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Grandparents' Experiences of Childhood Cancer, Part I: Doubled and Silenced

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Abstract

In this study, the authors examined the experiences of grandparents who have had, or have, a grandchild with childhood cancer. Sixteen grandparents were interviewed using unstructured interviews, and the data were analyzed according to hermeneutic–phenomenological tradition, as guided by the philosophical hermeneutics of Hans-Georg Gadamer. Interpretive findings indicate that grandparents suffer and worry in many complex ways that include a doubled worry for their own children as well as their grandchildren. According to the grandparents in this study, this worry was, at times, silenced in efforts to protect the parents of the grandchild from the burden of concern for the grandparent. Other interpretations include the nature of having one's universe shaken, of having lives put on hold, and a sense of helplessness. The grandparents in this study offer advice to other grandparents as well as to the health care system regarding what kinds of things might have been more helpful to them as one level of the family system, who, like other subsystems of the family, are also profoundly affected by the event of childhood cancer.

Keywords

pediatric oncology, psychosocial oncology, grandparents, hermeneutic inquiry, qualitative research

When a child is diagnosed with cancer, the family is delivered a diagnosis in which no member goes unaffected, unchanged, or untouched. A child diagnosed with cancer is a *family* experiencing cancer. Although remarkable and commendable research has occurred in the natural and biological sciences that has resulted in significant decreases in morbidity from childhood cancer, long-term cure, and exponential longevity of life, the experiences of family members and ways in which health care professionals can be most effective in mitigating family and child suffering has received relatively less attention in the research arena.

Each year in Canada, approximately 1300 children younger than 20 years develop cancer (Health Canada, 2003). Although the overall incidence of childhood cancer has remained stable since 1985 (144–159 per 1 000 000 children), childhood cancer mortality rates have decreased dramatically between 1985 and 2004 (Canadian Cancer Society, 2008). This decrease is largely because of aggressive, multimodal treatments such as chemotherapy, radiation, surgery, and bone marrow transplantation (Woodgate, Degner, & Yanofsky, 2003); improvements in supportive care; and the work of clinical trial consortia. In Canada, 3-year survival rates now exceed 80% (Health Canada).

With modern childhood cancer therapy, pediatric oncology patients in Canada will be admitted to the hospital 5000 times and spend 50 000 days in the hospital per year (Scott-Findlay & Chalmers, 2001). For the families of these children, these statistics translate into enormous disruptions in family life. Families must endure many challenges such as invasive procedures and treatments, severe symptom distress, increased emotional and physical work, changes in family members' roles, routines, and responsibilities, marital stress, disruptions in family life, financial hardship, generalized uncertainty, and an overall decrease in quality of life (Packman, 1999; Scott-Findlay & Chalmers, 2001; Woodgate, 2006a, 2006b; Woodgate & Degner, 2003). Along with the diagnosis of cancer, come a seemingly endless number of transitions for these families. From health into illness, through the different stages of treatment,

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remission to relapse, or from illness back into health, families must learn to cope with the physical, mental, and environmental demands of this disease as they journey together through the childhood cancer trajectory (Clarke-Steffen, 1993; Jacob, 1999; Kerr, Harrison, Medves, & Tranmer, 2004; Labay, Mayans, & Harris, 2004; McGrath, 2001; Woodgate & Degner, 2004).

Study Objectives

The objectives of this study were to first understand, from the perspectives of grandparents, the complexity and unique character of experiences of having a grandchild diagnosed, treated, and living with childhood cancer. Second, there was a conscious eye on the results to lead toward developing family focused, relational health care practices that address grandparents' roles, needs, and contributions in a family system. Ultimately, the research was designed to guide the initiation of a network of support to the eldest of three generations of family members who are touched by cancer at relational, emotional, psychological, and spiritual levels as they simultaneously care for their own children (parents of child) while loving, grieving, and worrying for their grandchildren.

Background Information and Literature Review

Childhood cancer is a profound event that deeply affects families at many complex levels. Although there has been research on the effects on the family, it has primarily focused on the general effects on the family system and function and the effects on the child, parents, and siblings (Clarke-Steffen, 1993; Jacob, 1999; Kazak et al., 2004; Kerr, Harrison, Medves, & Tranmer, 2004; Labay et al., 2004; McGrath, 2001; Packman, 1999; Scott-Findlay & Chalmers, 2001; Woodgate, 2006b; Woodgate & Degner, 2003, 2004). There are also a number of studies that have looked at the effect on grandparents of children with other health challenges, including autism, disability, and critical care admission (Hall, 2004a, 2004b; Katz & Kessel, 2002; Margetts, Le Couteur, & Croom, 2006). These studies have concluded that in varying degrees and ways, grandparents are affected emotionally, financially, and relationally by any health challenge facing grandchildren.

What has been little researched is the effects on, and experiences of, the grandparents of a child diagnosed, treated, and living with cancer. In a search of 8 databases and more than 1000 articles that were identified with keywords of childhood cancer, family, and grandparents, only 3 citations spoke specifically of this topic and they will be discussed below. There were a few references to a more general consideration of the grief of grandparents and

psychological work with them, some of which were research based (Dent & Stewart, 2004; Fry, 1997; Gerner, 1990; Nehari, Grebler, & Toren, 2007; Ponzetti, 1992; Ponzetti & Johnson, 1991; Reed, 2000). Although Nehari et al.'s (2007) research was specific to the bereavement of grandparents following a child's death of cancer, it did reflect some experiences of grandparents throughout the cancer trajectory. Reed (2000) addressed grandparent bereavement as "doubled pain" of the loss of their grandchild and the pain of their own child's grief. Ponzetti (1992) spoke of the bereavement as a "triple pain" as grandparents navigate their own grief along with the loss and worry for their own child and grandchild. Together, these works begin to highlight that the suffering of grandparents when a child dies is multilayered.

Indeed, this is a very meager showing of attention to the experiences of grandparents; Nehari et al.'s (2007) findings that grandparents live "the worst experience" (p. 66) are juxtaposed with the general lack of consideration of grandparents as a part of the bereaved family. Specific statements made by grandparents in Nehari et al.'s study such as "there is no place for grandparents' mourning" (p. 70) and "the REAL mourning is that of our children [the parents]. Who are we? Just grandparents" (p. 69) powerfully speak to the loneliness of this experience for grandparents and the disenfranchisement of the legitimacy to claim their profound grief. Nehari et al.'s study called the pain of grandparents as located in "a voice unheard" (p. 66) as bereaved parents struggle to live with their own grief and find themselves without resources to support their parents. Grandparents then, in watching the pain of their child, become silent and their grief muted and often unrecognized.

As mentioned, only 3 articles (Charlebois & Bouchard, 2007; Faulkner, Peace, & O'Keefe, 1995; Martinson, 1998) spoke specifically of research on the overall effect of childhood cancer experience on grandparents and not just focused on bereavement. Faulkner et al.'s (1995) British study included 15 grandparents and concluded that grandparents suffer in watching their own children and their grandchild experience pain. Martinson interviewed 19 Taiwanese grandparents with a focus on the ways in which the grandparents helped support the family. In a Canadian study, Charlebois and Bouchard interviewed 8 grandparents in a thematic analysis of the phenomenological "lived experience" of having their grandchildren diagnosed with cancer. Their findings identified that this experience for grandparents was an unimaginable experience, filled with a wide spectrum of emotions, a sense of injustice and powerlessness, and an offering of support but receipt of little themselves. The researchers concluded that this area requires more in-depth qualitative studies, including a greater number of participants.

Design

Methods

This qualitative study used a sophisticated method of research called hermeneutics, which is well documented under the umbrella of what is often referred to as phenomenological studies. Hermeneutic inquiry is described as the practice and theory of interpretation and understanding in human contexts (Chesla, 1995; Grondin, 1994, 1995; Moules, 2002). It is considered to be a reflective inquiry concerned with “our entire understanding of the world and thus . . . all the various forms in which this understanding manifests itself” (Gadamer, 1976, p. 18). There is a natural fit of interpretive methods to pediatric cancer in that the experience of cancer diagnosed in a child and adolescent is an interpreted experience, uniquely borne by families who received the diagnosis of what is often described as a “worst nightmare” moment come true. As health care professionals, we are obligated to understand as many aspects of this experience that allow us to be competent, effective, and compassionate practitioners.

As a research method, hermeneutics (Gadamer, 1960/1989) is one approach that allows us to make sense of the particulars of families’ experiences and arrive at deeper understanding. In this study, hermeneutics allows us to access how families experience the angst, worry, fortitude, and capacity to learn to “live alongside” (Wright, Watson, & Bell, 1996) life events that call forth the unimaginable. Childhood cancer is at some level an unimaginable, yet very real and profound human experience, that calls up relationships, interactions, and interpretations that unfold in unique and little-understood ways. This complexity cannot be adequately measured in traditional quantitative means. There are no measures that respectfully articulate what this life event asks of family members, children, caregivers, and health care professionals. Pediatric oncology is a physical and biological experience but, at its core, it is a human and relational experience that we are obligated to understand. Benner (1994) suggested that the *understanding* gained in interpretive inquiry is key to “becoming more effectively, skillfully, or humanely engaged in practice” (p. xv) and is a particularly useful approach when one seeks to understand meaning and practices that are often taken for granted and assumed. Hermeneutics offers the opportunity to conduct a more thoughtful practice (Smits, 1997), a desired outcome in the important work with families where prescription and assumed practices should not adequately satisfy the complexity of such practices.

Recruitment of Participants

The study participants were grandparents of children undergoing, or having completed, treatment of childhood cancer.

After ethical approval was granted through the Conjoint Health Research Ethics Board (University of Calgary), posters were placed in a local children’s hospital inpatient oncology unit and outpatient clinic. Primary health care providers also introduced and explained the study to interested participants. Potential participants were then instructed to contact the principal investigator (Dr. Nancy Moules) and a telephone or an e-mail conversation was conducted to discuss the research and provide further information. If consent was obtained, participants were then interviewed. Consistent with hermeneutic research, no limit was set to “power” or randomize the study. The number of participants in this type of study is determined by the richness of the data collected through strong exemplars of experience, therefore when the topic is richly informed, data collection can be concluded, recognizing that it can never be “complete.” We interviewed 16 participants, 12 women, and 4 men. Four couples were interviewed together and no men were interviewed alone.

Data Generation

Data sources consisted of unstructured interviews with participants as individuals or couples. Focus groups were offered but no participants chose this option. Interviews were conducted by three trained research assistants with experience in the practice area, family nursing, and therapeutic conversation. The interviews were audiotaped following informed consent.

Analysis and Interpretation of Data

Hermeneutic analysis is synonymous with interpretation. Interpretation is gained through understanding, which is itself characterized by engagement in reflective activity and the asking of questions (Chesla, 1995). Unanswered questions create worlds of possibilities and in this, Gadamer (1976, 1960/1989) suggested that understanding occurs through dialectic and the willingness to embrace what is questionable. The movement between conversations with others (research interviews with participants, interpretive memos of researchers) opens new understandings. The beginning individual interpretations are then moved to another level of interpretive analysis in the research team’s conversations and writing.

Arriving at interpretations in a hermeneutic study is a rigorous practice. Interpretation has a communal, reflexive, multilayered quality that brings together knowledge, information, conversation, experience, and data to join with intuition and understanding. The process of interpretation involves entering into the hermeneutic circle as an engaged participant. This circle is not a method for uncovering meaning but a metaphorical way of conceptualizing the process

of interpretation. The hermeneutic circle is the generative recursion between the whole and part, immersing in a dynamic and evolving interaction with the data as a whole and the data in part, through extensive readings, rereadings, reflection, dialogue, challenging taken-for-granted assumptions, and moving toward an understanding that opens up possibilities. Hermeneutic work must be a good description but does not end there; it must bear up the description by showing through exemplars and rich data that which it is proposing.

Unlike some other qualitative methods, such as classical ethnography, grounded theory, and thematic analysis, interpretive work is not in search of themes, semantic coding, constructs, or theories, but rather the event of understanding, of deepening our vision of a topic in such a way that the topic can be seen differently. Hermeneutic research does not involve an attempt to conserve the individual "stories" of participants, but what it tries to keep central is the topic or phenomenon itself. Therefore, in the representation of the data, it is not required that each participant be individually identified, rather, their experiences are represented as a whole.

In summary, the nature of this kind of research is that there are not universal and generalizable truths. Experiences, people, relationships, and context are particular and unique, and contradictions are expected in the context of human science research.

Interpretive Findings

The grandparents in the study, as one might expect, expressed a wide range of responses to having a grandchild with cancer, which changed over time, reflecting the course of the cancer and its treatment, and their place in family networks. In Part 2 of this study, we focus on the responses that had to do with how the grandparents perceived their roles within family systems, the supports they felt they needed and, significantly, the supports they were able to offer. In this article, we address other interpretations that arose from the data.

Speed at Which Your Life Changes: The Phone Call That Heralds a Shaking of a Universe

... the movement by which a life gets changed for keeps, a reach for what we only hope is there

—Bronwen Wallace, 1987, p. 55

In the interviews, many of the grandparents relived and recounted the events of learning of their grandchildren's diagnosis. This event, seemingly carved into memory,

ranged from being described as disbelief and shock, to being "universe shakers":

Well, your heart goes poof you know. It was devastating. It was worse than when my parents died and you get that call.

It was another one of those universe shakers.

Shocking to me . . . phoning me . . . It's the speed that your life changes. Just one phone call sets you in a completely different direction . . . you don't have time to take a breath . . . oh my god, we have cancer.

They got that call . . . the phone call that can change your life.

The shock of the first phone call was then followed, as most earthquakes are, with aftershocks that were often unexpected. The telephone often became the delivery method and was both a lifeline and a vehicle of anxiety in anticipation of bad news:

Well, when we got that phone call, then I cried . . . So I dreaded those phone calls . . . kind of felt guilty about it . . . don't phone, because if you're going to tell me something bad, you know?

Out of Sync, Unfair, and Trading Places

After the initial ground shaking, grandparents taught us that the process of questioning the unfairness of the situation was an immediate companion to the speed at which their lives all changed:

Why is it him, why isn't it me? With old people you expect that to happen and with young people I just don't. I just don't think it's fair.

Little boys don't get cancer.

I'm older. I've been around the hill 3 or 4 times. That's who gets cancer not little children . . . why not me?

Shakes your faith because you wonder, there is no rhyme or reason in my mind for children to suffer the way these little kids do . . . Why these babies?

It should have been me. Why her? Well, why not me? You keep thinking this shouldn't happen to a 4-year-old or a 12-year-old and I think that's what bothers you more than anything.

This haunting question of “why her/him?” was a lingering specter in some grandparents’ experiences and others were able to face the question and live with the unanswerability of it:

The natural question is why? Why my boy? I certainly do (ask the question to myself) but I know there’s no answer. I have no answers when I think about it and so I try not to.

There seem to be many ways of living with the question and this research did not offer us the answer to this existential dilemma. It did tell us that it is an important aspect of the grandparents’ experiences and they struggled to find their own answers or nonanswers.

A Knowing Silence

Sometimes the grandparents felt, because of their years of experience and their ability to be somewhat removed, that they were able to see and intuit how the grandchild was doing in ways different from the parent. One grandparent believed she had “an intuition as a grandmother around how [grandchild] was doing” but felt constraint in sharing this with the child’s parent. Beyond the parents, they felt ignored by the health care team on the knowledge they might hold and received a subtle message to not express their opinions and concerns:

I felt as a grandparent I wasn’t as important as they (parents) were . . . different people come in tend to not necessarily address the grandparent either. My issues weren’t as important. I noticed, (some professionals named) . . . would nod to me and say hello and then sort of turn away . . . the message I got was that what I was doing wasn’t very important.

This balancing act of knowing and not speaking, of staying optimistic and supportive, but bearing worry is difficult.

Recognizing that they needed to step in to support their children brought awareness at the time and, often later in reflection, that the grandparents themselves might have had no support. “I realized I didn’t have one.” Attempts to talk to friends were at times met with discomfort: “not a good conversation . . . not an easy one to have with anybody” and they found friends staying away from the difficulty of the conversation. Friends or others may have asked how the grandchild was doing and progressing but the question sometimes seemed perfunctory. A willingness to ask more and listen more deeply did not seem to occur.

You can’t really talk to people . . . I’ve found as a general rule almost everybody is kind of just . . . (sigh) a child with cancer is something that is just so awful.

The silencing of the grandparents’ worry is embedded in a deeper silence of childhood cancer. It is unspeakable. One grandmother in search of a grandparents’ support group believed that the group would help her in providing a “place to go and break down . . . and then go back to their kids to be a rock.”

Grandparents exerted a caution and attention to boundaries: “We’re not going to butt in unless we are asked to.” However, the silence did not mean that the grandparents did not see things or have opinions. For example, when a decision was being made about stopping steroids and the effect on the outcome of chemotherapy, the daughter was told that there would be no effect on the chemo, and the grandmother stated in the interview: “So, I’m in the background thinking: Why the hell is she still taking (the steroids) then?”

An aspect of knowing silences is also about not knowing and waiting, of balancing and walking fine and tactful lines to access secondhand information. Efforts not to intrude elicited a careful attention to and discernment of time and place, timing, and their appropriate right to a place in the conversation:

You’re not getting the information first hand. You’re not interacting with the doctors straight away. You’re waiting until they come home to find out what’s happening with them . . . they had the meetings with the surgeon or with the cancer doctors . . . You’re waiting to see, well what happened and yet there’s a fine line between . . . are they ready to talk about it? You’ve got that anxiety waiting to say . . . what’s happening today . . . all these questions she asked that doctor that you’re thinking of and I don’t get a change to ask . . . I’m not getting any first hand information about my questions . . . I don’t want to be making her (daughter) more worried about stuff by asking about my questions . . . so you just kind of swallow them . . . you’re not certain what’s happening and you’re afraid to ask or inquire too much because you don’t want to upset anybody. You can’t be so intrusive that you’re upsetting . . . because even though you want to know, there’s a time and place for it.

I totally backed off . . . I would stay downstairs or be out of the house, just letting her have her time.

Although our study data lead us to a general sense of feeling silenced, it needs to be noted that not all grandparents felt silenced and, in fact, some experienced having a freedom of voice and expression. “I think grandparents . . . we’re a little more removed from the immediate problem . . . and we can talk about it more freely.” Although grandparents may have at times experienced being silenced, there were occasions where they felt they had a voice and could

talk about the unimaginable in a way that the parents might not have been able.

Lives on Hold While a View of the World Changes: Holding One's Breath

There is something about changes that happened and how the world was seen through a new lens and the shifts in the grandparents' interaction with it. While some grandparents reported a loss of their sense of security in the world, they have also been awakened to a new sense of generosity and kindness. Other grandparents discovered a newfound intolerance of the mundane:

It's made me less tolerant of stupid acts done by people. Like ignorant things done. I have no time or patience for it. So if somebody's complaining about having put on 5 pounds . . . so you lose your tolerance of petty little things and people who whine and complain . . . I have no time for them . . . so you see so many people who are so generous and warm and giving and that's what you gravitate to.

For some grandparents, not only were lives put on hold, but they were also turned upside down in terms of routines, lifestyle, space, and place. Some took in children and families; some moved or relocated to be with them at least temporarily:

It's 4 months now . . . so it's a bit of disorientation because I'm sleeping downstairs and living out of a suitcase . . . my own home and my own things . . . you miss . . . at this point in my life, I miss that serenity of my things . . . my pillow, my bed.

As lives were turned upside down, those things that grounded and provided serenity were often removed. At a phase in life where one is typically settled and grounded, the grandparents have typically fit, physically and metaphorically, so well into familiar furniture, beds, and pillows that capture their forms and configurations. In the face of this, some grandparents found ways to fit into something that needed them but did not know their configurations:

You are in a different space . . . and you're just fitting in, fitting into to that little corner of the rumpus room . . . so I can be there to help and not intrude . . . what do you do? You've got to come and help.

Grandparents were at once a guest, but a needed one:

You don't want to be so intrusive that you upset people because this is their home and their family and yet you want to be supportive but you also don't want them to become too dependent on you.

In putting one's life on hold, there is an aspect of inertia or of holding one's breath, not being able to move forward or ahead until all was safe and well with the grandchildren. "I would sometimes hold my breath you know like (waiting for) the other shoe to fall kind of thing." The Damocles's syndrome, often described for survivors of cancer, can be extended to grandparents who are holding their breath for the drop of a sword that could take the life of their grandchild and their own children. The sword of Damocles is not directed, as in the ancient myth, to one person but to a network of those involved. As one grandparent said, "We have cancer." As an important part of this network, grandparents felt, and perhaps continue to feel, cancer suspended above them by a single horsehair: "Because it isn't, it's not like it's gone. It will never be gone really."

The Quest for Normalcy: A New Kind of Normal

Grandparents put their own lives on hold to help retain some normalcy in the lives of their children's families.

We weren't planning on this when we were planning our retirement . . . we would have been off, gone somewhere this year, but we didn't go. You have to put your life on hold . . . we dropped pretty much what we have.

Try to keep everything as calm and same as possible . . . supper's done; the dishes are done and everybody's got their bath; they're ready for bed . . . so there's normalness to stuff . . . nurturing and caregiving for everybody . . . so that it's less traumatic at home . . . it's a little bit of saneness.

Grandparents were instrumental in trying to maintain a sense of "normal" for all family members while recognizing that a new kind of normal was developing: "It's not back to normal, but getting back to normal." Grandparents often tried to keep things as normal as they could for the other children in the family:

It did upset their lives . . . I think by us being able to come and keep them in the home instead of them having to be taken here, there, everywhere, helped in their situation because they were at home. They were in their routines.

The effort goes into to trying to keep this as normal as possible for the kids and not as emotionally heavy.

"We did try to keep things the way they were . . . have family dinners, have the functions . . . but what is "normal" now? . . . Is this our new normalcy? What becomes normal and what isn't normal anymore?" This comment was in

reference to the disappointment felt by the grandchild when she was told she was going to have a central line and she would no longer be able to go to the “poke box.”

My god, what is normal anymore? . . . it becomes routine . . . it becomes normal, a part of your life . . . Everybody was really happy for her because she was getting this central line. It’s kind of funny, isn’t it . . . you get all happy over a central line.

The arrival of this new normal sometimes came in a quiet, even insidious way. “We didn’t talk about all the things we’d been through. We didn’t talk . . . we just accepted the new normal . . . We’ve painted and plastered over it.” Perhaps when one lives with events such as childhood cancer, there is little that can be done to prepare for how lives are shifted, and perhaps a semblance of normal finds its way in to comfort as best it can.

Helplessness: Nothing You Can Do

The helplessness experienced by the grandparents becomes attached to the worry: “It’s just pure helplessness.” Parents always want to protect their child, to make it right, to take away the pain, and in this situation where grandparents wish to protect their children and make everything alright, there is nothing to be done that can erase what is happening: “I wish I could make this OK and knowing that you can’t.”

You see your children going through this and there’s nothing you can do for your child never mind your grandchild who’s suffering.

You’re helpless. You stand by and you wish you could take them all . . . put your arms around them and make it all go away.

The toughest thing with being a grandparent . . . you just wish you could take it away for them, but you feel that pain more than your child. So to see them suffer is just so . . . and there nothing you can do.

In the midst of this sense of helplessness, is recognition that it must be harder on their children and the weight of the kinds of decisions that parents had to make is often a lonely weight to bear: “As a mother, I would think it would be 20 times as hard . . . a hundred times as hard . . . the guilt, questioning . . . Decisions are her’s not mine.”

Criticism, Blame, and Guilt

Children, even adult children, seem to be innately sensitive to what they perceive as criticism from parents and this seemed to play out especially in times of vulnerability.

Parents of children with cancer tend to often engage in guilt and self-blame and the handmaiden of guilt (Moules & Amundson, 1997) often invites sensitivity to other’s unintended criticism. In turn, sometimes the blame was turned onto grandparents. This is not a surprising finding in its own, as it is often that in times of hurt, worry, and stress, children often move into an anger and blaming of those most trusted in their own lives—their parents. This is seen in clinical practice, at times, that a child may get angry with the one person or persons where the anger can safely land as they know it will not sever a relationship or love:

He thought I was criticizing him . . . that he wasn’t a good parent . . . but then the blame all turned on me . . . dismissed me like I was a servant, you can go now.

There was at times a hurtfulness in all this to some of the grandparents:

To me, it was disrespectful and hurtful and no one else, not her family or friends not anybody knows how it felt. Because I was there more than anybody, like way more than anybody else, like I was in the trenches with them.

Although trenches are intended to offer protection of sorts, we know that they are in the middle of a battlefield, and in spite of them, people get hurt. A trench is no guarantee of protection; in fact, they are at the forefront of danger.

As much as grandparents tried to stay on the sidelines, the balance did not always work. Connected to the issue of silences and boundaries, there was a caution exercised about not stepping in too much: “You’re afraid to say too much ‘cause then you’re meddling into how they are raising their kids.”

The handmaiden of guilt, wherever it is placed or delivered as blame can land on the grandparents not from their children but from themselves. We are not sure if this is something that can be removed from the love and responsibility that is inherent in being a parent or a grandparent:

Ok, is there anything that I could have contributed to this? Noticed or prevented?

Only one grandparent interviewed spoke explicitly of guilt, but the interviewer directly asked only one about it and she related taking her grandchild to a sports park and as a result of an activity, hit his head where the helmet left a little bruise on his head.

I think about that (if it started the whole business). Other than that I don’t feel guilty for my genetics.

Grandparents' Needs

Many grandparents in the study did not see their needs as important at this time: "All our energies are focused on getting (grandchild) better and getting through this so anything that helps them will help me . . . my needs at this point are the family's needs." This notion of grandparents' needs being subsumed into the parents' and children's needs was consistently heard in the interviews, but it does not mean that the grandparents had no needs, simply that they either did not attend to them, could not attend to them, or saw them as less important than others' needs at the time.

Although they perceived that their needs might not matter at this time, it did not diminish how they felt: "Sometimes I just can't . . . and I have to sit down and have my cry and then say: OK, enough. That's it. You're done and carry on." There was an aspect of internal monitoring about giving into such feelings and needs, always saying, "I can't do this;" "So if I breakdown, if I feel like I'm breaking down . . . I'm ashamed of myself;" "You don't realize what you have to . . . with what the stress, this and that . . . basically as a grandparent you also need help."

Some grandparents learned to compartmentalize, attempts at which were not always successful. When asked how much of the day was taken up with thinking about what was happening to her child and grandchild, one grandparent stated,

I don't think about them until evening time and then I start to think about them before I get ready for bed. If it isn't too late, I'll call them . . . I try not to think about it. I don't think I consciously think about them but you know it's probably back there somewhere . . . I often wonder what it would be like to have a child die on you. Your own, your own son or daughter . . . I imagine it would be something you never ever get over and you're afraid to stop thinking about them, but it's sitting there at the back of your head, somewhere. It's sitting there, always ready to come forward.

Ironically, many of the grandparents stated that their needs were met by simply feeling needed. One grandmother, through her tears, recalled when her daughter, who was the mother of the grandchild with cancer, called her sister and said "I need my Mommy' . . . so that would be me."

Needless to say, it does make me feel good when they do call on me to do things and it makes me feel good that they appreciate me.

For some, their feelings were subsumed in being active and helping out:

I would say we were too involved in helping them out to really feel but being involved was helpful and healing to some degree. So to be down here and know what was going on and be sort of in the middle of it was much better than being at home and wondering.

The Reemergence of Sibling Rivalry in Adults

There has been much written about how siblings are the other victims in childhood cancer and how they bear weights and worry, life changes, and sometimes feeling shoved aside as the focus necessarily falls on the ill child (Woodgate, 2006b). Interestingly in this study, this phenomenon showed itself with adult siblings. As grandparents sometimes became closer to the parents of the children with cancer and were more present and available for them, their other children/grandchildren at times distanced and felt the loss of attention and care of the grandparent. One grandmother stated, "I've become obsessed with him (grandchild with cancer)," then described that, prior to cancer, she may have been closer to or communicated more often with her other child and his children. In this shift of availability, communication, and focus, her child and his children began to notice and feel left out and dismissed or at least taking a lesser focus: "My son makes comments . . . I'm thinking not resenting but obviously noticing . . . Drifting away or even having problems with their other children?" One grandparent clearly stated this, "You still have your other three (grandchildren) but your thoughts are more on that one . . . maybe I mention her (grandchild) too much."

One grandmother recommended to other grandparents that they need not focus entirely on the child/grandchild with cancer but also "take care of the other members of the family . . . not to put all your focus on that one situation but try to still maintain some balance with the other people in your life." This added concern about ensuring that everyone was evenly treated and attended to seems to become a part of the burden carried by the grandparents. Some grandparents felt a sense of "guilt . . . I'm really missing them and they've had to find other day care . . . I'm missing out on their lives,"—missing out on day-to-day life events in a child growing up such as birthdays, new births, swimming lessons, soccer, or skating. There is a notion of going "missing in action," in the action of how life continues, for others in the family even when their own feels put on hold.

Pride of Their Children

With little exception, the grandparents in this study spoke of how in awe they were of how their own children managed to handle something so difficult and something that was truly even unimaginable to them:

His mom too . . . she was just amazing . . . I knew what she was going through . . . she just held it all together. She was fantastic . . . We're very proud of her.

She's been very strong . . . when around her boys, I never saw her shed a tear . . . but when she was by herself or with me, she would cry.

It's amazing how strong she's been. We've all been just so proud of her . . . I've thought if I were her, would I be as strong as she is?

Advice From Grandparents to Other Grandparents

In the interviews, when the grandparents were asked directly, or when they offered advice, what they would offer to other grandparents going through a similar situation, the overwhelming advice was to "just be there."

Pay Attention to the Whole Family

Careful you're supportive of all of the children in the family and all the family. As much as you want to focus on that one child that's ill you have to be cognizant of the rest of the other children.

Be Prepared for the Ride

It's a rollercoaster, I will tell them that. It's an absolute rollercoaster. You will see things, hear things that you never want to see with these kids. It is devastating. At the same time when you are watching the doctors, you marvel.

Might not hit them right away, like it might hit them six months down the road . . . can happen years down the road.

Keep Perspective and Take Care of Yourself so That You Do Not Become a Burden

I think people have to keep things in perspective. You still have to look after number one . . . if you don't do that, you're eventually not going to be looking after anybody.

Take care of themselves so they can help take care of everybody else.

Just get through it one day at a time . . . and just hope for the best . . . what else can you do? Find someone you can talk to.

You learn to be more easy going and forgiving and value what's important.

Keep Optimism and Hope; Be Available and Step in Even at Times When Not Invited

Be as optimistic as possible . . . don't give up hope . . . be able to step in where they might need help because as parents you can see the need sometimes more so than what they can and they don't realize they should be asking for help.

Be available, be available. Be positive. Keep the faith. By being available is just that when they wanna talk or if they need you to go when they go to a treatment . . . taking the other kids to a show.

Sometimes . . . there's nothing you can do, just be there . . . just sit and be there.

Hang in as best you can because there's always hope . . . it may not end up the way you want it, but under the circumstances there's always that bit of hope that it will be all right in the end.

If they're not in the same city, move to the same city . . . not necessarily in their house, their children's house, but to move closer to be available because being available means so much to them . . . So I would advise grandparents to be there.

If they're not close enough to be involved . . . I would say just be available . . . your children need you. Do what you can under your circumstances.

Take worry out of your vocabulary, 'cause worry is useless thinking.

You might need to be sensitive to an awful lot of things without being a burden, without being a nuisance.

Be Prepared for the Curves That Happen Without Warning

You just do what needs to be done at the time. You know whatever comes your way. You have things that enter your life, some curves in the road that you don't expect in many ways and you just somehow the strength is there to deal with it when it comes . . . and you just do what needs to be done at the time.

As much as grandparents had sage advice for people in their similar situations, when invited, they also had advice for health care providers.

Grandparents' Advice for the Health Care System

The grandparents in this study were asked what kinds of things were helpful to them from the perspective of the ways they were treated and cared for in the health care system. They were also asked for any advice about what more could be done. Overall, the grandparents, though they at times felt invisible, experienced a general kindness of care from all health care professionals. They indicated that among the most important and useful things that occurred were acknowledgment, recognition, and inclusion:

Acknowledgement . . . include you in the jokes . . . they do lots of fun and teasing . . . if you're there when the doctor's there, they talk to you too.

I thought that I was part of the team with them here (at hospital). I think I was dealing with things better because I felt like I was helping and was contributing.

A part of recognition is being remembered: When asked if they felt welcomed at the hospital, one grandparent responded: "Absolutely, absolutely, you know you see them once and you tell them who you are once and they remember . . . 'Grandma, how are you today?' They were just wonderful." Grandparents were even remembered over time, months later: "Even today, they remembered me and I haven't been up there since, maybe the middle of April."

It should be noted that some grandparents said that they were never asked how they were doing. If they were asked, it was in a casual social way, rather than a deep and genuine inquiry into their well-being and emotional state.

There is an issue of timing here and who should be attended to in the moment. Some grandparents did not want the focus on them, enjoying the kindness, comfortability, friendliness, and acceptance of the staff at the hospital but not wanting to be the focus of care, appreciating that "it's all about the kids . . . They were there for the kids totally. Sometimes it was personal, I mean you get to know these doctors and nurses . . . a little banter and stuff . . . but it's all about the kids and it should be." When asked if they were ever asked directly by anyone in the hospital or clinics about how they were doing, there were negative responses to the question but also an appreciation for why:

There was none of that and that's not their job and I didn't expect that from them . . . they treat the kids and they were immensely . . . they were the best thing I've ever seen. I'm so impressed . . . I think they are the most wonderful people in the world.

Some grandparents, it should be noted, wanted to be asked: "You know have an actual person to talk to . . .

somebody to just come up to you and say 'hey, how you doing?'" Grandparents were also at times included in more formal ways such as family meetings and more informal interactions:

I can be there when the doctor talks. If (grandchild) is going into an examination room, I can go with her . . . I'm allowed to be in those discussions . . . the staff doesn't mind that I'm there . . . I never feel like I'm in their way . . . it's just always nice to be included.

Although we understood from the staff in the hospital where this study occurred, that there were attempts to organize gatherings for parents, grandparents, and other family members, such as Friday morning coffees in the playroom, the grandparents when asked seemed to think that they were good ideas but had not heard about them.

From the grandparents' perspective, there was overall satisfaction about their treatment as a part of the family: "They were so like family by the time you're done." Basic, kind, and respectful care is important and, for the most part, seems to have been experienced by the grandparents in this study. We do believe, however, that research of this kind obligates us to move practice ahead, and to offer some utility or actionability about it. We need to learn from the grandparents what more can be offered than acknowledgment and recognition.

So What?

The utility and actionability of human science research lie in the ways that understanding experience can make changes in practice. Out of this research, some possibilities or implications for practice emerge. These are discussed more thoroughly in Part 2 of this study but include possibilities of support groups, information brochures, connections through internet contacts, family meetings that include grandparents, and systemic awareness and policy changes. Ultimately, the most important thing we recommend from this research is the acknowledgment of and communication to grandparents that they matter.

Although some grandparents asked for direct access to the health care team in the absence of the parents, we acknowledge that this is a complex suggestion, for it has to be considered that some parents would not want their parents involved or intervening in this way. Furthermore, there are legal restrictions to what information the health care team can relay to persons other than the legal guardians. As much as we have discussed the protectiveness that grandparents feel in this whole experience, it needs to be remembered that children may feel protective of their parents as well. There are times when children want to, and do, filter information that is delivered to their parents. There is a caution here in this research that we do not fall into a temptation to romanticize grandparents. There are times

that they are, or can become, a further burden for parents and the complicating worry about them may be more than parents can endure during this time. It seemed that the grandparents in this study recognized that this was the case and many attempted to shore their burden alone for this very reason: "They've given us support. I think it's been a two way street. They could see that we were sort of distressed."

Process of the Research: Therapeutic Value of This Kind of Inquiry

From the point of contact with potential participants, it was apparent that, for many of them, there was a story that had not yet been told. This retelling of the events had a tone, not of a medical narrative though medical explanations and language were woven in, but the narratives held more of an accounting of what they recalled, experienced, did, felt, and heard around that time and experience. There were stories about waiting for diagnosis, surgeries, results, or treatments. At times, there was some embarrassment about the level of disclosure and the amount of emotion expressed: "I might be embarrassed about how much I've said, but it had to be said. You know, I can't white wash it." An experience such as childhood cancer cannot be whitewashed; it is there in all its color and complexity, pain and suffering. Even years after diagnosis and sometimes cure, the feeling and the pain arose again with intensity in the interviews: "I find it hard to talk about . . . shit (crying) I don't know why I do this. It's been 7 years since he's been cancer free and we're sitting here with tears in our eyes crying about it." This came from a grandmother speaking of her grandchild who was diagnosed 9 years ago with a very curable cancer and had been cancer-free for 7 years: "We had no idea how much we had bottled up inside."

This is the first time in nine years anybody said "how did you feel?"

Let me tell you something, this study is a great thing. We were really hoping to help. I mean part of the reason I agreed to do this was selfish as well . . . we haven't talked about this . . . we haven't gotten closure . . . maybe closure is the wrong word but to finally resolve that time in our life where we can put it and talk about it without leakin' (laughing).

Interviews of this nature are powerful and, although their intent is neither to create more suffering nor to be therapeutic, those who volunteer for such studies do so for many reasons. Some of the reasons are about wanting to make a contribution, about wanting the experience to count for something, about wanting to help others, but there are

times that people volunteer because they have a story that needs to be told and heard. It has been shown through research and clinical literature that research that involves talking about difficult subjects and suffering does not retraumatize people; rather, it is an aspect of healing (Moules, Simonson, Fleiszer, Prins, & Glasgow, 2007).

Summing it Up: Turning Into the Curve

You'll take a map, of course, and keep it open in front of you on the dashboard, though it won't help. Oh, it'll give you mileages, boundary lines, names, that sort of thing, but there are places yet where names are powerless and what you are entering is like the silence words get lost in after they've been spoken. What you're looking for are the narrower, unpaved roads that have become the country they travel over, dreamlike as the spare farms you catch in the corner of your eye, only to lose them when you turn your head. The curves that happen without warning like a change of heart, as if, after all these journeys, the road were still feeling its way through.

—Bronwen Wallace, 1985, p. 20

You can sum it up in about six words . . . When you find out your grandchild (starting to cry) has leukemia and it's AML . . . your heart is gone. Your heart is totally destroyed.

The arrival of childhood cancer is a curve that happens without warning. There will be maps given, treatments and studies described and initiated, information, statistics, care, procedures, good news, and bad news. None of these, however, even if kept "open in front of you on the dashboard" do really help. They may give "mileages, boundary lines, names, that sort of thing" but they do not really prepare anyone for what the experience will be like because there *are* places where names are powerless and words are lost in silence:

I'm living it. I'm living, breathing, eating, sleeping . . . the disease.

Grandparents live, breathe, eat, and sleep the disease when their "family has cancer." In this study, we learned

of the complexity of what grandparents experience and how, with dexterity, grace, and love, they navigate how to best be there for their children and grandchildren. They learn to bear the burden of doubled worry, knowing silences, and lives on hold, as they live out a juxtaposition of their own pain and needs with wanting to take care of the pain and needs of their families. This research is consistent with the results of studies of grandparents' experiences of other childhood illnesses, and it is difficult to discern if there is a difference between the pediatric oncology world and the general world of pediatrics. This study also does not inform us of differences within the childhood cancer spectrum. These gaps in understanding serve as invitations to future research.

The health care system has an obligation to acknowledge this particular family role and, in varying ways, assist in mitigating some of the suffering that grandparents experience as they "after all these journeys" are finding their own roads through. In the same way that grandparents offer advice to other grandparents to "be available" and "to just be there," at the very least, acknowledgment directly to grandparents that their suffering has been seen and heard is the first place to start.

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