

Grandparents of children with cancer: a controlled study of distress, support, and barriers to care

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Abstract

Objective: For families under stress, positive grandparental relationships provide a valued 'safety net'. However, coping with family stressors can place a heavy burden on older individuals who may be experiencing declining health/energy themselves. This mixed-methods study assessed the prevalence of distress in grandparents of children with, and without, cancer, aiming to identify predictors of grandparental distress and quantify their barriers to care.

Methods: Two hundred twenty-one grandparents [87 cancer group; 134 controls; mean age 65.47 years (SD = 6.97); 33.5% male] completed self-report questionnaires assessing distress, anxiety, depression, anger, 'need for help', support use, and barriers to psychosocial care.

Results: A higher proportion of grandparents in the cancer group reported clinically relevant distress (32.9% vs. 12.7%; $p < 0.001$), anxiety (48.8% vs. 23.9%; $p < 0.001$), depression (24.4% vs. 6.0%; $p < 0.001$), and anger (23.5% vs. 6.8%; $p = 0.001$). In the cancer group, distress was higher in grandmothers and in families with fewer siblings. Grandparents rarely accessed evidence-based psychosocial support (<5% in both groups), although grandparents of children with cancer were more likely to seek religious/spiritual support. Barriers to help seeking included lack of knowledge and rurality. Grandparents of children with cancer qualitatively described undisclosed feelings of uncertainty and helplessness and provided advice to other grandparents to facilitate their coping.

Conclusions: Grandparents of children with cancer were clearly more distressed than controls. Grandparents' capacity to support their families may be limited by their own, untreated, distress. Copyright © 2014 John Wiley & Sons, Ltd.

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The literature regarding grandparents' experiences of stressors threatening a grandchild's life is sparse [1]. When a grandchild is diagnosed with cancer, grandparents may experience shock comparable with the 'universe shaking' [2] and an instant change in their established role/family functioning [3]. During the child's treatment, grandparents can be heavily involved, providing intangible and tangible support [3–6]. Grandparental involvement can improve family closeness [3,5–8] and can be highly valued, with one study reporting that parents rated grandparents as a key source of help, second only to the child's physician [9].

However, grandparental involvement can be complicated by their relationships with the child's parents, and by their own distress, which may remain undisclosed [2,8,10]. Grandparents of unwell children can believe that their own distress is illegitimate in the context of the patient's, parents', and siblings' distress [5,8,10,11]. Grandparents may also have previous experiences of loss due to cancer with which they frame their thoughts about the child's illness [8]. They may also be cancer survivors themselves, which may raise concerns about possible heredity [12].

Given the recognized importance of the grandparent–grandchild relationship, predictors of positive and negative cross-generational relationships are well studied in

the general population [13]. Within families, it appears that lineage, grandparent gender, age and health status, and distance between family members' residences are important contributors to grandparent–grandchild closeness [13]. Typically, children's relationships with their maternal grandparents are closer than with their paternal grandparents [13]. Children are also likely to feel closer to their grandmothers than grandfathers [13]. These patterns are, however, confounded by grandparent age, because typically, maternal grandparents are younger than their paternal counterparts, and grandmothers are, on average, younger than grandfathers [13]. Distance is similarly confounded, as maternal grandparents tend to live closer to their grandchildren [13]. Between families, variability between grandparent–child closeness is high and more difficult to model [13].

Despite many papers acknowledging grandparents' vital role [3,9,14], grandparents' views have rarely been sought in pediatric oncology (one review [2] of eight databases identified three articles, each with <20 participants [10,15,16]). This study therefore aimed the following:

1. to assess the prevalence of psychological distress (via endorsement of the feelings of distress, anxiety, depression,

anger, and 'need for help' on the Emotion Thermometers tool), support use, and barriers to psychosocial care in grandparents of children with cancer;

2. to compare the prevalence of these outcomes with a group of grandparents of healthy children; and
3. to identify demographic/medical predictors of distress.

We hypothesized that grandparents of children with cancer would report significantly more distress than grandparents of healthy children. We anticipated that grandparents of children with cancer would report utilizing more support than the control group.

Methods

Participants and procedure

Grandmothers and grandfathers including step-grandparents were eligible [14]. The study received ethical approval (HRECID:10/196).

Grandparents of children with cancer

Parents of all living children treated for cancer (excluding 'surgery only' cases) during January 2011 to July 2012 at Sydney Children's Hospital (SCH), Australia ($n=162$ families), were sent a letter requesting that they distribute the enclosed four 'grandparent packages' to their child's grandparents. Additional packages were available on request. Packages were also distributed at an information day co-hosted by three hospitals (SCH, Westmead, and John Hunter).

Grandparents of children without serious illness

Urban grandparents were targeted through a 'not-for-profit' preschool 'Grandparent's Day' in the SCH catchment area. The Australian Country Women's Association and the Men's Shed distributed questionnaires to rural/remote grandparents (www.cwaa.org; www.mensshed.org). Grandparents with a seriously ill/injured grandchild were excluded.

The representativeness of the sample was assessed by collecting demographic details of all invited grandparents (including decliners/non-responders).

Measures

Validated scales and items designed by an expert panel (psychologist, oncologist, nurse, statistician, and four consumer representatives) assessed demographics and Internet access. Also assessed were distress (via the Emotion Thermometers tool), support usage (purposely developed open-ended questions), and barriers to accessing support (purposely developed tool). The measures administered included the following:

1. Emotion Thermometers tool. Validated in cancer patients [17,18] and family members [19]; assesses

distress, anxiety, depression, anger, and 'need for help' using a 10-point visual thermometer. As recommended [20], distress levels were dichotomized according to clinical relevance (responses ≥ 4 were coded as 'clinically relevant distress').

2. Support usage. Grandparents listed all support they had utilized since becoming a grandparent, grouped into 'informal' (e.g., family/friends), 'semi-formal' (e.g., religious groups), and 'formal' (e.g., psychologist). 'Since becoming a grandparent' was the chosen timeframe to ensure comparability between groups.
3. Barriers. Grandparents reported their experience of 10 potential barriers to accessing support. Items were divided into two 5-item factors: personal and practical (response options 0 = 'never' to 4 = 'always'; Cronbach's $\alpha > 0.7$ for both factors). The scale performed well, with a Kaiser–Meyer–Olkin measure of sampling adequacy of 0.85 and a significant Bartlett's test of sphericity ($\chi^2 = 682.69$; $p < 0.001$).
4. Open-ended questions. Grandparents qualitatively described the impact of their grandchild's cancer on their physical/emotional health, family roles, and relationships and provided advice to other grandparents (Table 1).

Analysis

Data were explored with descriptive statistics/graphs, using SPSS (v20; IBM, Armonk, NY, USA), R (v2.15.1; R Development Core Team, Vienna, Austria), and SAS 9.3 (SAS Institute, Cary, NY, USA). For aims 1 and 2, chi-squared and t -tests were used to determine between-group differences (two-tailed, $\alpha = 0.05$). Given that multiple tests were conducted, a sequential Bonferroni correction was applied to all p -values to account for the inflated risk of a type I error. Principal components analysis was conducted with oblique rotation on the 'Barriers' measure to inspect its factor structure.

For aim 3, we fit a series of linear regression models to identify factors that contributed to the continuous outcome variable, grandparental distress (Table 2). Predictors were determined by the theoretical framework described earlier [13]. Multilevel modeling allowing a random intercept was implemented because the assumption of independence was violated. This model allows intercepts to vary across families, accounting for the variability at both the individual and family level. A full model including all predictors was also fit, and backwards elimination was conducted to obtain a final model, using the Akaike information criterion.

Regarding power, using our theoretical model [13], we determined that ≤ 8 predictors were relevant, meaning that the minimum sample in the cancer group was 80 [21]. Predictors included grandparent (gender, lineage, and distance from child) and grandchild factors (age, gender, diagnosis, treatment status, and number of siblings).

Table 1. Illustrative quotations

Questions asked	
- How have your relationships with your children/grandchildren changed since your grandchild was diagnosed (if at all)?	
- How do you feel that your role/responsibilities have changed since your grandchild was diagnosed (if at all)?	
- What advice would you give to other grandparents who have a grandchild with cancer?	
Theme	Quotations
Distress	'...everytime I see my granddaughter I wish I could fix her immediately or at least take her place. It just seems so unfair to see the little ones suffer.' (maternal grandfather; neuroblastoma, and age 21 months)
	'Now I live with an underlying constant anxiety.' (paternal grandmother; medulloblastoma, and age 3 years)
Hiding emotions	'Emotionally I had some very low points but mostly kept this hidden' (maternal grandmother; ALL, and age 6 years)
	'I have had to be stronger and sometimes I have to hide my feelings.' (maternal grandmother; ependymoma, and age 3 years)
Coping with parents' distress	'Even though my daughter copes very well I see the sadness in her eyes and it breaks my heart.'
	(maternal grandmother; ependymoma, and age 3 years)
Physical and emotional health	'Emotionally, there have been times when it has all been a strain as I also assist with the care of five other grandchildren plus the siblings of the cancer patient' (maternal grandmother and age 11 years)
	'...deterioration in my physical health due to a great amount of driving and more than usual looking after siblings of granddaughter.' (maternal grandmother; ALL, and age 3 years)
Grandparental advice	'Don't underestimate the role of being there for your child, their spouse, siblings and especially your beloved grandchild.'
	(maternal grandmother; lymphoma, and age 5 years)

Table 2. Linear regression with distress as outcome

Variable	Distress	
	<i>b</i>	<i>p</i> -value
Univariate		
Cancer specific factors		
Time since diagnosis	-0.04	0.036
Diagnosis ^a		
Lymphoma	-1.33	0.376
Solid tumors	0.64	0.386
Other	-0.17	0.851
Distance from child	-0.00	0.905
Distance from hospital	-0.00	0.714
On/off treatment	1.02	0.110
Lineage	-0.10	0.877
No. of siblings	-0.28	0.419
Age at diagnosis	-0.02	0.823
Multivariate		
Final model		
On/off treatment	0.88	0.226
No. of siblings	-0.93	0.032
Gender (grandparent)	2.18	0.003
Distance from child	-0.00	0.236
Diagnosis ^a		
Lymphoma	-2.27	0.134
Solid tumors	1.13	0.197
Other	1.00	0.345

Significant differences are in bold data.

^aDiagnosis is categorical, with four levels. Leukemia is the base group.

Open-ended responses were inductively coded line-by-line and organized into hierarchical categories using QSRv8 [22]. Researcher bias was minimized by implementing tests of coding reliability on 20% of the data; random sections of text were blind coded by two trained, independent researchers. Coder disagreements were discussed with the team until consensus was reached. Thematic saturation was reached after coding approximately 40 grandparents' responses;

however, coding continued for the entire sample to allow calculation of the proportion of grandparents describing each experience.

Results

Two hundred twenty-one grandparents participated: 87 in the cancer group (response: 54%) and 134 controls (response: 70%). Non-responders did not differ from responders in gender, grandchild age, or grandchild gender ($\chi^2 = 1.15$, $p = 0.284$; $t = 0.22$, $p = 0.826$; and $\chi^2 = 0.03$, $p = 0.875$, respectively). There were no significant group differences between participating grandparents in age ($t = 0.75$; $p = 0.456$) and gender ($\chi^2 = 0.20$, $p = 0.663$) (Table 3). Compared with controls, more grandparents of children with cancer lived rurally ($\chi^2 = 7.48$; $p = 0.006$) and had no post-school qualifications ($\chi^2 = 4.05$; $p = 0.048$). Most grandparents had Internet access (86.2% cancer; 90.3% control), and their access was relatively frequent (90.6% cancer; 98.3% controls had 'daily'/'weekly' access).

Distress

Grandparents of children with cancer reported higher levels of clinically relevant distress (32.9% vs. 12.7%; $\chi^2 = 12.85$; $p < 0.001$), anxiety (48.8% vs. 23.9%; $\chi^2 = 14.19$; $p < 0.001$), depression (24.4% vs. 6.0%; $\chi^2 = 15.3$; $p < 0.001$), and anger (23.5% vs. 6.8%; $\chi^2 = 12.17$; $p = 0.001$) than controls. They also reported a greater 'need for help' (13.8% vs. 3.1%; $\chi^2 = 8.61$; $p = 0.005$); however, this was not significant when the sequential Bonferroni correction was applied. When the same analyses were run with education and rurality matched, prevalence statistics were similar (data available on request). The regression model in the cancer group indicated that

Table 3. Participant characteristics

Grandparent characteristics	Cancer (N = 87)	Control (N = 134)	p-value
Age in years: Mean (SD)	65.02 (6.60)	65.75 (7.21)	$t = 0.75$;
Range	46–81	45–87	$p = 0.456$
Gender: N (%) ^a			
Male	27 (31.0)	47 (35.1)	$\chi^2 = 0.20$;
Female	57 (65.5)	87 (64.9)	$p = 0.663$
Relationship to child: N (%)			
Maternal grandmother	32 (36.8)	NA	
Maternal grandfather	15 (17.2)	NA	
Paternal grandmother	21 (24.1)	NA	
Paternal grandfather	9 (10.3)	NA	
Other ^a	10 (11.5)		
Education: N (%) ^a			
No post-school qualifications	41 (47.1)	47 (35.1)	$\chi^2 = 4.05$;
Post-school qualifications	43 (49.4)	87 (64.9)	$p = 0.048$
Previous health training: N (%) ^f			
None	76 (87.4)	91 (67.9)	$\chi^2 = 10.31$;
Previous health training	11 (12.6)	42 (31.3)	$p = 0.002$
Number of grandchildren: mean (SD)	6.71 (5.23)	4.85 (3.42)	$t = 3.20$;
Range	1–35	1–22	$p = 0.002$
Distance from grandchild ^b : median	18.4	NA	
Range	0.3–1071.1		
Distance from hospital ^b : median	41.3	NA	
Range	4–1000		
ARIA: N (%)			
Major city	59 (67.8)	112 (83.6)	$\chi^2 = 7.49$;
Regional	28 (32.2)	22 (16.4)	$p = 0.008$
Internet access: N (%)			
Yes	75 (86.2)	121 (90.3)	
No	12 (13.8)	13 (9.7)	
Frequency of internet usage: N (%) ^d			
Daily	52 (69.3)	103 (85.1)	
Weekly	16 (21.3)	16 (13.2)	
Monthly	2 (2.7)	0 (0.0)	
Yearly	0 (0.0)	0 (0.0)	
Never	2 (2.7)	1 (0.8)	
Other	3 (4.0)	1 (0.8)	
Grandchild characteristics			
Age in years: Mean (SD)	6.11 (3.48)	6.17 (3.43)	$t = 0.13$,
Range	1.25–16	0.33–15	$p = 0.898$
Sex: N (%)			
Male	38 (43.7)	NA	
Female	49 (56.3)		
Diagnosis: N (%) ^c			
Leukemia	35 (40.2)	NA	
Lymphoma	4 (4.6)		
Solid tumors	28 (32.2)		
Other	14 (16.1)		
Time since diagnosis ^b : mean (SD)	19.70 (19.56)	NA	
Range	0.95–99.84		
One or more siblings: N (%)	67 (77.0)	NA	

Significant differences are in bold data.

ARIA, Accessibility/Remoteness Index of Australia; N, number of participants; NA, not assessed or not applicable; SD, standard deviation.

^aMore than one grandparent completed the same questionnaire (despite being sent separate packages) or was a step-grandparent.

^bDistance reported in kilometers, and time reported in months.

^cData missing due to incomplete questionnaires or unable to obtain child's diagnosis.

^dPercentage of those who answered 'yes' to Internet access.

grandparent gender and number of siblings were significant predictors: distress was higher in grandmothers ($b = 2.18$; $p = 0.003$) and in families with fewer children ($b = -0.93$; $p = 0.032$).

Support use and barriers to care

Grandparents of children with cancer were more likely to utilize support since becoming a grandparent than controls (70.1% vs. 41.8%; $\chi^2 = 17.02$; $p < 0.001$). They were more likely to find support in church/religious groups than controls (17.2% vs. 3.7%; $\chi^2 = 11.65$; $p = 0.001$). However, formal psychosocial support was rarely accessed in either group (3.4% in the cancer group and 4.5% in controls; $\chi^2 = 0.15$; $p = 0.701$) (Table 4).

Grandparents of children with cancer were more likely to report a lack of knowledge ($p < 0.001$) and geographical isolation ($p = 0.001$) as barriers than controls. Two components were retained in the final principal components analysis of these barriers (Table 5). Items clustering on the same components suggested that component 1 represented psychological barriers and component 2 practical barriers. When factor scores were compared between groups, factor 1 scores did not differ between groups ($t = -0.46$; $p = 0.648$). Although the differences between groups for factor 2 were initially significant (cancer mean = 1.1; control mean = 0.9; $t = 2.15$; $p = 0.034$), it was not significant at the Bonferroni-corrected level.

Grandparents' lived experiences (cancer only)

Many grandparents reported positive aspects of their experience, including improved family relationships ($n = 25$), 'Our granddaughter's illness has certainly brought us all closer together' [maternal grandfather, acute lymphoblastic leukemia (ALL), and age 13 years], particularly with healthy siblings ($n = 10$). Emotionally, grandparents also described a wide range of additional feelings, often resulting in exhaustion, 'Living with a grandchild's cancer is like living on a roller-coaster. You go from hope to despair in one phone call, then from despair to hope again...leaves you very drained' (paternal grandmother, ALL, and age 12 years). Grandparents described particular difficulty coping with the uncertainty of their grandchild's

Table 4. Support service usage, N (%)

	Cancer (N = 87)	Control (N = 134)	χ^2	p-value
Has utilized some form of support	61 (70.1)	56 (41.8)	17.02	<0.001
Family	35 (40.2)	41 (30.6)	2.13	0.144
Friends/other grandparents	30 (34.5)	32 (23.9)	2.90	0.089
Church/religious group	15 (17.2)	5 (3.7)	11.65	0.001
Doctor	8 (9.2)	8 (6.0)	0.81	0.370
Counselor/psychologist	3 (3.4)	6 (4.5)	0.15	0.701
Cancer support group	1 (1.1)	4 (3.0)	0.81	0.368

Significant differences are in bold data. Only support services with $n > 5$ were included.

Table 5. Barriers to psychosocial support, ordered by most commonly endorsed item, *N* (%).

	Factor 1	Factor 2	Cancer (<i>N</i> =87)	Control (<i>N</i> =134)	χ^2	<i>p</i> -value
Feeling that my concerns are too private to share	0.90	−0.14	31 (35.6)	28 (20.9)	4.86	0.030 ^b
Feeling that I should be over my concerns/worries	0.63	0.16	25 (28.7)	33 (24.6)	0.15	0.754
Not knowing where to look/who to ask	0.43	0.47	37 (42.5)	23 (17.2)	15.45	<0.001
Other responsibilities (e.g., caring for someone else)	0.23	0.53	26 (29.9)	25 (18.7)	2.91	0.103
Not being able to afford it	0.02	0.83	17 (19.5)	18 (13.4)	1.06	0.348
Being geographically isolated	0.07	0.65	22 (25.3)	10 (7.5)	12.42	0.001
Being too embarrassed	0.70	0.10	10 (11.5)	17 (12.7)	0.16	0.834
Other family members not wanting to access support with me	0.60	0.12	11 (12.6)	17 (12.7)	0.01	1.00
Feeling unmotivated	0.79	−0.12	10 (11.5)	15 (11.2)	0.00	1.00
Suffering from ill-health/disabilities ^a	−0.13	0.61	6 (6.9)	13 (9.7)	0.73	0.469
Eigenvalues	2.93	2.35	NA	NA	NA	NA
% variance	29	23	NA	NA	NA	NA
α	0.79	0.74	NA	NA	NA	NA
Factor scores			Cancer	Control	<i>t</i>	<i>p</i>
Factor 1: mean (SD)			0.04 (1.0)	−0.03 (1.0)	−0.46	0.648
Factor 2: mean (SD)			0.19 (1.1)	−0.13 (1.0)	−2.15	0.034

Significant differences are in bold data.

^aCronbach's alpha increases from 0.74 to 0.75 if item deleted.

^bNot significant after sequential Bonferroni adjustment.

prognosis. Concurrent with their own distress, grandparents described difficulty coping with the child's parents' distress, 'Dealing with the anger and blame that has been taken out on us. Whatever we do seems to be the wrong thing.' (paternal grandmother, neuroblastoma, and age 4 years). Nine grandparents explicitly reported minimizing their emotional/physical needs to remain strong for their family, 'I was distraught, in a lot of emotional pain, yet trying to be strong for my daughter' (maternal grandmother, ALL, and age 5 years).

Grandparents believed that their physical health had also been affected (*n* = 15/87), 'At first I was too shocked and exhausted to take care of myself physically. I ate badly, became overweight and I was very tired' (maternal grandmother, ALL, and age 6 years). Physical symptoms including 'elevated blood pressure', 'muscle tension', higher frequency of colds, increased arthritic pain, poor sleep, weight gain, and overall 'deterioration' of physical health were also reported.

Grandparental advice

Grandparents advised other grandparents to focus on providing support to their family (*n* = 46). More specific advice urged others to 'Try not to take emotional outbursts from your daughter/son personally' (maternal grandmother, medulloblastoma, and age 3 years) and keep abreast of new treatments/research. However, grandparents also emphasized the need to balance their involvement without overstepping boundaries, 'Give as much help to the parents...but tread carefully, as it's a very difficult process' (maternal grandmother, ALL, and age 3 years). The needs of healthy siblings were also highlighted, 'Remember the siblings; don't let them become left out and lost' (paternal grandmother, lymphoma, and age 5 years). Regarding

grandparents' needs, participants encouraged others to 'Use all services available!' (maternal grandmother, neuroblastoma, and age 21 months).

Discussion

Confirming our hypotheses, grandparents of children with cancer endorsed more feelings of distress, anxiety, depression, and anger than grandparents of healthy children. Almost half of grandparents of children with cancer endorsed anxiety scores high enough to be considered clinically relevant, and almost one quarter indicated similarly high levels of depressed feelings. Grandparents of children with cancer were more likely to have accessed support since they became a grandparent; however, in line with other research [8,11], many grandparents did not seek support, even when highly distressed. Barriers to care were prevalent among all grandparents; however, grandparents of children with cancer were more likely to cite a lack of knowledge and geographical isolation as barriers. Although this could be attributed to the higher proportion of rural families and lower levels of education among grandparents of children with cancer, our matched data suggest that these factors had little impact on the prevalence of distress in each group.

Grandmothers were most likely to report distress and may benefit from targeted support. Elderly women have higher distress (particularly anxiety) than men in general [23] and when diagnosed with cancer [24]. Mothers of cancer patients also appear more distressed than fathers [25,26]. However, women are also more likely to discuss their distress openly and seek help when required [24,25]. It is therefore important to not discount grandfathers' distress, a recommendation echoed with regard to fathers of unwell children [3]. Similar to grandparents of

disabled children [27], our findings highlight the potential for grandfathers (as well as grandmothers) to under-report their needs so as not to deflect resources/attention from the family.

The elderly are less likely to seek evidence-based psychosocial support, preferring to cope alone, or with non-professionals, such as friends, family, or clergy [28]. Participating grandparents' adoption of religious support echoes the findings of Moules *et al.* [5] and aligns with data on spiritual/existential development in survivors [7] and parents [6]. When faced with 'unexplainable tragedy', families may seek spiritual support to find meaning in their changed lives [3].

Grandparents can be reluctant to report physical symptoms to physicians also (assuming, for example, that their symptoms are part of normal aging) [29], especially in rural areas [30]. Importantly, physical and emotional well-being in the elderly can be co-dependent, such that those with poorer physical health are at increased risk of distress [31]. As older individuals recovering from stressful events experience poorer emotional and physical well-being [31], addressing the needs of grandparents of children with cancer is critical.

Higher distress among grandparents with fewer grandchildren was an unexpected finding, but may mirror research demonstrating parents' emotional/practical investment in single-child, or fewer-child, families, which is usually more intense than in larger families [32]. Grandparents may also have fewer opportunities to provide practical help (e.g., sibling childcare), which may heighten feelings of helplessness [5].

Clinical implications

Grandparents' capacity to support their families may be limited by their own, untreated, distress. It is of concern that grandparents' primary source of support appears to be other family members. Given that family members' distress is likely correlated, grandparents may be seeking support from equally, or more, distressed family [3]. Friends, too, may be ill-equipped to provide the care grandparents require [2]. Referral to psychosocial support for those who are clinically distressed is essential, given strong evidence of the effectiveness of psychosocial support in the elderly [33].

Children's cancer centers could improve grandparental education regarding available services. Although grandparent support groups may be an obvious solution, face-to-face groups are not often well attended or desired [5,34]. Innovations using online technologies might be a viable alternative given high rates of Internet use in this sample, and evidence of the efficacy of online support [35], its potential to overcome stigma [36], and its ability to overcome rurality, especially for elderly Australians [37].

Limitations

This cross-sectional study was limited by recruiting grandparents from only three hospitals. It was also limited in not differentiating between current and past support service usage. An additional limitation was the imbalance of rurality and education between groups. Although we demonstrated that this imbalance had little impact on reported distress between groups, we cannot be certain that these predictors did not influence the findings. Future studies delineating the impact of rurality of grandparental functioning to further explore the relationship between rurality and distress would be valuable.

Future directions

Longitudinal investigation into the impact of pre-existing family functioning, particular diagnoses, coping strategies, and psychological mechanisms maintaining grandparents' distress is needed. The impact of distress on grandparents' relationships with each other is also understudied [5]. It would also be valuable to investigate the 'fit' of theoretical models such as the resiliency model of family stress [38], to grandparental experiences.

Given that family responses to childhood cancer differ across regions and cultures [4,39], our findings may not be generalizable. Indeed, some collectivist cultures have different values surrounding children [40] and declining fertility rates [4,39] and may also have different attitudes toward mental health and help seeking, warranting further investigation [4,39].

Conclusion

This study provides an urgently needed snapshot of the prevalence of distress in a neglected population. By studying the experiences of maternal and paternal grandmothers and grandfathers, we have highlighted the importance of the extended family in childhood cancer. Reports of grandparents' needs being subsumed by the needs of the child and their parents have been common [5]. This study provides the first controlled data in support of these important experiential accounts.

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Conflict of interest

The authors have no conflicts of interest to disclose.

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