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Grandparents' Experiences of Childhood Cancer, Part 2: The Need for Support

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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 a hermeneutic–phenomenological tradition, as guided by the philosophical hermeneutics of Hans-Georg Gadamer. In Part 1 of this report, interpretive findings around worry, burden, silence, the nature of having one's universe shaken, of having lives put on hold, and a sense of helplessness were addressed. In Part 2, the authors discuss interpretations related to the notions of support, burden, protection, energy, standing by, buffering, financial shouldering, and relationship. The study concludes with implications that the grandparents in the study bring to pediatric nurses in their practices with families in pediatric oncology.

Keywords

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

As described in Part 1, the topic of the investigation of this study is the extension of childhood cancer to all levels of the family system. The parents, or other adult guardians, are, in most situations, the family members most intimately involved in every aspect of a child's treatment, whereas other family members may have less clearly defined roles. In this study, we address the experiences of grandparents of children with cancer and uncover a wide variety of effects that began unfolding with the first shattering news of the diagnosis. These effects were played out in numerous different ways throughout the family systems; as a part of the family system, the grandparents were significantly affected.

One of the themes that emerged from this study was that of support within families, raising questions such as, "Who provides supports to whom, and what forms do these supports take?" This theme, in turn, brings forth questions for health professionals of how and when we can most effectively support the family system of a child with cancer. When we stop to ask about the involvement of grandparents within each unique family system, we can begin to discern not only where grandparents may benefit from support but also how much support they may be already providing within the family. The goal of professionals should be to try to help optimize family systems functioning under the stresses of a child with cancer; this

need not require significant interventions, or indeed any interventions beyond showing an intelligent interest in the family, including grandparents.

In this article, we explore some of our findings about the need for support and offer suggestions for practice, based on a principle of recognizing the strengths that exist within families rather than a professional-centered model of assumed need for intervention. The background to this research, literature review, and study design are described in detail in Part 1 (Moules, Laing, McCaffrey, Tapp, & Strother). In this article, we focus on an extension of results and implications for practice.

Interpretive Findings

The grandparents in the study, as one might expect, expressed a wide range of responses to having a grandchild with cancer, responses that changed over time. The

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variable responses of the grandparents reflect the course of the cancer and its treatment and their place and involvement in their family networks. For the purposes of the current article, we have been selective in focusing on the responses that had to do with how the grandparents perceived their roles within family systems, the supports they felt they needed, and the supports they were able to offer.

Loving Double, Protecting Double, Worrying Double

Though grandparents expressed differing experiences of the impact on them of the child having cancer, they also identified an awareness of having a particular position as grandparents.

It's like your own child but a step past that . . . I think it's worse . . . I'm sure it's worse for parents but . . . still . . . You're getting a double dose because you suffer for your kids and also the grandkids. You have more to worry about . . . instead of worrying about your kids; you got two generations to think about.

Alternately, some grandparents thought that they were protected from how bad it must be for the parents, thinking that the generation removed them from some of the pain.

It's [experience of parents] a lot, lot worse than the experience of a grandparent. You're a little bit removed. . . one generation sort of thing. You're a little bit further away . . . much more devastating I think as a parent than a grandparent

The sense of a doubled impact for one grandmother led to an acute sense of wanting to protect her own child.

It's a double, it's a double hit. Because you don't want, as a mom, your kids to have any pain; you can't protect them all the time . . . to see him and them going through, it's unbelievable.

First of all, you're going there because it's your grandson and then there's your daughter and her pain and suffering.

There is necessarily a sacrifice that comes with parenting and a fierce protectiveness that came with an advocacy and defensive role.

I've been accused of being a female lion who protects her cubs.

Sometimes this meant protecting from the interference of others, including well-meaning relatives, friends, and

associates. The position of the grandparents within the family system thus often seemed to carry implications for providing support through a protectiveness, at once closer than anyone else to the parent-child unit but at the same time removed from it.

"It's the Right Thing to Do": Being Strong and Protecting From Burden

One of the dilemmas for grandparents was brought about by the belief that they did not want to burden their already overwhelmed children who were struggling with having their own children facing, undergoing, and being treated with cancer. This assumption is not an erroneous one; in fact there is a kindness, generosity, and caring shown by the grandparents in withholding their worry, recognizing that it was enough for the parents to worry about their own children, much less bear the weight of worry of the grandparents. As one grandmother told us, "I could hear it in her voice; it was like 'mom I can't have you getting upset about it' . . . and I realized I kind of burdened her." When the grandparents shared their worries, they recognized that it shifted the parents' need to what we have called protecting from the middle—caring and protecting for the child and the grandparent.

Thus, supportiveness could take the form not only of active helping but also that of tactful withholding. The children's parents needed their parents there but needed them to offer strength and support not worry. "She's got enough on her plate . . . to deal with, without having Mom get upset . . . she needs me to be there to help her stay strong." One grandparent spoke of her daughter's need for her to be strong.

Don't cry around me, don't come here and bring me your sad news, because I can't handle it. So, if you're going to cry, leave the room and come back and be happy. You can't break down in front of them . . . you can't feel sorry, or you can't say, you poor thing or why did this happen to you or I can't believe this is happening.

Not burdening takes work and effort on the part of the grandparent.

A lot of effort goes into trying to make sure that she doesn't have to worry about how I'm doing. I try to be careful . . . to be careful about what I say . . . and it's hard . . . I've been scared too.

We can't dump our worries, and our fears, and our problems . . . they've got way more than they can handle already.

I'm supposed to be the strength.

This strength could be expressed in a clear recognition of needing to take care of their children. Always parents themselves, the grandparents stepped in to care for the parents; the grandparents' hearts broke for their children *and* their grandchildren.

Some of the families were saying they had to get nannies because they had other children . . . They [the nannies] look after the children but they don't look after the parents of the children . . . the parents aren't getting support.

You know at night when you leave the hospital, She felt alone, I think [crying]. You know we'd all go home and she has to stay on that little cot.

Grandparents have a history of knowing how to love and care for their children and how to be there for them. "Well, honey, like I say, we had to do it once when they were growing up. We had to be there for them." This parenting and caregiving is familiar; they have done it before and know what it is like to be there unconditionally for their children.

As a grandparent or any kind of parent, your aim or goal in raising your children is to protect them and make things better for them.

The forms of caring and support, however, could not be foreordained. There is a sense in some of the grandparents' comments of families exploring this new unasked-for experience together. For some grandparents, there was discernment in recognizing and honoring their child's strengths while knowing when to step in.

As I watched my daughter and son-in-law get stronger and stronger, I kind of got strong with them too and was prepared to sort of . . . be there when they did fall apart which they did every now and then.

In an interesting twist on this notion of burden, some grandparents spoke of the issue that their children were asking more of them emotionally, wanting to see more emotional expression.

Sometimes I feel that she wishes I could show a little bit more emotion, I may be so stoic that I may appear not to care. So, every now and then I have to remind her that, yes, I am worrying like them and thinking about [grandchild] an awful lot. Then I think she feels OK for a while . . . for a few weeks that kind of takes care of things and then she doesn't have to worry about me . . . anymore for a while [chuckling] . . . she worries if I'm as worried as she is. But I think [on the other hand] she is

relieved that I'm there and I'm not dumping on her as I could and she doesn't dump on me either.

Worry was not a universal feeling for all grandparents, whether they consciously avoided it or it was not in their natures to give into worry. For some, it was about pragmatism and doing what needs to be done.

I don't think we were worried. You sort of take a day at a time and you just do what needs to be done at the time. We're not worrying people, I guess. We're concerned, yes . . . and you hurt for your grandchild. You hurt for her and her Mom and Dad . . . but as long as we could be involved I think that was therapy for us.

The Irony of Inverse Energy

There was a wide range of experience of how much grandparents felt able to offer. For many of these grandparents, there was an appreciation of the irony of needing energy and health most at a time when they felt a decline in it. This mirrors the "out of sync" nature of childhood cancer.

I think because I don't have the energy to do more. I don't have the energy or the health to do more . . . because there's so much more that needs to be done and you just don't have the energy to play with the kids . . . do more around their house . . . I just can't anymore . . . it's been a shock to me that I don't because I always thought I was very healthy and strong . . . it's like whoa, I just run out of energy here. I can't do anymore.

On the other hand, some grandparents found freedom and resources to be available for their children and families in a way they would not have had earlier in their lifetimes.

. . . different part of life right, because I've got the time to go up there . . . good health, and I've got some money.

Not all grandparents are going to be the age we are, cause there are a lot of young grandparents in their 50s and I think it might be a bit more difficult because they're at a different stage with their employers and what not . . . if you're a young, young grandparent versus one that's at that retirement age, where you can say well it's not really that important if I work if need be . . . I mean I would quit if I had to.

It is important to note the variation among grandparents in terms of time, station in life, money, availability,

and health. All these become factors in the experience of contributing to the family's response and underline that stereotypical expectations around grandparents may well be confounded when health care professionals open themselves to the unique constitution of each family.

Standing By: Bystanding, Buffering, and Balancing

In this sense of helplessness, grandparents learned to stand by, while standing back, buffering, and balancing for, often, the whole family. This is a delicate balance of roles, behaviors, feelings, and actions that required judgment and that took a toll.

You're a bystander . . . but you've involved. I think that's what the grandparents do. They're a bystander but then they're so involved in it but you still have to be that bystander.

I probably do put myself as a second class citizen because the parents are the primary people and I kind of keep that in mind. I put myself there.

I remind myself that I'm not a parent because my nature is to butt in and so I step back so I don't butt in too much. I don't act if I'm in charge.

You stand on the sideline and pray.

In standing back, however, the vantage point allowed grandparents to protect and buffer their children from many things.

The phone would be ringing every five minutes . . . people want to know what's happened and you're rehashing and telling everybody so it's almost like you were buffering her because she couldn't talk about it without getting upset.

I don't consider it a burden being on the standby . . . I'm excited and delighted when I can do something because as a grandparent you feel kind of useless after a while.

Another form of buffering came from protecting their children from the insensitivity and intended "helpfulness" of others and of even their own need to reassure their child.

She didn't want you to say, oh it's going to be fine . . . I mean she would get angry . . . she didn't want to hear platitudes. You couldn't just say it was going to be fine. You had to talk about the realities of what may or may not happen.

This required a balancing act of juggling hope and positivity with reality and often led the grandparents into questioning for themselves if they had said or done the "right thing." "You question yourself: Did I say the right thing? Like did I do the right thing?"

Buffering was not contained to just buffering things for their children but sometimes also for their spouses. "My husband . . . worries . . . so I can't be telling him because he'll get . . . you know I have to . . . state the facts in a positive way and just survive . . . we're all in survival mode." For some, it meant running interference with other family members who had "advice" on how the parent[s] should be handling things. "Whoa guys, I haven't walked in my daughter's shoes. I've never had a child with cancer. I've had a grandchild. So I found myself running interference between the rest of the family."

In support of their children and families, there is an aspect of balancing and walking tightropes, tightropes that are pragmatic, conversational, and emotional.

Sometimes she [daughter] had to talk . . . you want to let somebody get it out but you don't want them to be overly morbid, overly pessimistic. You wanna try to keep things good, but you also got to let them say what they gotta say and feel the way they feel so it's . . . a real conversational tightrope and an emotional tightrope . . . Am I doing the right thing? Don't piss off the doctors. Don't take any chance in jeopardizing the treatment. Don't get him [grandchild] worried. Don't get her [mother] worried. Don't . . .

Again, there was an aspect of knowing one's place and recognizing that the sidelines were where they should be and recognition that what the parent was going through was something unimaginable.

You can't be pushy . . . You can't go in and take over.

So, in a way you're almost protected as the grandparent. It is your child that is in the front line.

I'm the backup.

I'm on standby . . . gave the role to myself . . . because I'm the closest and she relies on me. She'll turn to me when nothing else works, and I'm really, really glad to be there, to step in.

Being on the sidelines and standing by implies aspects of waiting, standing beside, and being ready to step in. Some grandparents waited to be called but wished to be more active.

I'm delighted when they do call on me to help. I think if I had my own way I'd be a bit more of a nuisance and I'd be on their doorstep all the time . . . but I stay away, just to give them their private time.

These comments reflect the intricacies of families and grandparents' sensitivities in working out helpful roles for themselves.

The Whole Family: Changing Relationships

When families are joined through relationship, there typically needs to be negotiated and renegotiated acts of making room for in-laws and extended families. Family boundaries and other aspects of the family system change over time and family development but no more than in the face of illness (Wright & Leahey, 2009). Illness of any kind can change relationships in families; childhood cancer is no exception. "It started affecting my other relationships. Like with my mother, with my sister." Some grandparents noted a change in their relationships with their own children. In speaking of her son, one grandmother stated, "Very much closer . . . He'd never phone [before] and now when goes to hang up he always says, I love you Mom and Dad. Always you know." One family who saw themselves as a close family before found that their relationships with their family members "strengthened what was already there."

We know through the literature and clinical experience that illness can strengthen relationships, but we also know that it can unsettle, disrupt, and even destroy them. Not only are families with good relationships affected by childhood cancer; families who experience troubled or distant relationships are also not immune to childhood cancer. It is perhaps a limit of this study that possibly the grandparents who volunteered for this study represent only particular kinds of families with close or strong relationships.

Grandparents' Relationships with Each Other

The relationship of grandparents with each other also came up as another element in the complex crosscurrents of needing, finding, and providing support.

It's been difficult between the two of us because . . . we're not the best communicators anyways, so when he gets really short and he doesn't mean to, but that just his personality . . . and I was I have to admit getting really curt.

For some, this stress played out in their workplace. One grandparent found herself being "curt" at work and

was called in, and a shift in her behavior was noticed by her husband.

I was called in and told I was a bully . . . then it was time for performance review and they downgraded my team playing and communication skills . . . so that was a slap in the face, and they made me apologize to the staff . . . it was better if I wasn't at work . . . [Husband] was saying "you're awful sharp". And I was sharp and I couldn't control it. And for me to be sharp, I don't usually do that, do I dear? . . . No . . . She takes all my guff but this last little while she wasn't taking it anymore.

When tension between the grandparents existed, the parents sometimes felt this. One daughter told her parents that unless they were nicer to each other "we might not be able to come back . . . and that just broke our hearts . . . little sit down the two of us and say this cannot continue. We've got to be able to get that under control."

Some grandparents found their strength and support from within their own relationship.

He understands totally and he's right there . . . a lot of times; I don't have to explain, he understands. I can't see it being detrimental at all . . . we are way more tired, physically and emotionally.

We've always talked a lot about everything . . . we have our glass of wine before supper and we've always had that happen . . . we sit down and have a drink and we talk.

My strength came from [wife] and I think her strength kind of came from me, I mean we kind of supported each other through the whole thing . . . did different roles in the family too.

Support comes in many ways. Many found support from church, faith, prayer, or God in ways so that they "never felt alone. I have a very supportive group of friends; where my family is not supportive, my friends picked me up when I needed it." Support came in different forms such as the flexibility of employers in accommodating hours. "If I have to take time off, there's not a problem. I just phone and say I can't come."

Although some people had support from people at their places of employment, friends, community, pets, immediate family (sisters, brothers, church), the majority of grandparents in this study found their greatest support from their spouses, even when the spouse was not the parent of the child and was therefore a step grandparent. "If you've got a husband or a wife to talk to or cry to or whatever makes an awful difference."

Some grandparents, however, felt they had no one: "I can't let it out to [partner] and I can't dump on [daughter] . . . I can't be like this [crying] with daughter." The other social reality is that not all grandparents are partnered or have strong social supports. For some, their biggest support was their children, and suddenly the roles are reversed, and the grandparents bear the weight alone.

Financial Weight and Life Changes

In a similar way to social realities of relationships, not all grandparents have the same means and resources financially. Cancer has a financial impact, and its impact extended to the grandparents in varying ways. The impact of finances and life changes was not felt by all. "I'm not concerned about finances . . . my life just hasn't changed very much . . . except that I try to make myself more available than I used to"; however, most of the grandparents recognized that it was a factor that had to be considered.

After the disease, the next biggest impact on families is financial . . . it falls on the grandparents too to help financially because parking at the hospital is expensive, drugs are expensive . . . you've constantly going out buying things to bring in . . . it's such an expense you haven't counted on.

I had the ability to work my hours around or change things around so I could be available for a lot of the visits . . . You have to change. We couldn't stay in the same routine . . . I worked overtime and made other time up.

As far as financially, we don't lack anything, you know, and if we have to fly back and forth, we fly back and forth . . . but if you were a person, an older person alone with our situation, it could be really hard.

Illness affects family structure, development, and functioning (Wright & Leahey, 2009) at practical, spiritual, emotional, physical, and relational levels. This study offers some of the complexity of the impact on the first generation of most family systems. In the midst though, of all the heartbreak, the holding, the worry, and the silence, grandparents spoke very loudly about the pride they experienced in watching how their own children shouldered having a child diagnosed with and treated for cancer.

So What?

The utility and actionability of human science research lies in the ways in which understanding experience can make changes in practice. Out of this research, some pos-

sibilities or implications for practice emerge. Of these suggestions, it is important to bear in mind that this does not necessarily mean adding new commitments to already overloaded health care systems but rather a change of perspective and perhaps changes at practice and policy levels.

Support groups. The first response around psychosocial needs of populations of people often is to create support groups. Many of the grandparents instinctually said that a support group would be good but also readily admitted that they might not have joined one. This may reflect the complex relationship between supporting and being supported that is suggested by our data. The issue of support groups is a more complicated consideration than what is automatically assumed about them. Moules, Simonson, Fleiszer, Prins, and Glasgow (2007) explored some of this complexity related to grief support groups, concluding that although they are useful for some, they are not a fit for all people.

Support groups . . . maybe . . . for somebody who doesn't have anybody to talk to.

A class that's helpful, where you could go and share with other grandparents.

If they want to help grandparents, maybe they should have something for them . . . I don't know what . . . something we could have gone to. The last thing they [parents] need is a crying grandma . . . so if there is some place you can go with other people and say you know, just talk about it.

As mentioned, although the participants were quick to suggest support groups, they also admitted that they may not have participated in them. "I don't know if other grandmothers are like me, but I don't know if I would have actually taken part in something like that either because it opens things up more." Perhaps there are times when people need to contain, to keep things closed and hold on and not open up, and it is only the gift of time that allows the portal. "Maybe now would have been the only right time to be able to do this [9 years later]." When asked if something had been offered, one response was "I never thought about any of that . . . until long after." Perhaps during times of crisis, when the earth and universe has been shaken, it is enough to hold steady.

Some grandparents suggested online sites, such as Twitter, as a means of support and a variation of a group.

A quick little site people to go to that Twitters with an question and an answer back . . . You Tube . . . you can do a little clip in nothing flat and throw it on and yet your message on and it goes all over . . .

you can sent to all your friends and if you know of someone who's a grandparent off it goes.

Some grandparents are quite savvy with computers, and, in an interesting counterpart to young people, it is, for some, becoming their lifeline of connection. This is not the case though for all grandparents. One grandmother discovered our study in an online search for a support group for grandparents. She believed a support group, even an online one, would be helpful, but she also offered the suggestion that it would be useful if "the grandparents would be able to communicate with the docs directly and have direct access to the health care team." This is an interesting and again a complex suggestion, for it has to be considered that some parents would not want their parents involved or intervening in this way; parents might see it as their role. As much as we have discussed the protectiveness that grandparents feel in this whole experience, it needs to be remembered that children feel protective of their parents as well. There are times when children want to, and do, filter information that is delivered to their parents. As mentioned in Part 1, 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."

System awareness and policy level change. One recommendation that arises from this research is that support does not always have to come in an emotional, therapeutic way. When there is a more system awareness of the impact of this experience on grandparents, there is the opportunity to advocate for systemic change and even for policy and pragmatic change. Some of the participants found support from their employers in flexibility of work or time off work. Many work places and employers were very accommodating and supportive. "We were just on call [for their children] and work was very understanding all the way through." One grandmother even suggested that employers have programs for grandparents in these circumstances.

Needing time off work to get support . . . teach them at management levels . . . provide information to employers, whether it's received or not is a different story. I think most employers think that this is just a way of getting out of work. Look at how your employer treated you [husband to wife] . . . they treated it like it was just some made up story . . . saying they didn't think you should be talking

about it and when something traumatic like this happens in your life, that's what you want to do, you want to talk about it.

It was suggested that if an institution is "family centered," then it would be the simple things that would demonstrate the nature of family centeredness as acknowledging and supporting. These things might be institutionally bound, but, for example, one grandparent emphasized how helpful parking passes would have been: "More support for families . . . even parking passes should be free if your child is in the hospital after so long."

Information. It was apparent that, however it was delivered, the greatest need of the grandparents was information. "The biggest thing back then is that we knew so little. If there had been more information and more options and there was nowhere to talk." It was also suggested that there was often no one to talk to.

It would have been nice if we could have gone somewhere and dumped . . . a psychologist or something.

Maybe tell people more . . . the doctors would discuss everything with everybody, but you're just more or less ignored. You're just there . . . everything we learned we learned from [son]. Like a doctor hasn't got time to talk.

When asked if they felt included in the supports that were provided by the hospital or health care team for the parents and child, the general response was as represented in this comment: "Mmm, no. No, I don't think so, no."

Many grandparents suggested a brochure. This may sound simplistic but it might be about written and visual acknowledgment. The message in a tangible and visible document gives public testimony to the fact that this experience matters to grandparents as well, and it serves to symbolically break the silence and invisibility of grandparents.

A brochure or something that says it's okay for grandparents to guide their kids.

Maybe even a pamphlet at the [hospital] that says: Here! Other people are going through this.

An example of this possibility exists through a very polished leaflet available online and published through the UK Children's Cancer and Leukaemia Group, Leicester (Ablett & Ballard, 2005), and made possible through a family donation. The leaflet is a 24-page document titled (in boldfaced letters) *Grandparents: A Guide for Grandparents of Children and Young People With Cancer*. It includes topics such as "Early Questions," which includes addressing helplessness; "How You Can

Help," which includes supporting sons and daughters and grandchildren; and "Support for You," which addresses how grandparents can ensure they get what they need. There are additional contacts and books listed. The information that arises from this current study could well serve as the basis for a similar type of publication that makes clear that grandparents matter.

[Let them know] that it is a double whammy for them . . . and to know the pain that they are going through . . . even to give them a handout that said ok you know if at some point you need

Conclusion

One of the privileges of undertaking qualitative research is having the opportunity to see the world from another's standpoint, and this allows a beginning appreciation of the suffering of others and their capacity for endurance and ingenuity within this suffering. In the case of the present study, the keenness with which grandparents were able to share their experiences, and the variety of those experiences, served as potent reminders that older adults can be resourceful and adaptable in response to a family crisis such as childhood cancer, in which all family members are implicated. This is not to discount that there are families, and grandparents, who do not have good coping resources to begin with, nor that such a major point of stress within a family system can be felt in unpredictable ways. When it comes to the issue of grandparents and support, however, the results of this study lead us to the conclusion that the first responsibility of health care professionals is to work with families from a stance of respectful curiosity, to ask and to find out who in the family has what resources and how these can be most helpfully applied in a situation as challenging as childhood cancer.

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Bios

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