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ORIGINAL ARTICLE

Grandparents of children with cancer: a controlled comparison of perceived family functioning

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Abstract

Purpose Grandparents can be profoundly emotionally affected when a grandchild is diagnosed with cancer. They also often provide invaluable support for the family (e.g., caring for the sick child and/or siblings). Multigenerational family functioning may therefore change. Limited research has assessed grandparents' perspectives after their grandchild is diagnosed with cancer. In this study, we aimed to (1) assess differences in perceived family functioning among grandparents of a child with cancer and grandparents of healthy children and (2) assess the cancer-specific and demographic factors related to perceived family functioning in grandparents of a grandchild with cancer.

Procedure Grandparents of a child with cancer ($n = 89$) and grandparents of healthy children ($n = 133$) completed the general functioning, communication, and problem-solving scales of the Family Assessment Device. We used multilevel models with a random intercept to detect (1) between-group differences and (2) identify factors related to perceived family functioning among grandparents with a grandchild with cancer.

Results Grandparents with a grandchild with cancer reported poorer family functioning than grandparents with healthy grandchildren. Among the grandparents with a grandchild with cancer, impairments in family functioning were correlated with fewer years since diagnosis, providing care to their sick grandchild and/or siblings and living far away from the sick grandchild.

Conclusions The detrimental impact of childhood cancer likely extends beyond the immediate family members. Including grandparents in interventions—beginning at diagnosis—to reduce distress and increase cohesion for families of a child with cancer is warranted, particularly for grandparents who provide care to their sick grandchild or siblings.

Keywords Childhood cancer · Grandparents · Family functioning · Communication · Problem-solving

Grandparents can be an invaluable source of support for the family when a child is diagnosed with cancer [1–3]. The sparse literature on grandparents' experiences of a grandchild with cancer reveals the unique, difficult, and complicated position of grandparents [4]. Grandparents may "put their lives on hold" to become more involved in the family [5] and feel that it is their "duty" to provide support to their adult child and grandchildren after diagnosis [6]. Support may take the form of providing emotional comfort, caring for the siblings of the sick child, and accompanying the child with cancer to hospital appointments [5–7].

Though grandparents may become more immersed in the family after their grandchild is diagnosed with cancer, some grandparents report feeling like "bystanders" to the family, especially with regard to medical discussions and decision-making [8]. Not wanting to burden their family with their

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own distress, grandparents can be reluctant to ask for more information and communication from their children (the patient's parents), hiding the toll that the child's diagnosis has on their wellbeing and neglecting their own emotional needs [5, 6]. Parents of a child with cancer may become sensitive to perceived criticism from their own parents after diagnosis, which can lead to conflict [5]. Grandparents may withdraw from the family in order to avoid or resolve this conflict [5].

The above findings suggest that family dynamics, particularly communication and conflict resolution between grandparents and the rest of the family, may change after a child is diagnosed with cancer. Despite this, limited research has assessed the grandparent perspective, particularly with regard to their perceptions of their family. What has been published reflects that grandparents may become uncertain about how to help and communicate with their child and grandchildren after diagnosis [4], which in turn may affect how they interact as a family [9]. In the general population, grandparents who feel uncertain about their role within the family report poorer family functioning than grandparents who perceive they have a definite role [10].

Research regarding childhood cancer and family functioning has typically focused only on the nuclear family and has been garnered from the parent and survivor perspective. Results from these studies reflect varying degrees of family functioning, from perceived reduction in family conflict, to no difference in family functioning in comparison to control groups, to higher family conflict than controls [11–14]. One factor that may help explain this inconsistency is the amount of time that has passed since diagnosis. Parents report that, on average, the first 6 to 12 months after diagnosis is the most difficult for familial relationships [14, 15]. Similarly, siblings most commonly report family disruption (including loss of routine and attention) 6 months after diagnosis, with disruption reducing by 18 months post-diagnosis [16]. As such, the impact of childhood cancer on family functioning appears to be most profound in the early months after diagnosis. However, it remains uncertain whether this is the case for extended family functioning, including grandparents.

Demographic factors may also influence perceptions of family functioning. Age, marital status, and gender have previously been associated with perceived family functioning and wellbeing, albeit inconsistently, when a family member is diagnosed with cancer [17–19]. For example, a meta-analytic study found that mothers of children with cancer reported higher family conflict than controls, but this difference was not found for fathers [20]. While these factors have been commonly studied in nuclear families, very little is known about how demographic factors relate to multigenerational family functioning, especially from the perspective of grandparents.

In the current study, we therefore aimed to assess:

1. Whether perceptions of multi-generational family functioning differ for grandparents of children with cancer and grandparents of healthy children; and
2. Whether cancer-related factors (e.g., years since diagnosis) and demographic factors (e.g., distance from grandchild, grandparent sex) relate to multi-generational family functioning for grandparents of a child with cancer.

Method

Participants

Participants included grandparents of a child with cancer and control grandparents. Biological and step grandparents who had a grandchild aged under 18 years were eligible to participate in the study. Multiple grandparents from the same family could participate. There were no other eligibility requirements for the control grandparents. For grandparents of a child with cancer, the child had to have received cancer treatment in the previous 3 years.

Procedure

The study was approved by the SESIAHS Northern Network (ID 08/057). To recruit grandparents of children with cancer, we mailed letters to parents of all children treated for cancer at Sydney Children's Hospital between September 2013 and April 2015. In the letter, we asked parents to distribute the questionnaire to grandparents. We also recruited grandparents at an event hosted by three children's hospitals in New South Wales in which staff provided information about childhood cancer to families. In total, we invited 128 grandparents of children with cancer to the study. To recruit grandparents of healthy children, we distributed questionnaires at a preschool event for grandparents in Sydney and through two non-profit organizations: The Australian Country Women's Organisation and the Men's Shed. We invited 197 grandparents of healthy children.

Measures

Demographics Single items inquired about participant age, ethnic background, sex, and marital status. For grandparents of children with cancer, the questionnaire also asked the age and sex of their grandchild with cancer, how many siblings the child had, how far away they lived from their grandchild, when their grandchild had been diagnosed with cancer, and

what the diagnosis was. Caregiving duties were determined with the single item "Do you provide care for anyone in your family or wider community?" which was followed by the open-ended question "If yes, would you mind explaining your caring role in more detail?" For the purposes of this paper, only those who indicated that they provided care to their grandchild with cancer or the siblings were classified as "caregivers."

Family functioning We asked grandparents how they perceived the multi-generational family functioning (including grandparents, parents of the child with cancer, the child with cancer, and the siblings), using the Family Assessment Device (FAD). The FAD is a 60-item scale with six subscales [21]. For brevity, we used three subscales which we identified in the literature as being particularly relevant to grandparents' experiences after a child's diagnosis. Specifically, we used the general functioning subscale (12 items measuring overall wellbeing of the family unit), the problem-solving subscale (5 items measuring conflict resolution between family members), and the communication subscale (6 items measuring perceived communication between family members) [21]. Respondents rate their level of agreement with each statement on a 4-point Likert scale from 1 (strongly agree) to 4 (strongly disagree). Scores are averaged to range from 1 to 4 and higher scores indicate worse family functioning [22]. The FAD has sound convergent and discriminant validity and strong test-retest reliability [21, 22]. Acceptable internal consistency [23] was achieved with the current sample for general functioning (α = .87), problem-solving (α = .83), and communication (α = .66).

Data analysis

We conducted all analyses with IBM SPSS Version 25. We produced independent *t* tests and chi-square analyses to test for differences between the two groups of grandparents on the variables. We chose to dichotomize distance from grandchild for all analyses, using the median as the cutoff (50 km), given the large range (0 to 1415 km).

With regard to answering the two research questions, some of the participants were grandparents to the same child (i.e., married/de facto couples or in-laws). In order to statistically account for the non-independence of grandparents' data, we conducted multilevel modeling using a random intercept which accounts for variability at the individual and family levels. Missing data was less than 5% for each of the family functioning variables and Little's MCAR test revealed that data were missing at random $\chi^2(5) = 3.01$, $p = 0.699$. We used expectation maximization (EM) to estimate the parameters in the models in order to preserve statistical power for the analyses [24, 25].

To address the first research question, we produced three multilevel models for the whole sample with general family functioning, problem-solving, and communication, respectively, as the outcome variables. The predictor variables were grandparent age, sex and marital status, and whether the grandchild had cancer.

To address the second research question, we conducted three multilevel models within the sample of grandparents who had a grandchild with cancer only. Again, general functioning, problem-solving, and communication were the outcome variables. We needed to restrict the number of predictor variables given the reduced sample size. We used years since diagnosis, distance from grandchild (less than 50 km vs. greater than 50 km), grandparent sex (male vs. female), and caregiving (grandparents who provided care to their sick grandchild or the siblings vs. grandparents who did not report proving care) as predictors in the models.

Results

A total of 222 grandparents participated in the study. Eighty-nine participants were grandparents of children with cancer (57 families; response rate = 69.5%) and 133 were grandparents of healthy children (105 families; response rate = 67.5%). Grandparents of children with cancer were on average 65.9 years (SD = 7.7 years) and were mostly female (62.9%; Table 1). Grandparents of healthy children were on average 67.3 years (SD = 6.5 years) and the majority were also female (69.9%). One participant identified as Aboriginal or Torres Strait Islander. There were no significant differences between the cancer group and the control group on any of the demographic factors.

Research question 1

Table 2 displays the three multilevel models for the whole sample. Grandparents with a grandchild with cancer reported poorer general family functioning (95% confidence interval [CI] = .16–.51) and communication (95% CI = .07 to .34) than grandparents with healthy grandchildren. Group differences were not significant for family problem-solving (95% CI = − .02–.28).

Research question 2

The three multi-level models for the sample of grandparents with grandchildren with cancer are presented in Table 3. Grandparents reported worse general functioning (95% CI = − .14 to − .01), problem-solving (95% CI = − .09 to − .01), and communication (95% CI = − .11 to − .01) when less years had passed since diagnosis. Grandparents who provided care to their sick grandchild or the siblings reported worse general functioning (95% CI = .03 to .60) and worse communication

Table 1 Participant demographics and group comparisons

Grandparent characteristics	Cancer group $n = 89$	Control group $n = 133$	p value
Grandparent age, M (SD)	65.87 (7.68)	67.29 (6.54)	$t = 1.44$, $p = .152$
Grandparent sex, n (%)			$\chi^2 = 1.19$, $p = .276$
Male	33 (37.1%)	40 (30.1%)	
Female	56 (62.9%)	93 (69.9%)	
Marital status, n (%)			$\chi^2 = 0.73$, $p = .392$
Currently married or de facto	70 (78.7%)	109 (82.0%)	
Separated/divorced or widowed	11 (12.4%)	24 (18.0%)	
Did not respond	8 (9.0%)	–	
Grandparent ethnic background, n (%)			$\chi^2 = 2.88$, $p = .719$
Australian	64 (71.9%)	93 (69.9%)	
British	4 (4.5%)	8 (6.0%)	
New Zealand	1 (1.1%)	4 (3.0%)	
Greek	3 (3.4%)	2 (1.5%)	
Other	12 (13.5%)	23 (17.3%)	
Did not respond	5 (5.6%)	3 (2.3%)	
Survivor characteristics	$n = 57$ families		
Sex of child with cancer, n (%)			
Male	26 (45.6%)		
Female	31 (54.4%)		
Age of grandchild with cancer, M (SD)	7.18 (4.32)		
Diagnosis			
Leukemia	26 (45.6%)		
Lymphoma	5 (8.8%)		
Solid tumors	26 (45.6%)		
Years since diagnosis, M (SD)	2.71 (2.80)		
Provides care to grandchild with cancer or siblings, n (%)	9 (10.1%)		
Distance from grandchild with cancer, n (%)			
Less than 50 km	46 (51.7%)		
Greater than 50 km	41 (46.1%)		
Data unavailable	2 (2.2%)		
Number of siblings of the child with cancer, n (%)			
0	11 (19.3%)		
1	29 (50.9%)		
2	11 (19.3%)		
3 or more	6 (10.5%)		

Percentages may not total 100 due to rounding

(95% CI = .05 to .62) than grandparents who did not report providing care. Whether grandparents reported providing care was not significantly related to problem-solving (95% CI = − .08 to .44).

Distance from grandchild was not related to general functioning (95% CI = − .25 to .14) or communication (95% CI = − .21 to .12) but was a significant predictor of problem-solving. Grandparents who lived greater than 50 km away from their sick grandchild reported worse family problem-solving than grandparents who lived less than 50 km away (95% CI = − .35 to − 02).

Discussion

This study assessed whether grandparent-reported family functioning differed for those who had a grandchild with cancer and those with healthy grandchildren. We also aimed to determine whether cancer-specific and demographic factors were related to family functioning for grandparents who have a grandchild with cancer. We found that grandparents of children with cancer reported poorer family functioning than grandparents of healthy children, particularly in relation to general functioning and communication. Other than distance

Table 2 Multilevel models for family functioning with the whole sample

	Model 1: general functioning		Model 2: problem-solving		Model 3: communication	
	Estimate (SE)	*p*	Estimate (*SE*)	*p*	Estimate (*SE*)	*p*
Grandchild has cancer[a]	*.33 (.09)*	*.000*	.13 (.07)	.097	*.20 (.07)*	*.004*
Grandparent gender: male[b]	*− .14 (.07)*	*.034*	− .05 (.07)	.473	− .01 (.07)	.852
Grandparent age	− .01 (.01)	.445	− .01 (.01)	.061	− .01 (.01)	.481
Marital status: married or de facto[c]	− .10 (.11)	.392	− .06 (.11)	.590	− .11 (.10)	.291

[a] Reference group, grandchild does not have cancer; [b] Reference group, female; [c] Reference group, not currently married or de facto. *SE* standard error. Italic, significant

from grandchild, demographic factors did not appear to be related to family functioning. Instead, cancer-specific variables appeared to more heavily affect perceptions of family functioning. Specifically, family functioning appeared particularly impaired for grandparents in families where less time had elapsed since diagnosis and when grandparents provided care to their sick grandchild or the siblings, as well as when grandparents lived far away from their sick grandchild.

Grandparents with a grandchild with cancer reported poorer general family functioning and poorer family communication than grandparents of healthy children. The relationship between childhood cancer and family functioning has had mixed findings in previous research with parents [11–14]. The current study helps to elucidate this relationship to show that, from the grandparent perspective, childhood cancer may take a toll on general family functioning and overall family communication.

Grandparents in the general population perceive family functioning to be poorer when they experience greater family-related stress [10, 26]. Therefore, the distress grandparents' experience when their grandchild is diagnosed with cancer [4] may influence how they perceive the wellbeing of their family and impede their ability to engage with their family. Increased family conflict may be another factor contributing to grandparental perceptions of poor family functioning. Previous research has found that, according to grandparents, parents of the child with cancer can become sensitive to perceived criticism and may take their anger, fear, and frustration out on their own parents [5]. This may be one of the driving forces behind our findings. For instance, grandparents may feel as though they cannot openly communicate with their children and may censor themselves around their child in an effort to avoid conflict [5, 6].

Examining just the cancer group, we found that grandparents where grandchildren were more recently diagnosed reported poorer general family functioning, problem-solving, and communication, which is not surprising given the early stress of learning about the diagnosis. Research with other family members has found that the greatest impact on familial relationships typically occurs in the initial 6 to 12 months after diagnosis [14–16]. The current results show that grandparents appear to also experience the greatest disruption to family functioning when less time has lapsed since diagnosis. In their systematic review of childhood cancer and family relationships, Long and colleagues [14] describe a new sense of normalcy that tends to arise approximately 1 year after diagnosis. Families report that while they may never be the same as they were before the diagnosis, with time, family members find new ways to communicate with and relate to each other [3, 14, 27]. Over time, grandparents may also develop this new sense of family normalcy, though longitudinal research is needed to further explore this.

We found that grandparents who provided care to their sick grandchild or the siblings reported poorer general functioning

Table 3 Multilevel models for family functioning in grandparents of children with cancer

	Model 1: general functioning			Model 2: problem-solving			Model 3: communication		
	Estimate (SE)	*p*	95% CI	Estimate (SE)	*p*	95% CI	Estimate (*SE*)	*p*	95% CI
Years since diagnosis	*− .07 (.03)*	*.017*	*− .14 to − .01*	*− .05 (.02)*	*.044*	*− .09 to − .01*	*− .06 (.02)*	*.012*	*− .11 to − .01*
Distance from grandchild: less than 50 km[a]	− .06 (.10)	.579	− .25 to .14	*− .19 (.08)*	*.026*	*− .35 to − .02*	− .04 (.08)	.605	− .21 to .12
Caregiver to grandchild or siblings[b]	*.31 (.14)*	*.033*	*.03 to .60*	.18 (.13)	.180	− .08 to .44	*.34 (.14)*	*.022*	*.05 to .62*
Grandparent gender: male[c]	− .13 (.08)	.102	− .29 to .03	− .08 (.08)	.275	− .24 to .07	− .06 (.09)	.493	− .23 to .11

[a] Reference group, distance from grandchild: greater than 50 km; [b] Reference group, does not provide care to sick grandchild or siblings; [c] Reference group, female. *SE*, standard error; *CI*, confidence interval. Italic, significant

and overall communication than grandparents who did not report providing care. While the effect sizes were large, the proportion of grandparents in the current study who reported providing care to their sick grandchild or the siblings was relatively low so these results should be interpreted with caution. Further research is needed to confirm whether family functioning is disrupted when grandparents have to take on a caregiving role after their grandchild is diagnosed with cancer. Beyond pediatric oncology, when grandparents take on a caregiving role to their grandchildren, grandparents report greater daily intra-familial strain [10], which in turn may reduce family functioning.

The final finding of the current study was that family problem-solving was better for grandparents who lived closer to their grandchild than for grandparents further away. Closer proximity to their grandchild may be related to closer emotional relationships [28] and therefore better family functioning. For grandparents who live further away, their distance from the family may be a recurring problem and source of conflict, alienation, helplessness, and guilt. Parents may want greater instrumental support from grandparents, but the long distance to travel may impede grandparents' ability to provide this support to their family. Rurality has previously been identified as a barrier to receiving cancer-related support in countries like Australia with low population density [29], and it may also be a barrier to providing informal support to one's family.

Implications

Psychosocial interventions for families of a child with cancer have been developed [30]. For example, the Surviving Cancer Competently Intervention Program (SCCIP), a short family-based, evidence-based intervention developed by Kazak and colleagues [31], found success with childhood cancer survivors, their parents, and their siblings. The intervention involved cognitive-behavioral and family therapy approaches and was related to improvements in family functioning [31]. Problem-solving skills training (PSST) is another intervention that has shown to be feasible and efficacious in improving problem-solving skills among parents of children diagnosed with cancer, compared to standard care and non-directive supportive therapy [32–34]. Our results suggest that it may be valuable to include grandparents in interventions to increase cohesion in families after a child is diagnosed with cancer, which has previously been advocated by experts in the field [35]. Interventions may need to provide targeted assistance to families where grandparents provide care to the sick child or the siblings. Moreover, such interventions appear to be most needed in the early stages post-diagnosis. This supports Wiener and colleagues' [35] argument that multidisciplinary healthcare teams should assist families from the child's diagnosis through to recovery by assessing family functioning and the unmet needs of family members.

One way in which healthcare teams can provide support and information to grandparents is through the provision of grandparent-specific resources. Wakefield and colleagues [36] developed an information booklet for grandparents of children with cancer, which grandparents found to be helpful and informative. As well as medical information, the booklet provides information about managing family relationships including suggestions for how grandparents can support their family if they live far away [36]. Further research should assess whether grandparent-specific resources can help grandparents better interact with and support their family after their grandchild is diagnosed with cancer. With the parents' permission, grandparents may also be included in family meetings with the healthcare team or separate consultations with grandparents. This would remove the burden on stressed parents to provide medical updates to grandparents. It would also ensure that grandparents understand the medical experiences of their grandchild, and the prognosis, which will inform how they are able to support their family.

Strengths and limitations

The current study had several strengths; in particular, we sampled a typically under-represented group of important people affected by childhood cancer. We also had a large sample relative to this population. By recruiting a control group, we were able to make comparisons in perceived family functioning between grandparents of healthy children and grandparents of children with cancer. Additionally, most of the previous research with grandparents of children with cancer has been qualitative and our study quantitatively complements this data.

Nevertheless, the study also had limitations. Causal inferences cannot be made due to the cross-sectional design of the current research. As such, we cannot determine whether grandparent-reported family functioning returns to population norms or if it remains elevated over time. Future longitudinal research can clarify this relationship. Longitudinal research would particularly benefit from including a measure of the stage of treatment to assess whether this is responsible for the relationship between time since diagnosis and improvements in family functioning.

Parents identify grandparents as an important source for caregiving responsibilities after a child is diagnosed with cancer, especially to provide care for the siblings of the sick child [3, 5]. We measured this in the current study with an open-ended item about providing care to grandchildren. However, the proportion of grandparents providing care was relatively low suggesting that it may not have fully captured all the ways in which grandparents provide care to their grandchildren. Items with prompts and follow-up questions about frequency of care provided may have been more appropriate to measure grandparent caregiving responsibilities. In addition, as only a small number of grandparents indicated they provided care,

we were unable to determine if there were differences in perceived family functioning for grandparents who provided care just to the sick grandchild or to the siblings.

We did not assess how prognosis related to perceived family functioning, yet this is likely to have an important influence. Moreover, palliation was beyond the scope of this study, but research and interventions are also needed to help grandparents cope with their grandchild's terminal illness or death [37].

Grandparents of culturally and linguistically diverse backgrounds were underrepresented. Collectivist cultures and individualistic cultures have different family functioning norms, including role expectations, helping and caregiving behaviors, and conflict avoidance [38, 39]. The current results may not be generalized beyond grandparents of Anglo-Saxon backgrounds.

Conclusion

This study suggests that the detrimental impact of childhood cancer on family functioning extends beyond the immediate family members. Perceived impaired family functioning speaks to grandparents' own suffering. Including grandparents in interventions to reduce distress and increase cohesion for families of a child with cancer may help mitigate their stress and improve family communication. Interventions should begin at diagnosis and target grandparents who provide care to their sick grandchild or siblings. In addition, the healthcare team can make a conscious effort to include grandparents into family discussions when the parents support their inclusion.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

Control of data The authors declare they have full control of all primary data and agree to allow the journal to review the data if requested.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

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