

Grandparents of children with cancer: Quality of life, medication and hospitalizations

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Abstract

Background: Grandparents can play a crucial role of providing emotional and practical support for families facing childhood cancer. Yet, many have their own healthcare needs. This controlled study systematically assesses the impact of childhood cancer on grandparents' quality of life (QOL). Our objective was to compare QOL in grandparents of children with and without cancer and to identify factors associated with grandparents' QOL.

Procedure: Grandparents (N = 222) completed two patient-reported outcome (PRO) measures assessing QOL: EQ-5D-5L and WHOQOL-BREF. Secondary endpoints included sleep, medications and hospitalizations. We used independent samples t-tests and multivariate linear regression to assess between-group differences and identify predictors.

Results: Grandparents of children with cancer (n = 89) reported significantly worse QOL than controls (n = 133) [mean WHOQOL-BREF score: 75.6 (SD = 17.6) vs. 81.5 (15.6), $P = 0.007$; mean EQ-5D-5L index value: 0.777 (0.20) vs. 0.874 (0.14), $P < 0.001$]. They also reported more problems with anxiety and depression (47.2 vs. 21.8%, $P < 0.001$) and pain (64.8 vs. 49.6%, $P = 0.031$). Grandparents of children with cancer reported taking longer to fall asleep [mean: 30.4 min (55.6) vs. 18.2 (20.2), $P = 0.011$] and taking more medications in the last 4 weeks [mean: 2.9 (SD = 3.8) vs. 1.8 (SD = 2.3), $P = 0.012$]. Hospitalizations were comparable across groups. Grandmothers, those living in urban locations, and retired/unemployed grandparents experienced reduced QOL.

Conclusions: Grandparents are significantly affected by childhood cancer. The impact appears across many domains of life and results in meaningful QOL differences. Given that four or more individuals may be affected per child, and that grandparent well-being can influence the whole family, interventions targeting at-risk grandparents are needed.

KEYWORDS

childhood cancer, grandparents, health service use, hospitalization, medication use, sleep, quality of life

ABBREVIATIONS: EQ5D-5L, Euro QOL 5 Dimensions-5 Levels; MID, minimally important difference; PRO, patient-reported outcome; QOL, quality of life; SCH, Sydney Children's Hospital; WHOQOL-BREF, World Health Organization Quality of Life-BREF

1 | INTRODUCTION

Across all oncology settings, informal caregivers can assist patients to cope with treatment, manage their recovery and complete practical care tasks. Caregivers also represent substantial savings to the health-

care system, as they can reduce cancer patients' time spent in hospital and trips to emergency departments.¹ Grandparents represent an important source of informal support for families managing childhood cancer. They often provide emotional and practical support to the child and parents, as well as any healthy siblings.²⁻⁴ Yet, older caregivers

face their own challenges, as they balance their needs with those of their family.³

During difficult times, children with cancer can highly value grandparents' comfort and support.² Grandparents of children with cancer are a large group, as every child with cancer may have up to four grandparents (or more in step-families). However, little is known about the experiences of this group of elderly people, despite the important role they play.⁵ A recent Australian study reported that nearly half of grandparents of children with cancer experienced clinically significant anxiety and a quarter experienced clinically significant depression; more than double those of matched controls.⁶ Yet, fewer than 5% of grandparents had accessed psychosocial support.⁶

Qualitative evidence suggests that grandparents' experiences of childhood cancer may be broad. Grandparents describe feeling helplessness, guilty and isolated during their grandchild's cancer treatment.²⁻⁴ Grandparents also report physical symptoms, a decline in health, eating poorly, exercising less, sleeping less and experiencing more 'aches and pains'.^{4,6} These reports highlight the need to investigate the impact of childhood cancer on grandparents more broadly, using standardized patient-reported outcomes (PROs) to assess quality of life (QOL).^{3,4}

QOL is an individual's personal evaluation of their overall well-being across all aspects of life, including physical, psychological and social domains.^{7,8} Existing models stipulate that individual characteristics such as demographics (e.g., age, sex, education), current health status (that might give rise to changes in medication and health service use) and environmental factors (such as access to services and support) influence QOL.⁸ For grandparents, factors that affect the grandparent-grandchild relationship may also impact QOL. Factors associated with grandparent-grandchild relationship quality include grandparent and grandchild gender (grandmothers and granddaughters report closer relationships), lineage (maternal grandparents can have closer relationships) and age (stronger relationships can form between younger grandparents and younger grandchildren).⁹ The distance between grandparents and their grandchildren can also impact relationship closeness⁹ and may influence the degree of involvement grandparents have in the child's life.

This study aimed to assess QOL, sleep, medication use and hospitalizations in grandparents of children with and without cancer. The study also sought to identify predictors of grandparents' QOL in alignment with the models described above.^{8,9}

2 | METHODS

2.1 | Participants

We mailed study invitations and four grandparent opt-in cards to families of patients at Sydney Children's Hospital (SCH), Australia. Eligible families had children who were currently living, were aged less than 17 years and had received treatment in the last 3 years. Grandparents who opted-in were mailed a questionnaire. We made reminder phone calls to nonresponders after 4 weeks. We recruited a comparison group of grandparents of healthy children from community groups and preschools in the SCH catchment area and, given the large

catchment area of SCH, we also recruited through rural community organizations (Women's and Men's Sheds, Country Women's Association, Rotary). Grandparents with a seriously ill/injured grandchild were excluded. Respondents completed the survey only once, but all grandparents within the same family were eligible to participate. Study procedures were approved by the local human research ethics committee.

2.2 | Measures

The questionnaire assessed grandparents' demographic characteristics and the following.

2.2.1 | The grandchild's medical characteristics

Grandparents reported on their grandchild's diagnosis, age at diagnosis, treatment received (surgery, chemotherapy, radiotherapy, transplant).

2.2.2 | Quality of life

We assessed QOL using the WHOQOL-BREF and EuroQol EQ-5D-5L. The WHOQOL-BREF is a 26-item measure developed by the World Health Organization.⁷ It assesses four domains: physical health, psychological health, social relationships and environment using five response options (1 = 'very poor/very dissatisfied/not at all'; 5 = 'very good/very satisfied/extremely'). Overall QOL is measured with two items. We calculated domain and overall QOL scores in accordance with the developer's instructions, with scores ranging from 0 to 100 (higher scores indicate better QOL).⁷

The EQ-5D-5L is a six-item standardized measure of health status developed by EuroQol.¹⁰ It consists of five domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression with five response options ranging from 'no problem' to 'extreme problem'. The first five items are analyzed together to determine a QOL index value, while a sixth item indicates current health perceptions. Index values range from 0 to 1 (1 = perfect health, 0 = death). We calculated the EQ-5D-5L QOL index value using Australian sample (Model D) value set.¹¹ We calculated the proportion of grandparents reporting any domain-specific difficulties according to developer instructions.¹⁰

2.2.3 | Relationship changes

We asked grandparents of children with cancer to report on any changes to their relationship with their grandchild or grandchild's family. Responses were given as free text. We coded responses as indicating 'no change' or 'some change'. Where grandparents reported some changes, these were classified as positive, negative or mixed.

2.2.4 | Sleep quality

We adapted seven items from the Pittsburgh Sleep Quality Index¹² to assess sleep quality in the previous night and over the last 4 weeks and perceived impact of lack of sleep on daily living (see Table 2 for item wording).

2.2.5 | Medications/hospitalizations

Grandparents listed all medications they had taken in the last 4 weeks. We coded each medication according to its primary use and type

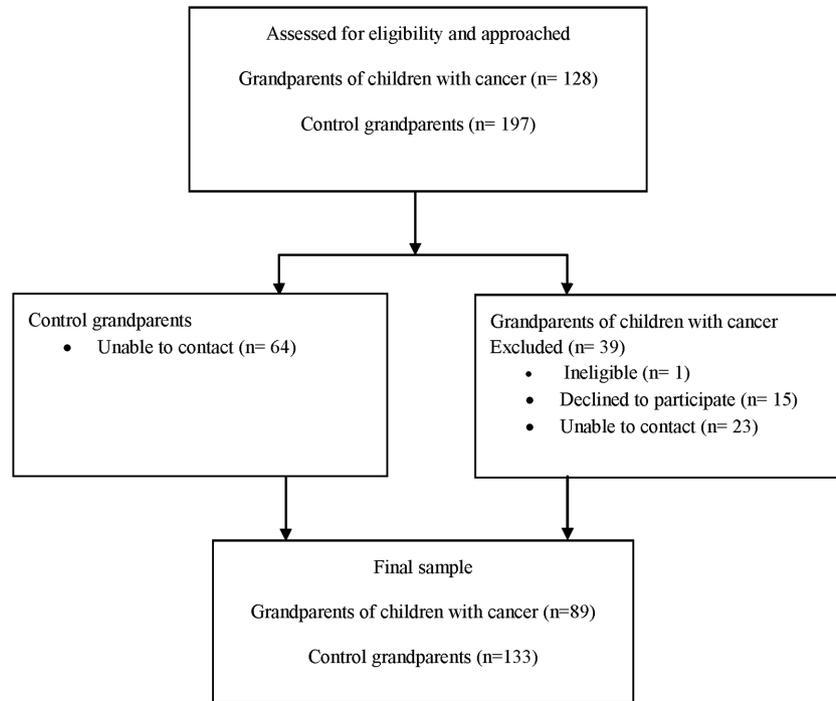


FIGURE 1 CONSORT recruitment flow diagram

(prescription, vitamin/mineral, or 'over-the-counter' medication). Four purposely designed items assessed hospitalizations, recording the number of visits to an emergency room, planned admissions and number of nights in hospital over the past 4 weeks and 6 months.

2.3 | Data analysis

We used IBM SPSS (IBM Corp, Version 22.0, Armonk, NY) to conduct the statistical analyses. We compared demographics between grandparents of children with and without cancer using two-tailed independent sample *t*-tests and chi-square tests, with significance at *P* less than 0.05. Where significant between-group differences were found, we controlled for these variables in subsequent analyses of outcome variables (QOL, sleep, medications, hospitalizations). We considered two cut-offs for a minimally important difference (MID) in QOL when comparing grandparents of children with cancer to controls. A difference of 10% on the WHOQOL-BREF overall score and domain scores, equivalent to 10-point reduction from perfect overall or domain scores, was considered a MID.¹³ For the EQ-5D-5L, a difference of 0.12 on the index value was considered a MID.¹⁴

To identify factors associated with QOL, we fit univariate linear regression models prior to building multivariate models. We considered variables in keeping with our QOL model (age, rurality, marital status, employment),^{8,9} together with variables that influence grandparent–grandchild relationships (lineage, distance from child, grandchild gender and time since diagnosis). These eight predictors required a minimum sample in the cancer group of 80 for sufficient power.¹⁵ We used multilevel linear modelling allowing a random intercept because the assumption of independence was violated (≥ 1 grandparent from each family could participate). Backwards stepwise regression was conducted until only significant predictors of each outcome remained.

3 | RESULTS

3.1 | Participants

In total, 222 grandparents participated: 89 in the cancer group from 57 families (response rate: 69.5%) and 133 in the control group from 105 families (response rate: 67.5%, Fig. 1). Grandparents of children with cancer (62.9% female) were on average 65.9 years old (SD = 7.7) and most (62.2%) were unemployed/retired (Table 1). Control grandparents (69.9% female) were on average 67.3 years old (SD = 6.5) and most (66.2%) were unemployed/retired. Compared with controls, fewer grandparents of children with cancer had obtained postschool qualifications (73.3 vs. 56.5%, respectively; $\chi^2 = 6.751$, *P* = 0.009). This difference was controlled for in all subsequent analyses. When the control group was restricted to a random sample of 89 grandparents matched to level of education, results of the statistical analyses remained the same. These results are available on request.

3.2 | QOL, sleep and medications

WHOQOL-BREF overall QOL scores were significantly lower in grandparents of children with cancer compared with controls [mean (SD): 75.6 (17.6) vs. 81.5 (15.6); $F(1,209) = 7.439$, *P* = 0.007]. Physical health, psychological health and environmental domains were also significantly lower for grandparents of children with cancer compared with controls (Table 2).

On the EQ-5D-5L, a higher proportion of grandparents of children with cancer reported experiencing slight to severe difficulties with pain ($\chi^2 = 4.674$, *P* = 0.031), anxiety and depression ($\chi^2 = 15.797$, *P* < 0.0001) compared with controls (Fig. 2). The overall QOL index value for grandparents of children with cancer was significantly lower than in controls [mean (SD): 0.777 (0.2) vs. 0.874

TABLE 1 Participant characteristics

	Cancer (N = 89)	Control (N = 133)	P value
<i>Grandparent characteristics</i>			
Age in years: mean (SD)	65.9 (7.7)	67.3 (6.5)	$t = 1.438, P = 0.152$
Range	44–83	43–83	
Gender: N (%) ^a			
Male	33 (37.1)	40 (30.1)	$\chi^2 = 1.185, P = 0.276$
Female	56 (62.9)	93 (69.9)	
Relationship to child with cancer: N (%)			
Maternal grandmother	33 (38.8)	–	
Paternal grandmother	20 (23.5)	–	
Maternal grandfather	20 (23.5)	–	
Paternal grandfather	12 (14.1)	–	
Education: N (%) ^a			
No postschool qualifications	37 (43.5)	35 (26.5)	$\chi^2 = 6.751, P = 0.009$
Postschool qualifications	48 (56.5)	97 (73.5)	
Number of grandchildren: mean (SD)	6.02 (3.69)	5.55 (3.57)	$t = -0.903, P = 0.368$
Range			
Distance from grandchild ^b : median	28.9	–	
Range	0–1415.20		
Distance from hospital ^b : median	119	–	
Range	3.20–8553.00		
ARIA ^a : N (%)			
Major city	55 (64.0)	101 (76.5)	$\chi^2 = 5.101, P = 0.078$
Regional and remote	31 (36.0)	30 (22.7)	
Marital status: N (%)			
Currently married or de facto	70 (86.4)	109 (82.0)	$\chi^2 = 0.734, P = 0.392$
Separated/divorced or widowed	11 (13.6)	24 (18.0)	
Religion: N (%)			
No religion	15 (17.9)	23 (17.7)	$\chi^2 = 1.359, P = 0.507$
Christianity	57 (67.9)	95 (73.1)	
Other religion	12 (14.3)	12 (9.2)	
Employment status: N (%)			
Unemployed or retired	51 (62.2)	88 (66.2)	$\chi^2 = 0.350, P = 0.554$
Employed	31 (37.8)	45 (33.8)	
Income: N (%)			
< \$60,000 p.a.	28 (43.1)	49 (47.6)	$\chi^2 = 0.324, P = 0.569$
> \$60,000 p.a.	37 (56.9)	54 (52.4)	
<i>Grandchild characteristics</i>			
Age in years: mean (SD)	6.78 (4.38)		
Range	1–22		
Sex: N (%)			
Male	42 (47.7)	–	
Female	46 (52.3)		
Diagnosis ^c : N (%)			
Leukaemia	35 (39.3)	–	
Lymphoma	7 (7.9)		
Solid tumors	47 (52.8)		

(Continued)

TABLE 1 (Continued)

	Cancer (N = 89)	Control (N = 133)	P value
Time since diagnosis ^b : mean (SD),	2.71 (2.80)	-	
Range	0.44–22.40		
Treatment ^c : N (%)		-	
Surgery	45 (55.6)		
Chemotherapy	84 (97.7)		
Radiotherapy	33 (41.8)		
Bone marrow/stem cell transplant	12 (15.4)		
One or more siblings: N (%)	73 (83.9)	-	

Significant differences in bold.

N, number of participants; SD, standard deviation.

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

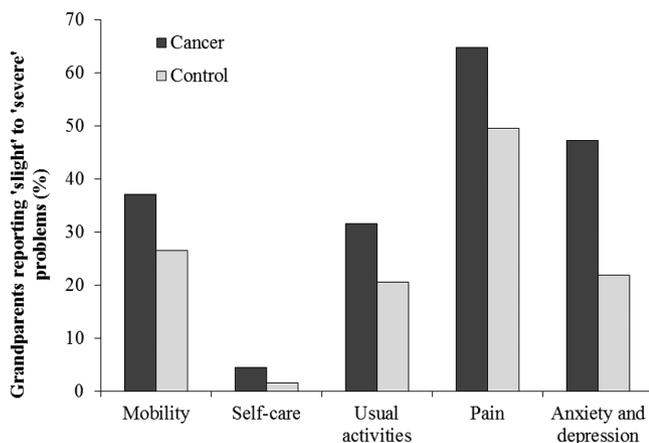
^bDistance reported in kilometers, time reported in months.

^cNot mutually exclusive categories.

TABLE 2 Grandparent's QOL as measured by WHOQOL-BREF

	Cancer	Control	P value ^a
Mean (SD)			
Overall QOL	75.6 (17.6)	81.5 (15.6)	F(1,214) = 7.439, P = 0.007
Physical	74.8 (16.1)	80.8 (12.5)	F(1,214) = 9.244, P = 0.003
Psychological	71.1 (15.2)	80.6 (11.4)	F(1,212) = 28.085, P < 0.0001
Social	72.8 (18.7)	76.2 (15.9)	F(1,212) = 2.811, P = 0.095
Environmental	82.4 (12.5)	86.1 (11.0)	F(1,214) = 5.652, P = 0.018
Minimal important difference, N (%)			
Overall QOL	74 (83.1)	100 (75.2)	$\chi^2 = 1.993, P = 0.158$
Physical	76 (85.4)	106 (79.7)	$\chi^2 = 1.170, P = 0.279$
Psychological	79 (91.9)	103 (77.4)	$\chi^2 = 7.731, P = 0.005$
Social	69 (78.4)	105 (79.5)	$\chi^2 = 0.041, P = 0.839$
Environmental	63 (70.8)	89 (66.9)	$\chi^2 = 0.370, P = 0.543$

^aMissing data in both cancer and control groups; significant differences bold, controlling for education.

**FIGURE 2** Proportion of grandparents of children with cancer compared with control grandparents endorsing difficulties across domains of QOL as measured by EQ-5D-5L. * $P < 0.05$

(0.14); $F(1,214) = 18.071, P < 0.001$]. More grandparents of children with cancer reported less than perfect QOL on the EQ-5D-5L index

value compared with control grandparents (62.9 vs. 42.9%; $\chi^2 = 8.589, P = 0.003$).¹⁴ Grandparents of children with cancer rated their health today as significantly worse than controls [mean (SD): 78.4 (14.9) vs. 83.8 (13.6), respectively; $F(1,213) = 9.009, P = 0.003$].

Grandparents of children with cancer spent similar amounts of time in bed and asleep compared with controls (Table 3). However, they reported taking on average 1.7 times longer to fall asleep (30.4 vs. 18.2 min; $F(1,211) = 6.609, P = 0.011$). Grandparents of children with cancer also had more frequent difficulties falling asleep than controls: 66.2% experienced difficulty falling asleep more than twice per week compared with 47% of controls ($\chi^2 = 5.419, P = 0.020$).

Grandparents of children with cancer reported using 1.6 times more medications in the last 4 weeks than controls (2.9 vs. 1.85 medications; $F(1,194) = 6.494, P = 0.012$; Table 3). Posthoc analyses indicated that they were taking more prescription medications than controls ($F(1,194) = 7.296, P = 0.008$) and more medications for managing stress/anxiety ($P = 0.001$), sleep disturbance ($P = 0.042$), cholesterol ($P = 0.028$) and blood pressure ($P = 0.027$). Few grandparents in either group were admitted to hospital for any reason in the last 4 weeks or

TABLE 3 Grandparent sleep and medication usage

	Cancer	Control	P value ^a
<i>Sleep</i>			
How long did it take you to fall asleep (min): mean (SD)	30.4 (55.6)	18.2 (20.2)	F(1,211) = 6.609, P = 0.011
How many times did you wake up during the night: mean (SD)	2.0 (1.7)	1.9 (1.4)	F(1,213) < 0.001, P = 0.984
How long did it usually take to fall back asleep (min): mean (SD)	16.6 (24.5)	12.6 (15.0)	F(1,191) = 1.690, P = 0.195
How many hours did you spend in bed: mean (SD)	8.0 (1.3)	7.9 (1.0)	F(1,213) = 0.851, P = 0.357
How many hours of actual sleep did you get last night: mean (SD)	6.7 (1.2)	6.8 (1.2)	F(1,210) = 0.534, P = 0.466
In the past 4 weeks have you had difficulty falling asleep (yes): N (%)	59 (67.8)	80 (60.6)	$\chi^2 = 1.176, P = 0.278$
If yes, did this occur more than two times a week (yes)	43 (66.2)	39 (47.0)	$\chi^2 = 5.419, P = 0.020$
If you experienced poor sleep did this upset you or interfere with daily living (yes)	18 (25.7)	18 (20.0)	$\chi^2 = 0.737, P = 0.391$
<i>Medication use</i>			
Total number of medications taken since becoming a grandparent: mean (SD)	1.3 (2.5)	1.3 (2.1)	F(1,193) = 0.045, P = 0.832
Total number of medications taken in the last 4 weeks: mean (SD)	2.9 (3.8)	1.8 (2.3)	F(1,194) = 6.494, P = 0.012
Vitamins and minerals taken: mean (SD)	0.7 (1.6)	0.6 (1.1)	F(1,194) = 0.208, P = 0.649
Over the counter medications: mean (SD)	0.4 (1.0)	0.2 (0.5)	F(1,194) = 3.054, P = 0.082
Prescribed medications: mean (SD)	1.8 (2.7)	1.0 (1.7)	F(1,194) = 7.296, P = 0.008

^aMissing data in both cancer and control groups, significant differences bold, controlling for education.

6 months (6.7% grandparents of children with cancer vs. 11.4% of controls in the last 6 months; $\chi^2 = 1.321, P = 0.250$). Nights spent in hospital were no different between groups [mean (SD): 2.1 (1.9) vs. 2.5 (2.6); $P = 0.748$].

Few grandparents ($n = 15/89$) reported any changes to their relationship with their grandchild or their family as a result of their grandchild's diagnosis with cancer. Of those grandparents who reported a change, they reported that they felt closer to, and more involved with their families ($n = 10$), including not only the grandchild with cancer but also the child's parents and their other grandchildren ($n = 2$). However, for grandparents of children still undergoing treatment, some grandparent's ($n = 3$) described interpersonal strain with their partners, caused by spending much of their time with their sick grandchild and family. One grandparent described "little time for holidays, breaks, [or] socialising because planning free time [was] almost impossible" (paternal grandfather of 4-year-old boy with Wilms tumor).

3.3 | Predictors of QOL

3.3.1 | WHOQOL-BREF overall score

In the final multivariate model, grandparents' relationship to the grandchild, rurality, employment status and grandchild's gender were significant influencers of QOL (Table 4). Paternal and maternal grandmothers experienced worse QOL compared with paternal grandfathers ($b = -13.00, P = 0.001$; $b = -13.29, P = 0.015$, respectively). Being a paternal grandmother reduced QOL by approximately 17 points compared with that of a paternal grandfather, controlling for the remaining covariates. Other detractors from grandparents' QOL were living in a major city compared with living in regional/remote areas ($b = -14.199, P < 0.0001$) and being unemployed/retired compared with being employed ($b = -8.421, P = 0.019$). Grandparents with female grandchildren had worse QOL ($b = -6.025, P = 0.041$).

3.3.2 | EQ-5D-5L index value

Rurality, employment and distance between grandparents and grandchildren significantly influenced EQ-5D-5L index values. Grandparents living in urban locations reported worse QOL than rural/remote grandparents ($b = -0.087, P = 0.049$), while living further from their grandchildren was also associated with worse QOL ($b = -0.0002, P = 0.005$). Unemployed/retired grandparents reported worse QOL than those who were currently employed ($b = -0.120, P = 0.003$).

4 | DISCUSSION

Grandparents of children with cancer experienced poorer overall QOL compared with grandparents of healthy children as measured by two QOL instruments: the WHOQOL-BREF and EQ-5D-5L. Reduced functioning was prevalent across several domains, including psychological, physical and environmental. These QOL reductions were within the range considered clinically meaningful. More grandparents of children with cancer reported reductions in overall QOL on the EQ-5D-5L and psychological well-being on the WHOQOL-BREF that were consistent with a MID.^{13,14} Grandparents of children with cancer experienced more difficulties falling sleep and took longer to fall asleep. Although there were no differences in the number of hospitalizations, grandparents of children with cancer reported greater use of prescription medications.

More grandparents of children with cancer reported current problems with anxiety and depression compared with controls, consistent with previous studies.^{3,4,6} These emotional difficulties may have been linked to grandparents of children with cancer reporting difficulties falling asleep and greater use of medications for managing stress and anxiety. Sleep difficulties are commonly associated with anxiety, and many caregivers for adult cancer patients report ongoing sleep problems and anxiety after treatment completion.¹⁶ Our results indicate

TABLE 4 Regression of grandparent and grandchild variables predicting overall QOL in grandparents of children with cancer

Variable	WHOQOL-BREF total score				EQ-5D-5L utility value			
	Univariate		Multivariate		Univariate		Multivariate	
	b	P value	b	P value	b	P value	b	P value
<i>Grandparent variables</i>								
Age	0.153	0.653			-0.003	0.365		
Relationship to child ^b		<0.0001		0.002		0.277		
Maternal grandmother	-10.256	0.066	-13.29	0.015	-0.050	0.236		
Paternal grandmother	-17.509	0.000	-13.00	0.001	-0.058	0.094		
Maternal grandfather	-5.219	0.345	-9.894	0.109	-0.040	0.342		
Paternal grandfather ^a	0	-	0	-	0	-		
<i>Rurality</i>								
Major city	-15.707	0.001	-14.199	<0.0001	-0.039	0.382	-0.087	0.049
Regional/remote ^a	0	-	0	-	0	-	0	-
<i>Current employment</i>								
Unemployed/retired	-2.647	0.721	-8.421	0.019	-0.081	0.038	-0.120	0.003
Employed ^a	0	-	0	-	0	-	0	-
<i>Marital status</i>								
Separated/widowed	-1.582	0.787			-0.004	0.927		
Married/de facto ^a	0	-			0	-		
<i>Grandchild variables</i>								
Grandparent distance to grandchild	-0.002	0.942			-0.0002	0.003	-0.0002	0.005
<i>Gender of grandchild</i>								
Female	-3.975	0.641	-6.025	0.041	-0.086	0.053		
Male	0	-	0	-	0	-		
Time since diagnosis	-2.864	0.255			0.0003	0.983		

^aComparator group for categorical variables.

^bOverall variable P value is presented for categorical variables with more than 2 levels; significant differences in bold, controlling for education.

that grandparents, although usually removed from direct caregiving duties, similarly experience ongoing reduced psychological well-being. One possible explanation is that grandparents of children with cancer experience 'doubled worry': worry about the well-being of their grandchild as well as their own child (the child's parent).³ This doubled worry may prevent grandparents from falling asleep easily and cause them to seek pharmaceutical treatment for anxiety/stress.

Corroborating available qualitative reports,^{4,6} we also observed that grandparents of children with cancer also experienced reduced QOL in the physical domain and greater difficulties with pain than control grandparents. Grandparents of children with cancer also rated their overall health significantly lower than controls. Self-reported health is consistently associated with mortality and morbidity,^{17,18} and these results indicate that having a grandchild with cancer impacts life beyond emotional well-being. Grandparents may neglect their own health while looking after and supporting their grandchild, any healthy siblings and the wider family.⁶ This is an important finding given the importance of proactive self-care in the elderly to prevent premature mortality, the development of serious health conditions in old age and, at a societal level, potentially mitigate healthcare costs.¹⁹

Our data also demonstrate that current employment may act as a potential protective factor against declines in QOL when faced with a

family stressor. Alternatively, grandparents who are generally fit and healthy with good QOL may be able to work for longer. For many, caregiving comes with a financial cost.^{1,4} Parents of children with cancer often report significant out-of-pocket costs associated with treatment.²⁰ This impact can be compounded by a reduced ability for parents to engage in employment.^{20,21} For grandparents, employment may act as a protective factor by providing greater disposable income and therefore greater ability to support their family through this financially challenging time.^{4,20,21} In addition, active employment can provide psychological and social benefit. The structure and daily purpose of regular employment at a time when grandparents may be facing existential challenges relating to their grandchild's diagnosis may be crucial for maintaining QOL. The additional opportunities for social engagement and social support outside of the family may also be important for grandparents.

Grandmothers experience worse QOL than grandfathers, consistent with previous research demonstrating grandmothers experience higher distress associated with their grandchild's cancer diagnosis.⁶ Grandmothers are often reported to be closer to their grandchildren than grandfathers and more frequently participate in leisure activities and practical aspects of childcare.⁹ Changes in this usual relationship with both the sick grandchild and any healthy siblings has the potential

to meaningfully impact grandparents' QOL. As such, our results may reflect that those who are emotionally close to their grandchildren may feel the impact of a cancer diagnosis most acutely.

In our sample, living in a regional/rural location was associated with better overall QOL compared with living in urban settings. In contrast, informal carers for adult cancer patients in rural locations commonly report more unmet information and support needs.²² This discrepancy may be due to the burden and responsibility of care, which lies with parents rather than grandparents, unlike caregivers of adults, who may be more intimately involved.²² In the general population, those living rurally tend to experience better overall QOL and psychosocial well-being and to cope better with life stressors, possibly due to increased community involvement and social support.²³ As such, rural grandparents in this study may have had greater connection to their community and better support networks than urban grandparents.

This study indicates a need for more targeted preventative supportive care interventions. Despite the crucial psychological and practical support role grandparents play in supporting the child, the child's parents, and any healthy siblings through a diagnosis of childhood cancer, grandparents are removed from the direct care and treatment decisions associated with their grandchild's cancer. As such they often receive less psychosocial support and only 'second-hand' information.^{4,24} This lack of support and information may exacerbate concerns about their grandchild or feelings of isolation.²⁻⁴ One way to ameliorate this gap is through additional psychosocial intervention and information provision tailored to grandparents' needs.^{24,25} Supportive care interventions with caregivers of adult cancer patients consistently show improvements in a number of outcomes including QOL.^{26,27} When family caregivers are well supported, the well-being of the cancer patient may also be significantly enhanced,²⁸ highlighting the importance of extending supportive care interventions beyond the traditional family unit.

As this study was cross-sectional, causal inferences cannot be made. We did not assess grandparents' pre-cancer QOL or the pre-cancer grandparent-grandchild relationship. A grandchild's cancer diagnosis may have only served to compound existing concerns for grandparents, or heighten grandparents' awareness of reduced QOL. We did not quantitatively assess the level of involvement grandparents had in caring for their unwell grandchild or their other grandchildren. Our results suggest that factors typically associated with grandparent-grandchild closeness, such as physical proximity and gender, were important determinants of grandparent QOL. However, these are proxy measures, and assessing relationship quality, emotional closeness and level of involvement are likely to be important determinants of grandparent QOL that should be considered in future research. The study also relied on self-report. This approach may have resulted in bias and inaccuracies, particularly as grandparents were asked to self-report on medication usage (but not dose/treatment intensity) and hospitalizations. While evidence suggests that research participants are reasonably accurate in self-reporting their healthcare use, particularly when the recall period is short (e.g. under 3 months),²⁹ future studies collating medication/hospitalization data from medical records (as well as general practitioner consultations) would be valuable. Grandparents were only recruited from one hospital, and the experiences of grand-

parents from culturally and linguistically diverse populations were not represented. The results presented here therefore may not reflect the experiences of all grandparents.

Study strengths included the large sample size of a typically neglected population. We employed two well-validated QOL measures,^{7,10} and the results from these two measures demonstrated convergence. In addition to assessing self-perceptions of QOL, we evaluated medication usage and hospitalizations: process outcomes that have a financial implication for individual grandparents and the health system. This study indicates future studies addressing any costs to grandparents are warranted. In addition to incurring health-related costs, some grandparents may contribute financially to families caring for a child with cancer either by directly contributing funds for treatment, travel or food, or indirectly through time taken off work to care for healthy siblings or help with household tasks.

5 | CONCLUSION

Having a grandchild diagnosed with cancer affects multiple aspects of grandparents' lives and has a clinically meaningful impact on their QOL. Given that poor self-rated health status and health-related QOL are associated with increased healthcare costs and even risk of mortality in elderly individuals,¹⁷ further consideration of supportive care interventions for grandparents of children with cancer is warranted. Intervening to support at-risk grandparents may result in improved outcomes for the grandparent, as well as the wider family unit.

ACKNOWLEDGMENTS

We would like to thank Sarah Ellis, Jordana K. McLoone, Sixuan Lin and Dalena Tran for their contributions to this research. Claire E. Wakefield is supported by a Career Development Fellowship from the National Health and Medical Research Council of Australia (APP1067501). The Behavioural Sciences Unit is proudly supported by the Kids with Cancer Foundation.

FUNDING SUPPORT

None.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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