Psychometric evaluation of the Sibling Cancer Needs Instrument (SCNI): an instrument to assess the psychosocial unmet needs of young people who are siblings of cancer patients

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Abstract

Purpose The current study sought to establish the psychometric properties of the revised Sibling Cancer Needs Instrument (SCNI) when completed by young people who have a brother or sister with cancer.

Methods The participants were 106 young people aged between 12 and 24 who had a living brother or sister diagnosed with any type or stage of cancer in the last 5 years. They were recruited from multiple settings. The initial step in determining the dimensional structure of the questionnaire was exploratory factor analysis and further assessment followed using Rasch analysis. Construct validity and test–retest reliability ($n = 17$) were also assessed.

Results The final SCNI has 45 items and seven domains: information; practical assistance; "time out" and recreation; feelings; support (friends and other young people); understanding from my family; and sibling relationship. There was a reasonable spread of responses across the scale for every item. Rasch analysis results suggested that overall, respondents used the scale consistently. Support for construct validity was provided by the correlations between psychological distress and the SCNI domains. The internal consistency was good to excellent; Cronbach's alphas ranged from 0.78 to 0.94. The test–retest reliability of the overall measure is 0.88.

Conclusions The SCNI is the first measure of psychosocial unmet needs which has been developed for young people who have a brother or sister with cancer. The sound psychometric properties allow the instrument to be used with confidence. The measure will provide a substantial clinical benefit in highlighting the unmet needs of this population to assist with the prioritisation of targeted supportive care services and evaluating the impact of interventions targeted at siblings.

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Adolescents and young adults (AYAs[1]) who have a brother or sister with cancer face significant changes in family dynamics, as they adjust to a major disruption in the family's life and

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[1] In the Australian context, AYAs have traditionally included young people aged 15–25 years [1]. However, as the organization developing the SCNI has members aged 12–24 years, this age group is used throughout this study.

process the emotional stress of a cancer diagnosis in their family [2–5]. Parents have expressed the belief that current support for siblings is inadequate and a willingness for their child to be involved in therapeutic interventions [6]. Health professionals likewise recognise the psychosocial impact a young person's cancer diagnosis has on their siblings and the need to extend psychosocial care to siblings, but they also acknowledge the challenges associated with this [7]. It is therefore essential that methods and tools for assessing psychosocial needs of siblings are established to assist in the provision of appropriate support. Siblings of cancer patients often feel isolated and that their needs are ignored, due to the focus on the needs of the patient [8]. Additionally, they may experience a range of negative emotional reactions [2, 3, 9], be more likely to experience post-traumatic stress symptoms than other adolescents [10] and display poor behavioural and emotional functioning [11]. Even though siblings experience significant difficulties, they report few opportunities to talk about how they are feeling and experience a lack of support in coping with their feelings [9, 12].

Given both the range of negative emotional and psychological issues that AYA siblings of cancer patients can experience and the lack of clarity as to how to extend psychosocial care to them, the development and validation of a brief self-report instrument that facilitates the expression of their unmet psychosocial needs is critical. Such instruments

rapidly identify areas of most need for the individual and can inform the development of services and interventions to address the needs of this group of young people. Our group recently reported the initial development of a measure for AYA siblings of cancer patients: the Sibling Cancer Needs Instrument (SCNI) [9]. However, this initial study had several limitations that necessitated further refinement and evaluation of the instrument. First, participants were from one peer support organisation for young people living with cancer (CanTeen, the Australian Organisation for Young People Living with Cancer), thereby potentially biasing the results. Further, there were some shortcomings in the initial response scale that required revision. These included a long-time frame for responses (in the last 12 months) and complex response options (two-step process of identifying the level of need and whether or not it was met). Since then, we have revised the SCNI to create a simplified format to capture self-expressed needs that are currently unmet and this paper describes the evaluation of the revised SCNI measure. See Table 1 for the original [9] and revised domain structure.

The aims of the study were to evaluate and establish the psychometric properties of the revised SCNI when completed by a larger sample of young people impacted by their brother or sister's cancer, recruited from multiple settings, and to identify problematic and redundant items for removal so that the instrument imposes less burden on respondents.

Table 1 SCNI domain descriptions

Needs domains used in validation	Original need domains [9]	Description
Information about my sibling's cancer	Information	This domain entails young people having access to information about their sibling's cancer, and for this information to be presented to them in a way that they can understand.
"Time out" and recreation	Respite and recreation	This domain deals with the need for young people to be involved in sport and social activities. It also encapsulates the need for occasional escapism and "time out" from the pressures of having a parent with cancer.
Practical assistance	Access to support services and professional help Instrumental support	The practical assistance domain covers the following areas: a need for assistance with the household duties; transport; assistance with attending and staying on task at school, TAFE, university, and/or work; having access to professional support services.
Support from my friends and other young people	Peer support (similar experience) Peer support (friends)	This domain encompasses both the need to feel supported from one's own friendship group, and from other young people who share a similar experience of having a sibling with cancer.
Dealing with feelings	Expressing and coping with feelings	This domain focuses on the need for young people to be able to express how they are feeling about their sibling's cancer, and also the need for help in dealing with these feelings.
Understanding from my family	Involvement in the cancer experience Acknowledgment and attention for self	This domain covers the need for young people to feel supported by their families; to be more involved in their sibling's cancer experience and not feel excluded from it; to have attention from immediate or extended family members; and to have open and honest communication with them.
My relationship with my sibling with cancer	Sibling relationship and support	This domain addresses the need for help with issues involving their relationship with their sibling with cancer and navigating any challenges in that relationship that may arise as a result of the cancer experience.

SCNI Sibling Cancer Needs Instrument, *TAFE* Technical and Further Education

Method

Participants

The study was open to all siblings aged between 12 and 24 years who had a brother or sister (of any age) diagnosed with any type or stage of cancer within the last 5 years and who was still living.

Measures

A survey assessed socio-demographic and medical information, the SCNI and psychological distress.

Socio-demographic and medical questions Participants were asked for demographic information about themselves (e.g. age, gender, CanTeen Membership status) and demographic and medical information about the patient and their cancer (e.g. age, gender, type of cancer). All information was provided by the sibling, and due to anonymous nature of the survey, no checking of the cancer information was undertaken.

Needs instrument—the Sibling Cancer Needs Instrument [9] The SCNI contains 73 items clustered into seven domains as shown in Table 1. Items are answered according to the sentence stem "I currently need" and used a four-item response scale where: 1 = *no need* ("I don't have any need for help with this issue"), 2 = *low need* ("I have a low need for help with this issue"), 3 = *moderate need* ("I have a moderate need for help with this issue") and 4 = *strong need* ("I have a strong need for help with this issue"). In addition, a page of instructions for the SCNI was provided (see Fig. 1). See Table 2 for a complete list of items. Participants were given the option to list up to three additional unmet needs and to rate their level of need (low, moderate or strong). They were also asked to respond to two questions about how easy the SCNI was to understand and whether they felt distressed when completing it, using a four-point scale from 1 = *strongly disagree* to 4 = *strongly agree*.

Kessler 10 [13] The Kessler 10 (K10) is a 10-item measure widely used to measure psychological distress. Amongst adults, the K10 has been found to have very high internal consistency reliability (Cronbach's alpha=0.93) and very good discrimination (area under the curve=0.85) [13]. In Australia, the K10 has been used in national studies with people aged 16 and over [14]. Participants reflect on how they have been feeling over the last 4 weeks and respond using a five-point scale from 1 = *never* to 5 = *all the time*, where a higher total score indicates greater psychological distress.

Fig. 1 Instructions provided with the SCNI measure

We would like to know what your current needs are regarding your experience of having a brother or sister with cancer.

For each statement, please indicate whether you need help with this issue by putting a circle around the number that best describes how you feel about each issue.

The scale below describes what each number means.

No Need	Low Need	Moderate Need	Strong Need
1	**2**	**3**	**4**
I don't have any need for help with this issue	**I have a low need for help with this issue**	**I have a moderate need for help with this issue**	**I have a strong need for help with this issue**

FOR EXAMPLE:

I CURRENTLY NEED…	No need	Low need	Moderate need	Strong need
friends to understand what I'm going through	1	2	3	4

- If you think that your friends **do** understand what you're going through, *or* it's not important to you that they understand – **then you would circle 1.**

- If you feel as though your friends have **some** understanding, but not as much as you would like them to have – **then you would circle 2 or 3.**

- If you feel as though your friends **don't** understand as much as you would like them to, and you have a strong need for help with this issue – **then you would circle 4.**

Table 2 A list of the original SCNI items (and their means) specifying those retained in the final version and their final domain

Items relating to:	Original item number	Item retained	Final item number	Mean
Information about my sibling's cancer				
To be spoken to by health care professionals in a way that I can understand	1	Y	1	1.97
To be informed about my sibling's condition—good or bad	2	Y	2	2.64
To be able to get information about my sibling's type of cancer and its treatment in a way that I can understand	3	Y	3	2.42
Information about what happens after my sibling comes home following treatment	4	Y	4	2.39
To be able to speak with my sibling's doctor about my sibling's condition, as often as I need to	5	N		1.95
Information about the impact that the cancer and treatment may have on my sibling's life in the future	6	Y	5	2.65
To feel that health care professionals include me in discussions about my sibling's cancer	7	Y	6	2.14
To be informed about what is involved in my sibling's treatment	8	N		2.43
Information about the chances of my sibling's recovery	9	N		2.65
Information about the side effects of my sibling's treatment	10	Y	7	2.66
Information about what to do if I notice a particular side effect or symptom in my sibling with cancer	11	N		2.72
"Time out" and recreation				
To be able to do activities that other young people are doing	12	N		2.28
To be able to have fun	13	Y	9	2.52
To feel like a "normal" young person, which it seems I've lost as a result of my sibling's cancer	14	Y	10	2.25
Somewhere to go when it gets too hard to deal with my sibling's cancer	15	Y	11	2.46
To have "time out" from the extra duties that I have taken on at home	16	Y	12	2.28
To be involved in activities that distract me from the way that my sibling's cancer makes me feel	17	N		2.36
Access to fun and interesting activities while my sibling is in hospital	18	N		2.26
To have time to look after myself and focus on my own needs	19	Y	13	2.36
To spend more time with friends	20	N		2.48
Practical assistance				
Assistance with managing daily tasks	21	Y	15	1.55
To have people around me who can help out by taking over some of the things that my parent/s don't have time to do anymore	22	Y	16	1.93
Help concentrating on tasks at school, TAFE, university or work[a]	23	Y	14	2.17
Someone to take me to social events and activities	24	N		1.85
My teachers and/or boss to understand my situation and be more flexible[a]	25	Y	8	2.12
Help being linked in with an appropriate support service	26	N		1.89
Access to information about support services that are available to me	27	Y	17	1.92
Assistance with jobs and chores around the house	28	N		1.64
Assistance with learning practical life skills (e.g. cooking, cleaning, etc.)	29	N		1.71
Support from my friends and other young people				
My friends to understand what I am going through	30	Y	18	2.37
The opportunity to spend time with other young people affected by their sibling's cancer	31	Y	19	2.27
To talk with someone my own age who has been through a similar experience with cancer	32	N		2.36
To be able to learn from other young people who have been through a similar experience with cancer	33	N		2.37
To be linked in with a social support network with others who share a similar experience	34	Y	20	2.11
Support from my friends	35	Y	21	2.57
To know how to talk to my friends about my experience with my sibling's cancer	36	Y	22	2.32
To feel supported by peers who have a similar experience with cancer	37	Y	23	2.32
My friends to feel comfortable talking to me about my experience with my sibling's cancer	38	N		2.48
Help dealing with being left out by friends	39	N		2.06
Dealing with feelings				
Help dealing with feelings of anxiety and feeling scared about my sibling's cancer	40	Y	26	2.37

Table 2 (continued)

Items relating to:	Original item number	Item retained	Final item number	Mean
Help dealing with sadness related to my sibling's cancer	41	Y	27	2.44
Help dealing with feelings of guilt related to my sibling's cancer	42	Y	28	2.13
Help dealing with grief	43	N		2.06
To know how to talk to my family about how I am feeling	44	N		2.30
Help with feelings about the possibility that my sibling with cancer might die	45	Y	29	2.50
Help dealing with other people's reactions regarding my sibling's cancer	46	N		2.17
To talk with a counsellor/psychologist/social worker	47	Y	30	1.85
To talk with someone regarding the issues I have about growing up	48	N		1.70
To learn ways of coping with the added stress placed on my family	49	Y	31	2.37
Information about the different feelings I might have because of "the cancer"	50	N		2.16
To have someone close to discuss my feelings about my sibling's cancer[a]	51	Y	24	2.25
To be able to express how I feel about my sibling's cancer without worrying about upsetting people	52	Y	32	2.38
To be able to talk about how I am going (and not how my sibling is going) without feeling guilty[a]	53	Y	25	2.35
To be able to still have fun and enjoy myself without feeling guilty	54	N		2.31
Help dealing with feelings of frustration and anger about my sibling's cancer	55	Y	33	2.30
Understanding from my family				
For my family to have access to counselling	56	N		1.89
For my family to acknowledge that this is happening to me too	57	Y	34	2.04
To be treated as a member of the family rather than as a "bystander"	58	N		2.00
To know my parent/s haven't forgotten about me	59	Y	35	2.01
To be able to spend time with my parent/s—just me and them	60	Y	36	2.12
To be noticed and have some of the attention from family members	61	N		2.02
To feel that I am just as important and valued as my sibling with cancer	62	Y	37	2.16
To feel that I can openly talk with my family about my sibling's cancer	63	Y	38	2.05
To feel that my parent/s are being open with me about what is going on regarding my sibling's cancer	64	N		2.16
My relationship with my sibling with cancer				
Help with understanding how my sibling is feeling	65	Y	39	2.31
To know how to talk to my sibling about how they are feeling	66	N		2.37
To know how to talk to my sibling about how I am feeling	67	Y	40	2.38
To have "time out" with my sibling away from "the cancer"	68	Y	41	2.55
Help dealing with changes in my relationship with my sibling	69	Y	42	2.20
To be able to spend more time with my sibling while they are in hospital	70	N		2.48
To know ways of giving emotional support to my sibling	71	Y	43	2.56
To know ways of giving practical support to my sibling	72	Y	44	2.44
To feel included in my sibling's cancer experience	73	Y	45	2.27

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[a] Following evaluation, these items have been placed in different domains. Item 23 (14) is in the time out and recreation domain. Item 25 (8) is in the information domain. Items 51 (24) and 53 (25) are both in the support from my friends and other young people domain

Procedure

Participants were invited to complete the survey using the following three recruitment approaches: (1) posters and notices directing people to an online version of the survey were displayed at three hospitals located in Sydney and on oncology consumer websites; (2) paper copies of the survey were posted to new members of CanTeen, and to people who ordered relevant resources from CanTeen; and (3) siblings of patient members of CanTeen (who were not members themselves) were invited to participate via their brothers and sisters. The intention was to reach an extensive and broad sample of siblings. Participants were also invited to complete a retest of the SCNI and 17 participants did this within the required 2-week window. Ethics approval was obtained from the ethics committees of CanTeen Australia and the

participating hospitals. Parental consent was gained if the young person was less than 18 years of age.

Statistical analyses

Exploratory factor analysis Exploratory factor analysis (EFA) using principal axis factoring was conducted as an initial step to determine the dimensional structure of the questionnaire. A direct oblimin rotation was employed to allow domains to be correlated. The suitability of the data for EFA (i.e. the degree of correlation amongst the items) was established by examining the Kaiser–Myer–Olkin (KMO) measure of sampling adequacy (>0.8 indicates suitability) and the Bartlett test of sphericity ($p < 0.01$ indicates suitability) [15].

Parallel analysis [16] and a scree plot were employed to determine the number of factors (i.e. domains) to select. Factor loadings were examined and, using a cut-off of 0.3, items with low factor loadings or high cross-loadings were considered for removal from the questionnaire. No item was eliminated from the instrument based on any of the statistical analyses without consideration of its content. Missing data was excluded from the EFA analysis at an item level.

Rasch analysis Items were further assessed using Rasch analysis [17], in which the observed responses to items are assumed to reflect an underlying latent variable, such that the probability of endorsing an item is a monotonic increasing function of the latent variable. Rasch analysis was performed separately for the dimensions identified using EFA and was conducted using RUMM2020 [18], which allows modelling of polytomous (i.e. more than two response options) items, as in the present case. The aim of this analysis was to determine whether any of the items exhibited problems with fit to the Rasch model[2] (fit residuals greater than 2.5), item response threshold ordering or differential item functioning (DIF) across sibling gender, who was diagnosed with cancer (patient gender), patient age and the stage of treatment of the diagnosed person. Any items that exhibited such problems, or were shown by high residual correlations to be redundant, were considered for removal from the questionnaire. Test–retest scores also contributed to determining which items to remove. The targeting of each domain to the participants was also assessed. Missing data was excluded from the Rasch analysis at an item level. This general method is described in more detail by Pallant and Tennant [19].

Item reduction As described above, Rasch analysis identified items that could be removed from the questionnaire. The decision about which items to remove was based on several factors, including the frequency of moderate and high responses to each item, the test–retest score, the correlation between items and the clinical significance of the items.

Validity and reliability testing Correlations amongst domains, internal consistency (using Cronbach's alpha [20]) and test–retest reliability (using intraclass correlations, ICC) of the items, domains and overall questionnaire were examined. A Cronbach's alpha of 0.80 and above was identified as good and 0.90 and above as excellent [20]. An ICC value of 0.70 and above indicated good reliability [21, 22]. Test–retest reliability was estimated using the ICC found by taking the variance between participants divided by the total variance (between plus within) of each item, domain score and total score.

Although no current measure exists with which the SCNI can be directly compared to assess criterion validity, the hypothesised relationship between unmet needs and mental health was examined [23]. It was expected that a higher number of unmet needs would correlate positively with psychological distress as measured using the K10. In addition, it was expected that the domains more associated with feelings and emotions would associate more strongly with the K10. Content validity has been determined previously through the development process which involved a focus group and interviews with siblings, a survey with professionals working with this population, a literature review, pilot work and asking participants if they had any additional unmet needs not addressed in the questionnaire after completing it [9]. In this study, it is further assessed by again asking participants if they have additional unmet needs not addressed in the questionnaire.

Results

Participants

A total of 123 young people responded; however, 17 were excluded because they did not meet the eligibility criteria, leaving a total eligible sample of 106 (age $M = 16.6$ years, SD=3.6). Participants were removed for the following reasons: they were not of correct age ($n = 1$), they were bereaved ($n = 1$) and the time since diagnosis of their sibling was greater than 5 years ($n = 15$). Over half (68.2 %) of the respondents were members of CanTeen; of those 81.3 % had been a member for 12 months or less.[3] The mean time since their brother or sister's diagnosis was 16.2 months (SD=13.8) and the average age of the sibling when their brother or sister was diagnosed was 14.8 years (SD=3.7). The mean age of the brother or sister with cancer at the time the survey was

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[2] Item and person fit refer to items or respondents whose response patterns deviate from the expectations of the Rasch model. See Pallant and Tennant [16] for a concise summary of these statistics.

[3] There were no differences between people who were members of CanTeen and people who were not with regard to total K10 scores ($t_{96} = -1.67$, $p = 0.10$) or total unmet needs scores ($t_{95} = -1.21$, $p = 0.23$).

completed was 14.3 years (SD=5.1, range=3–27). The sample had a strongly Caucasian background with most mothers (88.8 %) and fathers (90.6 %) being born in Australia, New Zealand, the UK or the USA. Most families spoke only English at home, four spoke English and another language, and one family spoke only German. Most participants lived with both parents (67.0 %), with 7.5 % living with neither parent and the remainder lived with one parent. See Table 3 for more details concerning the sibling and their brother or sister with cancer.

Exploratory factor analysis

The results of the EFA are summarised in Table 4. The suitability of the items for EFA was adequate (KMO=0.84; Bartlett's χ^2=8,191.20, p<0.0005). Both parallel analysis and the scree plot suggested the extraction of four domains which accounted for 60.23 % of the variance. Overall missing data for the SCNI was low; of 106 participants, three missed one item and six missed five or more items of the SCNI.

Table 3 Demographic characteristics of participating siblings and their brothers and sisters with cancer (n=106)

	No	Percent
Participating siblings		
Gender		
Male	33	31.1
Female	73	68.9
Country of birth		
Australia	82	77.4
New Zealand	14	13.2
England	3	2.8
USA	3	2.8
Other	4	3.8
Brother or sister with cancer		
Gender		
Male	54	50.9
Female	52	49.8
Most common cancer types[a]		
Leukaemia	38	35.8
Hodgkin's lymphoma	15	14.2
Brain	14	13.2
Bone and soft tissue	13	12.3
Reproductive	12	11.3
Other	19	17.9
Treatment stage		
Recently diagnosed	2	1.9
On treatment	70	66.0
Finished treatment	32	30.2
Unsure	2	1.9

[a] Some people had more than one type of cancer

Domain 1 (factor 2) contains items 1–11 (information about the sibling's cancer), item 25 (my teachers and/or boss to understand my situation and be more flexible) and item 70 (spend time with sibling while in hospital). Domain 2 (factor 4) contains items 12–20 ("time out" and recreation), items 30–39 (support from friends and other young people) as well as items 23 (tasks at school), 24 (take to social events), 51, 53 and 54 (dealing with feelings). Domain 3 (factor 1) contains items 21, 22, 26 and 27 (practical assistance); items 40–50, 52, 55 (dealing with feelings) and 56 (counselling for family); as well as items 65–69 and 71–73 (relationship with sibling). Domain 4 (factor 3) contains items 57–64 (understanding from family). Items 28 and 29 did not load onto any domains.

Rasch analysis

Rasch analysis was conducted separately on each of the domains identified above. A summary of the Rasch analysis for all domains is in Table 4.

Domain 1: information about sibling's cancer

This domain included items 1–11, 25 and 70. The overall model and person fit were good, and although overall item fit was also good, items 25 and 70 exhibited misfit and were excluded from the analysis. No items exhibited disordered thresholds and the domain was well targeted. Item 10 (information about side effects) exhibited non-uniform DIF, where respondents at the higher end of this trait with the same trait score scored higher on this item if their brother had cancer than if their sister had cancer. Item 8 also exhibited non-uniform DIF, with older respondents scoring higher in the middle range of this item than younger respondents but not differently for lower and higher trait scores. Items pairs with high residual correlations are indicated in Table 4.

Domain 2: "time out" and recreation, support from friends and other young people, practical assistance and dealing with feelings

The overall item and model fit were good, but person fit was poor. Inspection of residual correlations suggested that this domain should in fact be represented by two domains:

(2a) Items 12–20, 23 and 24 ("time out"/recreation and practical assistance)
(2b) Items 30–39, 51, 53 and 54 (support from friends and dealing with feelings)

For domain 2a, the overall model, item and person fit were good. Thresholds for items 18 (fun and interesting activities) and 24 (social events) were disordered, but these were remedied by combining the two lowest response categories. This disordering may have been driven by the higher

Table 4 Exploratory factor analysis, Rasch analysis, and retest results

Factor	Factor analysis				Rasch analysis					Retest results
	1	2	3	4	Location[a]	Fit[a]	DT[b]	DIF[c]	RC[d]	
Item										
1	0.23	*0.46*	0.13	0.01	0.82	0.14				0.66
2	−0.03	*0.91*	−0.05	0.13	−0.43	0.08			3	0.74
3	0.09	*0.88*	0.00	0.09	0.01	−1.73			2	0.65
4	0.04	*0.72*	0.15	−0.09	0.15	−1.25				0.86
5	0.15	*0.50*	−0.03	−0.10	0.90	0.97			7	0.75
6	0.00	*0.80*	−0.14	−0.14	−0.54	−0.48			9	0.85
7	0.14	*0.47*	0.23	−0.06	0.63	1.08			5	0.75
8	0.09	*0.72*	0.02	−0.08	0.00	−1.20		Age[e]		0.73
9	−0.14	*0.75*	0.02	−0.18	−0.44	−0.02			6	0.81
10	−0.17	*0.77*	0.02	−0.21	−0.48	0.70		Who[f]	11	0.76
11	0.01	*0.69*	0.03	0.05	−0.60	1.43			10	0.54
12	0.04	0.04	0.10	*−0.61*	−0.05	0.14			13	0.60
13	−0.12	0.04	0.17	*−0.69*	−0.53	−0.31			12	0.64
14	0.16	0.04	0.18	*−0.58*	−0.04	−1.06			17, 20	0.58
15	0.22	0.17	0.10	*−0.49*	−0.44	−1.75			17	0.63
16	0.20	0.06	0.17	*−0.34*	−0.15	0.88				0.53
17	0.18	−0.06	0.02	*−0.77*	−0.34	−1.76			14, 15	0.42
18	−0.13	0.28	0.23	*−0.44*	0.66	1.34	X		24	0.49
19	0.21	0.07	0.18	*−0.40*	−0.21	−0.35				0.81
20	−0.07	−0.06	0.11	*−0.75*	−0.49	−0.08			14	0.45
21	*0.39*	−0.07	0.27	−0.16	1.24	0.20				0.27
22	*0.45*	−0.11	0.18	−0.28	−0.50	0.81				0.78
23	*0.35*	−0.06	0.04	*−0.44*	0.15	1.59				0.59
24	0.14	−0.08	0.24	*−0.44*	1.45	0.65	X		18	0.54
25	0.12	*0.31*	0.24	−0.12						0.58
26	*0.42*	0.27	0.21	−0.01	−0.41	−0.04			27	0.39
27	*0.40*	0.32	0.17	−0.04	−0.33	0.10			26	0.47
28	0.16	0.12	0.24	−0.22						0.35
29	0.26	0.03	0.16	−0.21						0.80
30	−0.01	0.24	0.13	*−0.54*	−0.08	0.15			35, 38, 39	0.55
31	−0.06	0.17	−0.04	*−0.76*	0.08	−0.78			32, 33, 34	0.63
32	0.09	0.04	−0.02	*−0.64*	−0.07	0.65			31, 33, 34	0.47
33	0.10	0.11	−0.02	*−0.65*	−0.13	−0.76			31, 32, 34	0.77
34	0.21	0.05	0.07	*−0.54*	0.72	−0.04			31, 32, 33	0.82
35	−0.12	0.21	0.14	*−0.66*	−0.44	0.54			30, 39	0.67
36	0.13	0.12	0.06	*−0.62*	−0.03	−1.28			37, 38	0.90
37	0.05	0.17	−0.04	*−0.68*	0.07	−1.55			36	0.88
38	0.16	0.06	−0.10	*−0.69*	−0.32	1.40			30, 36	0.83
39	0.20	0.07	0.02	*−0.51*	0.08	−0.04	X		30, 35	0.24
40	*0.68*	0.09	0.09	−0.09	−0.39	0.17			41	0.63
41	*0.82*	0.02	−0.16	−0.16	−0.69	−1.57			40, 42	0.83
42	*0.59*	0.07	−0.05	−0.16	0.30	0.44			41	0.67
43	*0.62*	0.03	0.16	−0.11	0.31	−0.32				0.75
44	*0.53*	0.15	0.20	0.09						0.53
45	*0.79*	0.12	−0.06	0.02	−0.74	0.53				0.74
46	*0.50*	0.13	0.02	*−0.31*	0.09	−0.72			50, 52	0.83

Table 4 (continued)

Factor	Factor analysis				Rasch analysis					Retest results
	1	2	3	4	Location[a]	Fit[a]	DT[b]	DIF[c]	RC[d]	
47	*0.74*	−0.07	0.20	0.04	0.85	0.44			48	0.58
48	*0.61*	0.01	0.32	0.03	1.34	−0.39			47	0.38
49	*0.60*	0.00	0.19	−0.18	−0.49	0.07				0.77
50	*0.41*	0.17	*0.33*	−0.12	0.06	0.16			46	0.68
51	0.18	0.15	*0.32*	*−0.36*	0.14	0.35				0.74
52	*0.49*	0.07	0.04	−0.30	−0.40	0.52			46	0.87
53	0.30	0.02	0.20	*−0.37*	−0.05	1.52			54	0.64
54	*0.35*	0.03	0.05	*−0.47*	0.02	0.73			53	0.85
55	*0.57*	−0.02	0.11	−0.28	−0.25	0.07				0.76
56	*0.62*	0.03	0.29	0.20						0.78
57	0.13	0.11	*0.70*	−0.09	0.29	−0.16			58	0.48
58	0.15	0.10	*0.67*	0.03	−0.32	0.79	X		57	0.65
59	−0.02	0.02	*0.83*	−0.10	0.35	−0.90				0.72
60	0.00	−0.06	*0.75*	−0.22	−0.68	0.24	X		61	0.68
61	0.00	−0.06	*0.80*	−0.14	0.28	−0.25			60, 62	0.58
62	−0.13	0.00	*0.85*	−0.14	−0.12	0.74			61	0.57
63	0.23	0.28	*0.60*	0.09	0.27	−0.06			64	0.80
64	*0.31*	*0.33*	*0.48*	0.08	−0.06	1.22			63	0.77
65	*0.55*	0.28	−0.20	−0.30	0.31	−0.12			66	0.87
66	*0.60*	0.20	−0.24	−0.26	0.04	−0.35			65, 67	0.84
67	*0.46*	0.23	−0.14	−0.26	−0.15	1.22			66	0.53
68	*0.43*	0.20	0.08	−0.30	−0.42	1.81				0.58
69	*0.46*	0.18	−0.03	*−0.33*	0.58	−0.24				0.43
70	0.30	*0.37*	0.12	−0.23						0.71
71	*0.55*	0.27	−0.10	−0.20	−0.55	−0.46			72	0.76
72	*0.50*	0.14	−0.01	−0.29	−0.16	−0.98			71	0.77
73	*0.41*	0.18	0.27	−0.20	0.34	1.23				0.71

Factor loadings greater than 0.3 appear in italics

DT disordered threshold, *RC* residual correlation

[a] Location and fit statistics were obtained from final Rasch analyses on each domain (i.e. with items deleted or rescored as described in text)

[b] "X" indicates disordered item thresholds

[c] The variable across which differential item functioning (DIF) is exhibited

[d] Local dependency; the numbers given are item numbers with which the item has residual correlation

[e] Age—of sibling

[f] Who—gender of person diagnosed

frequencies observed in the first and third response categories than in the second category (i.e. a bimodal distribution).

For domain 2b, the overall model and item fit were good, while person fit was poor. Item 39 (dealing with being left out) exhibited a disordered threshold, which was remedied by combining the two highest response categories. This disordering may have resulted from high frequencies observed for the first response category. For domains 2a and 2b, targeting was fair, although items did not cover lower trait scores adequately. No DIF was exhibited.

Domain 3: practical assistance, dealing with feelings, relationship with sibling

Although the model, item and person fit were all good, inspection of residual correlations suggested that this domain should be represented by three domains:

(3a) Items 21, 22, 26 and 27 (practical assistance)
(3b) Items 40–50, 52, 55 and 56 (dealing with feelings, counselling for family)

(3c)   Items 65–69 and 71–73 (relationship with sibling)

For domain 3a, the model, item and person fit were all good. There were no disordered thresholds or DIF. The domain was, however, poorly targeted, with the items not covering lower trait scores adequately.

For domain 3b, model and person fit were all adequate, but item fit was poor, with items 44 (know how to talk to family) and 56 (family have access to counselling) exhibiting misfit. Model fit was good when these two items were removed from the analysis. There were no disordered thresholds or DIF, and the domain was well-targeted.

For domain 3c, the model, item and person fit were all adequate. There were no disordered thresholds or DIF, and the targeting of the domain was fair, although the items did not cover lower trait scores adequately.

Domain 4: items 57–64 (understanding from my family)

This domain included items 57–64. Model, item and person fit were all poor, with items 58 (treated as member of family) and 60 (spend time with parents) disordered. This disordering may have resulted from the lower frequencies observed in the third response category than in the second and fourth categories. When items 58 and 60 were rescored by combining the two highest response categories, model and item fit, but not person fit, were adequate. Targeting was fair, although the items did not cover lower trait scores adequately.

Item removal and retention

Based on the results of the EFA and Rasch analysis, and after consideration of the content of the items flagged as problematic in these analyses, several items were removed from the questionnaire and domain membership reorganised. The domain structure of the final instrument is the same as the revised version of the instrument except for items 23, 25, 51 and 53 (see Table 2). Although the Rasch analysis suggested item 25 be removed, due to its clinical significance in asking about an important need for this population, it was retained in the final measure. In total, 28 items were removed. The analysis described below was conducted using the final version of the SCNI.

Unmet needs endorsement

The mean and standard deviation for each item is given in Table 2 and the mean score for each domain is given in Table 5. The items with the highest endorsement tend to come from the information domain, for example, *information about the side effects of my sibling's treatment* and *to be informed about my sibling's condition—good or bad*. Other items with strong endorsement were associated with the sibling relationship (items 68 and 71), concerns about their brother or sister dying (item 45), support from their friends (item 35) and to be able to have fun (item 13). This is supported by the domain means; the information domain has the highest mean (taking into consideration the number of items), followed by the sibling relationship, and "time out" and recreation domains.

Table 5 Domain means (and standard deviations), internal consistency (Cronbach's α), inter-domain correlations, correlations with Kessler 10 and final Rasch fit statistics for each domain

					Correlations with other domains*						Rasch fit				
		M	SD	α	1	2	3	4	5	6	K10	Model[a]	Item	Person	Target
1	Information	18.42	6.61	0.89							0.52*	0.38	1.16	1.21	Good
2	"Time out" and recreation	14.05	5.32	0.89	0.68						0.61*	0.08	1.18	1.17	Fair
3	Support (friends and peers)	18.53	7.29	0.93	0.73	0.82					0.48*	0.45	0.95	1.75	Fair
4	Practical assistance	5.74	2.70	0.78	0.57	0.70	0.65				0.44*	0.67	0.37	1.11	Poor
5	Feelings	18.31	7.45	0.94	0.66	0.77	0.76	0.66			0.67*	0.81	0.62	1.29	Good
6	Relationship with sibling	16.70	6.87	0.94	0.69	0.74	0.77	0.68	0.81		0.53*	0.14	1.01	1.62	Fair
7	Understanding from family	10.37	4.79	0.92	0.53	0.65	0.67	0.57	0.62	0.58	0.44*	0.15	0.69	1.99	Fair
	Total SCNI	103.89	34.88	0.98							0.62*				

Domain means (and standard deviations), internal consistency (Cronbach's α), inter-domain correlations and correlations with Kessler 10 are based on the 45 items retained in the final SCNI (Sibling Cancer Needs Instrument). Final Rasch fit statistics is based on the 73 original items, except where items were removed from the analysis as indicated in "Results." The range for each domain is as follows: information about my sibling's cancer (8–32), "time out" and recreation (6–24), support from my friends and other young people (8–32), dealing with feelings (8–32), practical assistance (3–12), my relationship with my sibling with cancer (7–28), understanding from my family (5–20). The range for the total SCNI is 45–180

*$p < 0.01$ (significant)

[a] p value for the person–item interaction χ^2. None of these were statistically significant when assessed against the Bonferroni-adjusted criterion

Construct validity

Convergent validity was determined by examining the pattern of the domain correlations with respondents' K10 scores. As shown in Table 5, all correlations were moderate to large and statistically significant [24]. The highest correlation with K10 was with the feelings domain. The need for "time out" and recreation domain also correlated comparatively highly with the K10. The other domains had lower correlations with the K10 which were comparable with each other.

Internal consistency

Internal consistency for the domains was found to be good to excellent, with the lowest Cronbach's alpha scores being 0.78 (for the practical assistance domain). The "time out" and recreation, and information domains had a Cronbach's alpha of 0.89. All other domains had Cronbach's alphas between 0.92 and 0.94, and the Cronbach's alpha for the overall SCNI is 0.98 (see Table 5 for details).

Stability over time

Stability over time was measured by looking at test–retest correlation coefficients ($n = 17$). At an item level, retest coefficients for retained items ranged from 0.27 to 0.90 (see Table 4). Domain retest scores are as follows: information domain, 0.92; "time out" and recreation domain, 0.69; practical assistance domain, 0.62; support from friends and other young people domain, 0.89; dealing with feelings domain, 0.88; understanding from my family domain, 0.76; and my relationship with my sibling domain, 0.84. Overall, the measure demonstrated good test—retest reliability at the domain level (six out of seven domains ICC>0.70) and at the questionnaire level where the retest coefficient was 0.88.

Content validity

Content validity was assessed by looking at the additional unmet needs that participants listed. In total, 17 people listed 21 items; of these, 14 are covered by existing items within the SCNI, 3 are outside the scope of the SCNI (e.g. "give parents a break") and 4 were not covered by the SCNI. These four items covered coping with the family travelling away for treatment, coping with stress, money concerns within the family and behavioural problems at school. These items were not included as it was felt they were similar to existing items or were too specific to the individual.

Reading ease and participant acceptance of questionnaire

The majority of participants (87.8 %) agreed or strongly agreed that the SCNI was easy to understand, (8.5 % did not respond). The Flesch reading ease of the SCNI is 80.0, meaning it is suitable for children aged 11 years and above. The majority also reported that it was not distressing to complete (70.8 %). Of those who did find it distressing, 2.8 % strongly agreed it was distressing (17.9 % agreed it was distressing, 8.5 % did not respond).

Scoring the SCNI

The overall SCNI score and domain scores are determined by summing the responses to all items and items within each domain. This gives a range of possible SCNI scores from 45 to 180 (domain ranges are provided in Table 5). The mean score and standard deviation for the SCNI are provided in Table 5. A half-mean imputation rule is used for missing items in the SCNI scale: if half or more of the items of the subscale are completed, missing items are replaced by the mean of the subscale to which the item belongs.

Discussion

The purpose of this study was to evaluate the psychometric properties of the SCNI, a self-report measure of unmet needs amongst AYA siblings of cancer patients. The SCNI was developed so that a validated self-report needs instrument would be available to assess the unmet needs of AYAs who are siblings of cancer patients, with the results informing appropriate care. Siblings of cancer patients have been found to experience psychological difficulties and often need support [2–6, 9], yet to date there has been no measure developed to assess the needs of this group of young people.

This study presents the final version of the SCNI, which was determined using EFA and Rasch analysis, and guided by consideration of the test–retest scores and the content of the items. This resulted in a reduced instrument of 45 items, with the same seven domain structure as the initial SCNI, and good psychometric properties. Support for the construct validity of the SCNI was satisfactory and was provided by assessments of convergent validity, content validity and internal consistency. Convergent validity was determined by exploring the correlations between psychological distress as measured by the K10 and the SCNI domains. As expected, the highest correlation was between the dealing with feelings domain and respondents' K10 scores. The domain that had the next highest correlation with the K10 was "time out" and recreation, while the remaining domains shared a lesser but still substantial relationship. These findings indicate that while the feelings that arise from having a brother or sister with cancer are likely to have the largest association with siblings' levels of psychological distress, interruptions to their daily lives such as to their recreation and schooling, changes in their relationships with their family and friends and lack of

information about their brother or sister's cancer can all contribute. Detailed exploration of the impact of demographic, cancer and other variables on levels of unmet need have been examined and will be reported separately [25].

In regard to content validity, only four items were suggested by siblings that were not already covered by existing items. Combined with the previous consultation with siblings and professionals, literature review and pilot work reported elsewhere [9], this finding further supports the content validity of the SCNI. Additionally, internal consistency and test–retest reliability indices were moderate to high. Although stronger evidence for test–retest reliability could be obtained from a sample larger than in the present analysis ($n = 17$), these values provide initial support for the stability of the instrument. There was also a reasonable spread of responses across the scale for every item, and the Rasch analysis suggested that respondents typically used the response scale consistently.

Further support for construct validity is provided by the similarity in domain structure between the SCNI and other needs measures for similar populations. While the SCNI uniquely explores the needs of AYAs who have a brother or sister with cancer, it includes domains present in other measures of unmet needs for cancer populations such as those developed for patients, their carers and for young people who have a parent with cancer [23, 26–29]. These domain similarities include the need for help with information, relationships, emotional support and daily living.

Limitations

It was not possible to measure the response rate or how representative the sample was of siblings more generally, given that the recruitment methods involved general advertisements and people opted into the study. It was hoped that by advertising widely, a sample would be achieved which had reasonable representativeness. The sample size for this study is not large; however, the potential population is small and can be difficult to access. This is reflected by the lack of measures developed for this population previously. While more female siblings participated in the study, the young people with cancer were evenly split between males and females. The participants were slightly older on average than their brothers and sisters with cancer; however, the range of ages of participants provided a good representation of the age group 12 to 24 years. The cancers present amongst participants' brothers and sisters were also typical childhood cancers [30].

Further, as the sample for the development of the initial version of the SCNI was drawn from one peer support organisation, one of the aims for the development of the latest version of the SCNI was to glean a broader sample. Whilst this was partially achieved, two thirds were members of CanTeen,

who may have had fewer needs than siblings not associated with a support organisation. Having said this, over 80 % had been members of the peer support organisation for 12 months or less.

Implications for practice

The SCNI is an important addition to the area of needs measures for those impacted by cancer, addressing an underserviced group. It is anticipated that the SCNI will be useful in identifying individual unmet needs as well as domains with high levels of unmet need, thereby facilitating the provision of targeted psychosocial support.

Using a self-report format is a major advantage in obtaining an accurate assessment of siblings' psychosocial needs, as parents have been found to generally underestimate the burden of the cancer experience on siblings, particularly emotional and behavioural problems [11]. AYA siblings of cancer patients have reported clinically relevant emotional problems 2 years after the ill child's diagnosis [11]; therefore by identifying and meeting their psychosocial needs soon after diagnosis, it is possible to avoid long-term adjustment problems.

Conclusions

This study supports the psychometric properties of the SCNI. Measures of validity and reliability are all adequate to allow the instrument to be used with confidence. The instrument will assist in highlighting the unmet needs of a vulnerable group of young people, the development of targeted interventions to redress these needs and in the prioritisation of resources.

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