Assessment

'What they're not telling you': A new scale to measure grandparents' information needs when their grandchild has cancer

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ARTICLE INFO

ABSTRACT

Objective: To determine the information needs and preferences of grandparents of children with cancer, to identify clinically useful predictors of high information need, and to develop the first validated scale to assess grandparents' information needs regarding their grandchild's cancer.
Methods: Grandparents of children with cancer completed a questionnaire, including a newly developed instrument to measure information needs.
Results: Eighty-seven grandparents participated (mean age 65.02 years, range 46–81, 31% male). Grandparents' information needs were high, especially among young and paternal grandparents. Grandparents' greatest need was for information pertaining to their grandchild's chance of survival (81.6% reported "high need"), possible consequences of the child's cancer (81.6%), and phases of their treatment (72.4%). Ninety-three percent endorsed the development of a grandparents' booklet, distributed at diagnosis and available online.
Conclusions: Grandparents of children with cancer desire more information for their own reassurance, to reduce their reliance on 'second-hand' information from their grandchild's parents and to improve the support they provide their families. Grandparents strongly endorse the development of grandparent-targeted educational resources.
Practice implications: Administration of this short, 15-item questionnaire can help staff identify the information needs of grandparents. Findings will inform the development of evidence-based resources for this important (but oft-neglected) population.

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1. Introduction

Despite extensive literature documenting the information needs of cancer patients [1], survivors [2–4], parents [2,5,6] and siblings [2,7,8], the information needs of grandparents of children with cancer remain largely unknown. Grandparents' experiences during their grandchild's cancer treatment and recovery are different to the experiences of other groups affected by cancer (including the child's parents and patients their own age who may have cancer themselves). While grandparents are not usually responsible for making treatment decisions or providing primary care for their grandchild, they often play a critical role during the child's cancer treatment/recovery [9]. This may include providing

emotional support for parents, child-minding for healthy siblings, and financial aid to cover treatment and other costs [10].

Grandparents of children with cancer are also highly likely to experience distress and uncertainty with regard to how to care for, and communicate with, their unwell grandchild, which can be exacerbated by the 'double generation' gap between the grandparent and their grandchild [9]. Grandparents also uniquely experience 'double-grief', feeling concern for both their own child (their grandchild's parents) and their grandchild [9]. Placed on the periphery of the family circle, grandparents must also negotiate the boundaries parents place around information about the grandchild, and manage any complexities regarding aligning their grand-parenting approach with those of both parents. Grandparents may also uniquely provide this support while managing their own health as they age, and need to learn about this rare disease and its complex treatment, which has changed drastically in recent decades. Each of these experiences represent challenges that require specific information, tailored to a unique context.

Only one study has collected information/support data from grandparents directly, who qualitatively described the need for

information as their 'greatest need' and reported feeling 'excluded' and 'invisible' to the healthcare team [11]. However, this study had a sample size of only 16 participants, limiting its generalizability. An additional study, which described the information needs of grandparents from parents' perspectives, also identified information about their grandchild's illness as a key area of unmet need for grandparents (48% of 127 parents) [5]. This data suggests that the information provided to parents is insufficient to meet the information needs of grandparents.

Given the clear need to develop evidence-based resources for grandparents of children with cancer [5,11], and recent calls for including (and educating) relatives on the periphery of the child's 'caring circle' [12], this study aimed to:

1. Determine the information needs and dissemination preferences of grandparents of children with cancer;
2. Identify clinically useful predictors of high information need; and
3. Develop the first validated scale to assess grandparents' information needs regarding their grandchild's cancer.

2. Methods

Parents of all living children treated for cancer (excluding surgery only patients), between January 2011 and July 2012, at Sydney Children's Hospital (SCH), Australia, were sent 'grandparent packages' for parents to distribute. Additional packages were distributed using the same eligibility criteria to grandparents attending an information day co-hosted by three hospitals (SCH, Children's Hospital at Westmead and John Hunter Children's Hospital).

2.1. Measures

As well as collecting demographic information, including education and prior health training, the questionnaire comprised items designed by an expert panel (psychologist, oncologist, nurse, statistician and four grandparent consumers [two grandmothers, two grandfathers, from urban and rural areas]). The questionnaire assessed:

1. Information preferences style: a validated scale [13] used in cancer [14,15] [response options: 1 = 'I prefer as little information as possible', to 5 = 'I prefer as much information as possible'].
2. Preferred dissemination mechanism ['Booklet' and/or 'Online'], timing ['At diagnosis', 'During treatment', 'After treatment'], format/length ['A4′, 'A5′, number of pages].
3. Information needs: assessed using a modified version of the validated Patient Information Needs Questionnaire (PINQ) [16], previously used for cancer patients and carers [17]. For this study, 15 items were developed to assess grandparents' specific needs for information related to their grandchild's cancer. Grandparents were asked to rate their need for information regarding topics unique to grandparents, such as 'how best to support your own children (i.e. the child's parents)' and 'how best to support other grandchildren in the family' (see Table 1 for a full list of items).

2.2. Analysis

Data were explored using SPSS Statistics (*v20*), R (*v2.15.1*) and SAS (*v9.3*). Multi-level modeling with random intercepts was implemented to take into account intra-family correlation between grandparents of the same child. Since lineage and grandparent age can be confounded, their interaction was included in all models as recommended [18]. To identify predictors of information needs in each domain, factor scores were calculated and added to the dataset using the regression method. A series of regression models with each factor as an outcome were then tested.

2.2.1. Assessment of new scale

Internal consistency was evaluated using Cronbach's alpha. Factor structure was examined using principal components

Table 1
Grandparental need for information: instrument items, EFA results and percentage of responses.

At any point in your grandchild's cancer journey, to what extent did you need information about...	Factor 1	Factor 2	Factor 3	Factor 4	Indicated some need, *n* (%)	Indicated high need, *n* (%)
Your grandchild's specific type of cancer	**0.68**	−0.24	0.09	0.25	24 (27.6)	57 (65.5)
The chance of your grandchild surviving their cancer	**0.79**	0.05	−0.19	0.30	9 (10.3)	71 (81.6)
The possible phases of your grandchild's cancer (including their treatment regimen)	**0.78**	0.23	0.00	−0.06	20 (23.0)	63 (72.4)
Possible long term consequences/effects of your grandchild's cancer	**0.79**	0.16	−0.21	0.15	13 (14.9)	71 (81.6)
The treatment procedures/medications	**0.87**	−0.06	0.21	−0.17	28 (32.2)	54 (62.1)
The benefits or goals of their cancer treatment/medication	**0.87**	0.08	0.17	−0.17	25 (28.7)	55 (63.2)
How best to support yourself emotionally	0.08	0.21	**0.62**	0.12	46 (52.9)	14 (16.1)
Where to get help if you are experiencing emotional difficulties	0.07	0.04	**0.81**	0.12	38 (43.7)	10 (11.5)
How to keep (or get) yourself physically healthy (e.g. exercise and diet)	−0.01	−0.01	**0.88**	0.04	27 (31.0)	8 (9.2)
How best to support other grandchildren in the family	0.00	0.13	0.29	**0.67**	32 (36.8)	26 (29.9)
How best to support your own children (i.e. your grandchild's parents)	0.16	0.00	0.05	**0.78**	32 (36.8)	41 (47.1)
Advice/stories from other grandparents who have had a similar experience	−0.08	0.07	0.05	**0.80**	47 (54.0)	17 (19.5)
Information about relapse	0.2	**0.85**	−0.09	−0.05	26 (29.9)	52 (59.8)
Information about palliative care	−0.05	**0.79**	0.08	0.14	24 (27.6)	23 (26.4)
Information about special issues for grandparents if a grandchild dies	−0.05	**0.80**	0.19	0.06	19 (21.8)	38 (43.7)
Eigenvalues	4.07	2.44	2.30	2.27	NA	NA
% of variance	27.13	16.26	15.33	15.13	NA	NA
α	.91	0.82	.82	.81	NA	NA

Abbreviations: N, number of participants; NA, not assessed, or not applicable.
Note: factor loadings over 0.6 appear in bold.