 3) the child's medical treatment included chemotherapy or radiation therapy. Participants included 8 fathers of childhood leukemia survivors, 9 fathers of childhood brain tumor survivors, and 8 fathers of children with other childhood cancer diagnoses.

Procedure

This study was approved by the university institutional review board. A total of 82 potential participants were identified from the survivor database and mailed a letter describing the study and a consent form. One week after the letters were mailed a research associate followed up with a phone call to determine if they had any questions. If interested in participating in the study, fathers were given the option of scheduling either a face-to-face meeting or a telephone interview to complete the measures. Of the fathers contacted, 42 (51%) were not reached due to incorrect or missing contact information, 15 (18%) declined to participate, and the remaining 25 (30%) participated in the study. No differences were noted between fathers who participated and those who declined on child's age, gender, ethnicity, diagnosis, age at diagnosis, or time since completion of medical treatment.

Measures

Demographic Information—Ten fathers completed the study in-person at the hospital and fifteen completed the study over the telephone. No differences were noted between participants who completed the study in-person or over the phone on child's age, gender, ethnicity, diagnosis, age at diagnosis, and time since completion of medical treatment. All in-person and phone interviews were conducted with the father alone in a quiet room. After providing consent, fathers completed the demographic questionnaire, including information about the child's diagnosis, treatment modality, age at diagnosis, time since completion of treatment, gender, ethnicity, and father's level of education. Fathers were also asked questions regarding religious identification, household composition, income, occupation,

health insurance, home relocations, and stressors both at the time of diagnosis as well as post completion of their child's medical therapy.

Benefit Finding Questionnaire—Participants completed a benefit finding questionnaire, originally developed by Behr, Murphy, and Summers (1992) and adapted by several other researchers for use with adult and childhood cancer populations (Antoni, Lehman, Kilbourn, Boyers, Culver, Alferi, et al., 2001; Phipps et al., 2007). All participants rated the 17 questions on a 5-point Likert scale, where 1 indicated "Not at all true" and 5 indicated "Extremely true." Responses were averaged to obtain a global measure of benefit finding. When used in past research (Antoni et al.) this scale represented a unitary dimension with good internal reliability ($\alpha = .95$). Concerning convergent validity, the inventory was positively related to optimism ($r = .24$) in Antoni and colleagues' sample.

Interview—Participants responded to open-ended questions regarding benefit finding from their child's cancer experience. The interview guide was developed based on a resiliency framework (McCubbin et al., 2002), findings from paternal coping literature (e.g., Brody & Simmons, 2007) and feedback from two expert psychologists in the field. Interview questions included any positive changes that had occurred in their roles and responsibilities within the family, use of social support, and how they had benefitted from the challenges they endured during their child's cancer diagnosis and treatment. Each interview took 45 to 60 minutes to complete. The interview questions are listed in Table 3.

The first author took detailed notes during the interviews to record participants' answers. Each interview response was coded by two coders according to a *descriptive code*, which summarized the information provided for each answer. These codes were then grouped into categories based on similarity of content. Each participant's responses were then classified according to one or more categories/themes. There was 95% agreement between the two coders. If there were discrepancies among the coders, the two coders met to discuss interpretation of the interview content.

Results

Fathers of childhood cancer survivors reported experiencing benefit finding in several areas including positive changes in self, a deepened spiritual life, and relationships with others. The mean rating on the benefit finding questionnaire was 4.10 on a 5-point scale. Our sample showed good internal reliability on this scale ($\alpha = .90$). Table 4 lists mean scores of each item and the percentage of participants reporting positive change for each item (defined as a 4 or 5 on the 5-point Likert scale). The most highly rated items on the quantitative benefit finding questionnaire corresponded with information provided by the fathers during the interview.

Three major themes emerged from the narrative interview information indicating benefit finding in the domains of: (1) personal strength; (2) spiritual change; and (3) relating to others. All participating fathers reported experiencing positive changes in one of the three domains. Forty-eight percent of fathers reported experiencing positive changes in two domains, while 16% reported experiencing positive changes in all three domains. Table 4 categorizes each item on the questionnaire into one of these three domains.

1. Personal Strength

Endorsement on the benefit finding questionnaire of the items 'Having had a child with cancer has helped me become a stronger person, more able to cope effectively with future life challenges' ($M = 4.60$, $SD = .64$) and 'Having had a child with cancer has taught me how to adjust to things I cannot change' ($M = 4.64$, $SD = .49$) was consistent with themes of

benefit finding in coping and development of personal strength reported in the interviews. Although 96% of fathers experienced emotional challenges throughout their child's cancer journey (e.g., "it's hard not to worry about the what-ifs..." and "it's hard to get over the fact that my child might die"), 40% reported increased strength from the experience; while 32% reported experiencing a shift in perspective on what was important in their lives.

Overall, during the interviews fathers reported that their child's cancer experience made them more resolved and confident in facing future life challenges and described having an "inner strength" that they had lacked in the past. Participants provided several specific examples of personal strength. For example, one father described the cancer experience as serving as a catalyst that could either strengthen or weaken an individual. Another participant reported an increased awareness of learning to identify the controllable and uncontrollable factors in his life. He reported that learning this helped him more effectively deal with future life adversities.

2. Spiritual Change

During the interviews 48% of the participants described having a deepened spiritual life (e.g., "I'm closer to God" and "my faith was tested and strengthened"). Additionally, although 28% of the fathers reported experiencing religious challenges, including questioning why God let this happen to them, their child, and their families during treatment, the overwhelming feeling after treatment was a closer relationship with a higher power.

During the interviews fathers reported that having faced numerous emotional challenges strengthened and deepened their faith and religious belief system. Several specific examples of spiritual growth were provided by the participants. A couple of the participants reported that their family as a whole was more spiritual from having gone through this experience. Another participant mentioned that this experience drew him to a more personal walk with a higher power.

3. Relating to Others

Consistent with the item on the benefit finding questionnaire, 'Having had a child with cancer has helped me become more aware of the love and support available from other people' ($M = 4.52$, $SD = .82$), 56% of the participants reported positive change and growth in their relationships with family members and friends. Participants provided several specific examples of relationship growth during the interviews. Specifically, they described an increased sense of connection with family members including being physically and emotionally present for their wives, children, and friends, and actively participating in more family activities. In fact, four fathers mentioned that having survived their child's cancer journey made them realize the "importance and value of spending as much time as possible" with family members, and three fathers reported actually spending more time with their family than they had in the past. Fathers also described a change in the quality of their relationships with their children in that they realized the importance of making every moment matter. They reported an increased focus on "quality of time" spent together (e.g., "embrace the time we have with our kids. It's not going to be perfect, but it's the quality time we have with our children that is going to last"). Increased family togetherness and focus on fostering "positive memories" served to strengthen family ties and bonds over time.

Additionally, 16% of fathers reported having an increased awareness of the needs of others. Participants provided several specific examples indicating this change and sensitivity to others and willingness to reach out and assist in any way possible. One father described that the positive change stemmed in part from the outpouring of support offered during his child's cancer journey. Fathers reported being surprised by the outpouring of social support

offered by extended family members, as well as community and church friends. These positive experiences contributed to their desire to reciprocate by reaching out to others and assisting them.

Discussion

This retrospective mixed method study furthers the literature by providing narrative data examining benefit finding in fathers of childhood cancer survivors. Findings from our data delineate three specific domains of benefit finding. First, fathers were more confident in their ability to face future adversity, specifically to cope with future life challenges. Second, they reported a deepening in their spiritual life. Finally, fathers endorsed developing a closer and more meaningful relationship with their wives, children, other family members, and friends. Additionally, based on the overwhelming support received during their child's cancer journey, many fathers felt they were more sensitive to the needs of family members and others. Fathers did not report change in the area of new possibilities as reported by Tedeschi and Calhoun (1996), although appreciation for life themes were intertwined in the domain of relating to others.

In the current sample, all fathers described themselves as being Christian and relying on a higher power through this experience. It is likely that reliance on their faith led to a new perspective and more positive view of the experience. There is some research suggesting that cancer survivors experience increased *spiritual* growth in various domains after such a traumatic experience (Denney, Aten, & Leavell, 2011). A systematic review of posttraumatic growth, religion, and spirituality indicates that religion and spirituality are typically helpful to people dealing with trauma and may lead to finding benefit in the experience (Shaw, Joseph, & Linley, 2005). However, there is little research examining the relationship among these constructs in parents of children with cancer.

There is a body of literature examining the relationship between demographic and disease variables with posttraumatic growth, including time since completion of treatment (Barakat et al., 2006). We did not find any such associations in our investigation. This is likely related to methodological differences including a small sample size and use of a different measure of benefit finding.

Overall, the benefits reported in our sample of fathers of childhood cancer survivors is consistent with those outlined by Barakat and colleagues (2006), as well as other studies of adults diagnosed with cancer (e.g., Mols et al., 2009; Tedeschi & Calhoun, 1996). Our study builds on these earlier investigations by further examining the specific domains of benefit finding as well as how the cancer experience contributed to paternal benefit finding. Growth is conceptualized as leading to preparedness, which buffers against the effects of subsequent trauma in both the adult and child literature (Calhoun & Tedeschi, 2006). This buffer was certainly reported by the fathers in our study. Moreover, the worldly assumptions held by people who encounter trauma are said to be revised through the trauma, allowing for new perspectives on life and resilience to future stressors. The fathers in our study also described developing new priorities. Based on this conceptual framework, fathers may have experienced a deepening of their faith and trust in a higher power for aspects of the situation they could not control.

Fathers also likely utilized their available social support to help buffer against the stressors of their child's cancer journey (Norberg, Lindblad, & Bowman, 2006; Speechley & Noh, 1992). Utilizing available social support might help fathers deal adaptively with challenges and contribute to benefit finding over time (Brody & Simmons, 2007; Wolff, Pak, Meeske, Worden, & Katz, 2010). Additionally, their desire to give back to others who are in the same

or similar situations more clearly illustrates the positive impact of their experience. Consistent with other research, our findings support the use of a positive framework to study benefit finding in individuals who have experienced a traumatic event.

Limitations

Because this investigation was a pilot study with the focus on descriptive data, the sample size was small, precluding the investigation of more detailed relationships between benefit finding and demographic or medical variables. We did not collect quantitative information on fathers' perception of the influence of their child's illness on their lives or posttraumatic stress symptoms, which also limits interpretation of relationships between benefit finding and other variables. Future studies should include larger samples and examine the relationship between benefit finding and posttraumatic stress in this population. As a retrospective study requiring fathers to reflect back on their experience of having a child with cancer, results are open to memory biases inherent in this type of data (Neugebauer & Ng, 1990). A prospective study might yield further insights into the nature of changes over time in perceived benefit after the experience of a traumatic medical event in their child. The relationship between benefit finding and father-rated quality of life should also be investigated, to determine if the positive correlation between these variables found in adult cancer patients holds true in this population as well (Mols et al., 2009).

Finally, our entire sample of fathers were self-reported Christians from the Southeastern United States, and predominantly Caucasian. To increase the generalizability of our results, future studies will need to include fathers from more diverse religious beliefs, ethnicities, and geographic diversity.

Conclusions and Future Directions

There is a growing interest in understanding how families experience positive changes in the face of a life-threatening diagnosis in one of their children. Findings from this pilot study indicate that fathers were able to find benefit in the experience leading to lasting positive changes in their lives in the domains of self-growth, spirituality, and relationships with others. Future studies should be conceptually based and experimentally designed to examine both benefit finding and PTSS in a larger sample in order to discern ways to promote benefit finding in families of childhood cancer survivors.

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Table 1

Child Demographic and Medical Variables.

Characteristic	N (%)	Mean (SD)
Gender		
Male	9 (36)	
Female	16 (64)	
Race/Ethnicity		
Caucasian	19 (76)	
African American	2 (8)	
Asian American	2 (8)	
Hispanic	1 (4)	
Native American	1 (4)	
Child age *		11.7 (3.9)
Age at diagnosis		5.7 (3.5)
Time since completion of treatment		4.5 (2.0)
Diagnosis		
Leukemia	8 (32)	
Brain tumor	9 (36)	
Other childhood cancer	8 (32)	
Treatment modality		
Chemotherapy only	7 (28)	
Radiation only	0 (0)	
Surgery only	0 (0)	
Radiation + Chemotherapy	6 (24)	
Radiation + Surgery	3 (12)	
Chemotherapy + Surgery	2 (8)	
Chemotherapy + Surgery + Radiation	7 (18)	
Child's Insurance		
Yes	22 (88)	
No	3 (12)	

Note.

* current status (versus at diagnosis).

Table 2

Father Demographic Variables.

Characteristic	N (%)
Marital Status [n (%)]	
Married	22 (88)
Single	1 (4)
Divorced	2 (8)
Education level [n (%)]	
Some High School	1 (4)
High School Diploma	5 (20)
Some College	5 (20)
Bachelor's Degree	10 (40)
Post-Graduate Training	1 (4)
Graduate Degree	3 (12)
Income *	
<\$20,000	2 (8)
\$20,000-\$39,999	2 (8)
\$40,000-\$59,000	4 (16)
\$60,000-\$79,000	4 (16)
\$80,000-\$100,000	2 (8)
>\$100,000	10 (40)
Occupation	
Higher Executive	3 (12)
Administrator	4 (16)
Manager/Minor Professional	7 (28)
Technician/Semiprofessional	1 (4)
Skilled Manual Worker	2 (8)
Semiskilled Worker	5 (20)
Unskilled Worker	1 (4)
Unemployed	2 (8)
Religious Identification	
Christian	25 (100)
Other	0 (0)
Household Composition	
Child lives with father	3 (12)
Child lives with father and mother	22 (88)
0 siblings	5 (20)
1 sibling living in the home	11 (44)
2+ siblings living in the home	9 (36)
Insurance	
Yes	22 (88)
No	3 (12)

Characteristic	N (%)
Home Relocations	
Yes	6 (24)
No	19 (76)
Stressors Currently	
Yes	8 (32)
No	17 (68)
Stressors during treatment	
Yes	11 (44)
No	14 (56)

Note.

* one participant declined to answer this question.

Table 3

Interview Questions.

1	In what ways did your child's cancer diagnosis impact your family role and responsibilities at diagnosis, throughout treatment, and after the completion of treatment?
2	During your child's cancer journey, what sources of support were available to you? How much did you make use of the offered support?
3	What were the greatest challenges for you during your child's cancer journey?
4	How has the cancer experience changed you?
4a	Positive changes/personal growth?
4b	Negative changes?
5	When you tell the story of your child's diagnosis, treatment, and journey, what parts do you find the most difficult to recall or relay to others?
6	After having been through this experience, what advice would you give to fathers who are currently going through their cancer journey?

Table 4

Benefit Finding Questionnaire.

Item: "Having had a child with cancer has..."	Mean (SD)	N (%) reporting benefit finding
Domain: Personal Strength		
1. Taught me how to adjust to things I cannot change	4.6 (0.49)	25 (100)
2. Helped me become a stronger person, more able to cope effectively with future life challenges	4.6 (0.65)	23 (92)
3. Helped me become more focused on priorities, with a deeper sense of purpose in life	4.4 (0.86)	21 (84)
4. Helped me take things as they come	4.3 (0.63)	23 (92)
5. Led me to be more accepting of things	4.2 (0.83)	19 (76)
6. Taught me to be patient	3.9 (0.93)	15 (60)
7. Led me to deal better with stress and problems	3.9 (0.97)	19 (78)
Domain: Relating to Others		
8. Helped me become more aware of the love and support available from other people	4.5 (0.82)	22 (88)
9. Made me more sensitive to family issues	4.3 (0.94)	22 (88)
10. Brought my family closer together	4.2 (0.94)	20 (80)
11. Taught me that everyone has a purpose in life	4.2 (1.1)	19 (76)
12. Shown me that all people need to be loved	4.0 (1.2)	18 (72)
13. Made me more aware and concerned for the future of all human beings	3.8 (1.3)	17 (68)
14. Helped me realize who my real friends are	3.7 (1.5)	17 (68)
15. Made me realize the importance of planning for my family's future	3.6 (1.4)	15 (60)
16. Led me to meet people who have become some of my best friends	3.2 (1.5)	10 (40)
Domain: Spiritual Change		
17. Contributed to overall emotional and spiritual growth	4.3 (0.94)	21 (84)

Note. Benefit finding is defined as a score of 4 (Quite a bit) or 5 (Extremely) on the 5-point rating scale.