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The Supportive Care Needs Survey for Partners and Caregivers of Cancer Survivors: Development and Psychometric Evaluation

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Abstract

Objective: Begin to test the psychometric properties of the Supportive Care Needs Survey - Partners and Caregivers (SCNS- P&C) designed to capture the multi-dimensional supportive care needs of cancer caregivers. **Methods:** Draft SCNS-P&C items were developed with reference to the literature and existing instruments and reviewed for face and content validity. The final SCNS-P&C was then completed by 547 cancer caregivers. Psychometric analyses conducted included principal factor analysis, internal consistency, and construct validity through the known-group approach. **Results:** Factor analysis revealed four domains of needs: *Health Care Service Needs*, *Psychological and Emotional Needs*, *Work and Social Needs*, and *Information Needs,* with Cronbach's alpha coefficients ranging from 0.88-0.94. Construct validity of the SCNS-P&C was partially supported. A greater proportion of younger participants experienced at least one unmet moderate or high need within the *Psychological and Emotional Needs* and *Work and Social Needs* domains. Proportion of reported unmet needs varied across cancer types for the *Health Care Service Needs* and *Information Needs* domains. In addition, across all domains, individuals with anxiety or depression were more likely to report at least one unmet moderate or high need in comparison to non-anxious or non-depressed participants. **Conclusions:** The SCNS-P&C has the potential to comprehensively assesses the range of caregivers' supportive care needs, across the illness trajectory. Analyses supported the tool's internal consistency and construct validity. The SCNS-P&C can be used by researchers and clinicians to determine caregivers' unmet needs, prioritize health care resources and tailor supportive cancer care services accordingly.

Introduction

Cancer affects not only the life of the individual diagnosed; it also affects the well-being of those close to them by imposing countless physical, psychosocial, and financial demands [1-4]. Recognition of the impact of a cancer diagnosis on caregivers has led contemporary approaches to psychosocial care to integrate in-depth documentation of their supportive care needs [5,6]. Such a comprehensive approach to cancer care offers caregivers an opportunity to call attention to their own needs and express the issues they want recognized [3]. Current evidence suggests that caregivers' supportive care needs cluster in the domains of information [2, 5-7,8,10], emotional/psychological [2,8,10], physical health [8,10], health care professionals and cancer care [6,9], relationship with the patient [10], practical support [8,10], and legal and financial [10]. Despite researchers and clinicians efforts towards addressing caregivers' needs, many of these reportedly remain unmet [1,2,6,10,11]. In a study by Soothill et al. [12], 28% of cancer caregivers identified three or more significant supportive care unmet needs.

Whilst several supportive care need assessments are available, they have the following limitations in terms of large-scale use with a generic population of cancer caregivers. First, some of the measures focus on a specific domains of needs and provide a limited account of the broad range of caregivers' supportive care needs [7]. Second, they focus on caregivers' needs at a particular stage along the illness trajectory [9,10,13], restricting the tool's suitability across the cancer continuum. Third, some measures appear out-dated [14] and/or have no reported psychometric properties [12]. To date, there is no psychometrically robust measure that provides a comprehensive assessment of the multi-dimensional supportive care needs of cancer caregivers, across the illness trajectory. This paper reports on the development and psychometric testing of a questionnaire designed to address this gap in the literature: the Supportive Care Needs Survey - Partners and Caregivers (SCNS- P&C). To our knowledge, this is the first study evaluating such a measure among a large population-based sample of caregivers of individuals diagnosed with the eight most incident cancers in Australia.

Methods

Item Generation

The SCNS-P&C items were based on: 1) a literature review to identify the main supportive care needs of caregivers of individuals diagnosed with cancer, 2) an examination of the existing tools assessing caregivers' unmet needs, and 3) the adaptation of the items from the Supportive Care Needs Survey (SCNS) [15,16]. Initial items were reviewed for face and content validity by experts in psycho-oncology, members of the general public, and cancer caregivers of cancer survivors. Suggestion were integrated, which resulted in a 44-item tool that measures caregivers' unmet needs across the information, health care services, daily living, and psychological domains. Items are rated on a 5-point response scale (1 'No Need - Not applicable' to 5 'Some Need – High') modelled on the one of the SCNS [15,16].

Construct Validity and Internal Consistency

Participants

Caregivers were referred to the Partners and Caregivers Study by cancer survivors participating in the Cancer Survival Study conducted by the research team [17]. A caregiver was defined as a person nominated by the survivor as most involved in supporting them through the illness [6]. The study was named the 'Partners and Caregivers' Study to emphasise that a caregiver can include someone who performs hands-on care and/or provides emotional support. For the purpose of this paper, the term 'caregiver' encompasses both partners and caregivers. All English-speaking caregivers, caring for or living with someone who had pathologically confirmed colorectal, female breast, prostate, lung, or head and neck (HN) cancer, or leukaemia, non-Hodgkin's lymphoma (NHL), or melanoma, and able to provide written consent were eligible to participate in the Partners and Caregivers Study.

Procedure

Cancer survivors were recruited into the Cancer Survival Study through the New South Wales and Victorian cancer registries. At six to eight months post-diagnosis, participants were sent, along with their own survey, a separate Partners and Caregivers Study information package to pass on to their caregiver. Ethics approval was obtained from the University of Newcastle Human Research Ethics Committee. Interested caregivers returned their Partners and Caregivers Study consent form to the research team.

Data Collection

Consenting caregivers were mailed a self-administered, scannable survey measuring the demographic characteristics and the health, financial, and psychosocial variables of interest, including unmet needs (SCNS-P&C) and anxiety and depression (Hospital Anxiety and Depression Scale) used to test the validity of the SCNS-P&C. Participants returned their survey in the reply paid envelope provided.

Data Analysis

The psychometric analyses of the SCNS-P&C was undertaken using SAS Version 9. The responses 1 ‘No need-satisfied’ and 2 ‘No need-not applicable’ were re-coded as 1 ‘No need’ and subsequent response categories were rescored accordingly (1-4) to ensure a linear response format.

Descriptive item statistics were examined to identify flooring or ceiling effects. Factor analysis using principal factor analysis with oblique rotation [18, 19] was performed to identify underlying needs domains (no firm a priori expectations of these). The eigenvalue < 1 rule, scree plot, and parallel analysis were used to determine the number of factors to retain [18,19]. Items were primarily included in the factor where their loading was the highest (minimum.30) [18]. A factor’s final composition was determined also by its internal consistency (minimum alpha = .70) [20]. Missing values were managed using pairwise deletion.

Construct validity was examined via the known groups approach [20]. Construct validity of the SCNS-P&C is supported if the scale can discriminate between groups of individuals hypothesised to experience different levels of unmet needs. Most compelling in the literature is that higher levels of unmet supportive care needs are reported by individuals reporting high levels of distress, including anxiety or depression [9,11]. For instance, Janda et al. [11] found that clinical anxiety and depression significantly predicted higher than average supportive care needs in caregivers of patients with a brain tumor ($OR_{anxiety}$=2.20, $OR_{depression}$=5.75). Although the evidence remains equivocal, some studies also tend to indicate that several types of unmet supportive care needs are experienced more frequently among women caregivers than men caregivers [10] and among younger caregivers (less than 60 years of age) than older caregivers [9, 10]. Based on this evidence, the primary hypothesis put forward to establish the construct validity of the SCNS-P&C was that a greater proportion of individuals with anxiety or depression (HADS score of eight or more) would report at least one unmet moderate or high need across domains. The secondary hypotheses tested were that a greater proportion of participants less than 60 years of age and women would report at least one unmet moderate or high need across domains. It was also hypothesised that the proportion of participants identifying at least one unmet moderate or high need for each domain will vary across cancer types. Although there is no other study documenting caregivers' level of unmet needs across the eight most incident cancers in Australia; it can be expected that participants caring for patients with a poorer prognosis (eg lung cancer) will identify more unmet needs across domains in comparison to caregivers of other patients. For this last analysis, the small proportion of individuals diagnosed with leukaemia was excluded (< 10%). As the endorsement of unmet needs was skewed towards no unmet needs and based on the recommendations of others [9,11], it was chosen to dichotomise this variable as 'no unmet need' or 'at least one unmet moderate or high unmet need'. These hypotheses were tested using Chi-square analysis and a p-value of less than .05 was considered significant. Post-hoc analyses were conducted using 95% confidence intervals (CI).

Results

Participants

Analyses were conducted with 547 participants (survey return rate= 82.6%). Participants' age ranged from 16-85 years (mean = 60.6, SD= 11.1) and more than two-thirds of them were women (69.8%). Most participants were born in Australia (81.0%), English-speaking (96.5%), with partner (95.8%), living with (92.4%) or caring for their spouse/partner with cancer (90.3%). The average age of the cancer survivor at diagnosis was 60.5 years (range=24-80, SD=10.5). Cancer survivors had a diagnosis of prostate cancer (32.0%), NHL (13.9%), melanoma (11.5%), breast (13.2%), colorectal (11.3%), HN (8.6%), or lung cancer (7.1%) or leukaemia (2.4%).

Item Distribution

Item raw means ranged from 1.06 to 1.61 (Table 1)**.** Items 18, 19, 24, and 25 showed a significant flooring effect ('no need' responses endorsed by more than 90% of participants) and were deleted from subsequent analyses.

Factor Analysis

Four factors were retained and provided a clear factor solution that is conceptually and practically relevant (Table 1). With the exception of items 2 and 6, all items loaded more on the chosen factor.

Factor 1 relates to receiving optimal health care services and/or appropriate support from health care professionals [14,15] and is labelled '*Health Care Service Needs*'.

Factor 2, labelled ‘*Psychological and Emotional Needs*’, assesses needs pertaining to preserving or managing emotions, thoughts, and/or relationships with the patient and others [14,15]. Items 32, 33, and 34 were included in factor 3 despite cross-loading on factor 2, as their loading was greater on factor 3 and it is thought that conceptually these items are more fitting within this grouping of items.

Factor 3 addresses needs regarding the caregiver’s or patient’s work and those pertaining to interpersonal exchanges and/or talking about cancer [14,15]. This domain was termed ‘*Work and Social Needs*’.

Factor 4 relates to the caregiver’s information needs or understanding of the illness and is termed ‘*Information Needs*’. After much consideration, items 2 and 6 were retained in the *Information needs* domain, despite greater loading on the *Health Care Service Needs,* as conceptually these were developed to assess information needs.

Item 15 did not load on any factor and was excluded from subsequent domain analyses.

Scale Reliability

As shown in Table 1, the reliability coefficients for all four factor-based domains were found to be appropriate and range from alpha=.88 - .94.

Construct Validity of the Needs Domains

Although across domains a greater proportion of the younger participants identified at least one unmet moderate or high need in comparison to older participants, these differences were only significant for the *Psychological and Emotional* (p <.01) and *Work and Social Needs* (p< .01) (Table 2). In addition, across all domains significantly more participants with anxiety or depression identified experiencing at least one unmet moderate or high need than non-anxious or non-depressed participants (Table 2). The proportion of participants identifying at least one unmet moderate or high need significantly differed across cancer types for *Health Care Service* (p <.01) and *Information Needs* (p=.04) (Table 2). Analyses did not support the hypothesis that women would experience more unmet needs than men. Findings were similar wether items 2 and 6 were included in the *Health Care Service Needs* domain instead of the *Information Needs* domain and whether items 32, 33, and 34 were included in *Work and Social Needs* instead of *Psychological and Emotional Needs*.

Discussion

The SCNS-P&C is a promising tool to measure the multi-dimensional unmet needs of cancer caregivers across the illness trajectory and to discern among groups experiencing different levels of unmet needs. Factor analysis identified four underlying needs domains - *Health Care Service Needs, Psychological and Emotional Needs, Work and Social Needs,* and *Information Needs*. These domains echo the need patterns generally reported in the cancer caregiver literature [1,8,10]. The strength of this factor structure primarily lies in that most items loaded on the factor that was consistent with conceptual expectations, with the exception of items 2 and 6. Item 6 might have been problematic, as it seemingly embeds two related needs: one related to information - ‘need for treatment and information’- and the other to health care service -‘need to participate in decision-making’. Item 6 will be revised in subsequent version of the SCNS-P&C. However, reliability and construct validity analyses support the use of the *Information Needs* domain in its present form.

The identified rank-ordering of unmet needs in this study is similar to the one reported by Janda et al [11], who administered the SCNS-P&C to 70 caregivers of individuals diagnosed with a brain tumour. However, a greater proportion of caregivers in Janda et al’s [11] study reported experiencing these unmet needs. In addition, some unmet needs such as ‘decision making in uncertainty’ and ‘involved in patient care with medical team’ were rated higher than in our study. These differences might be explained by differences in illness severity and further supports the SCNS-P&C responsiveness to different care giving contexts.

Furthermore, analyses supported that anxious or depressed individuals are more likely to report at least one unmet moderate or high need than non-anxious or –depressed participants. It is foreseeable, when examining the top five unmet moderate or high needs identified in this study, that experiencing any one of these, even if just one unmet need, can be quite distressing. Until further studies are conducted, the authors would caution against any assumptions made about a ‘clinically significant’ level of unmet need and trivialisation of the level of unmet needs reported by the caregivers in this sample. Also, according to our findings and the analyses conducted by other studies [9, 11], future psychometric studies of the SCNS-P&C will examine whether a dichotomous response format is more appropriate. Moreover, our findings are consistent with other studies [9,10] suggesting that younger caregivers are more likely to experience certain types of unmet needs, particularly in the *Psychological and Emotional Needs* and *Work and Social Needs* domains.

Last, to our knowledge, this is one of the first studies comparing caregivers’ level of unmet needs across a range of cancers with the highest incidence in Australia. The hypothesis that the proportion of caregivers experiencing unmet moderate or high needs would vary across cancer groups was supported, particularly for the *Health Care Service* as well as *Information Needs*.

Although the construct validity of the scale was partially supported via the known groups approach, the cross-sectional nature of this analysis did not allow us to examine the predictive validity of the SCNS-P&C and, as no other needs assessment measure was concurrently given to participant, convergent validity of the scale was not assessed.

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Table 1 Item mean, frequency of unmet needs, and underlying factor structure of the SCNS-P&C (n=547)

SCNS-P&C items “In the last month, what was your level of need for help with...”	Mean (±SD)	Some Need		Factor 1 (α=.94)	Factor 2 (α=.94)	Factor 3 (α=.90)	Factor 4 (α=.88)
		Low (%)	Moderate-High (%)				
1 Information carer needs	1.21 (.59)	8.0	5.8				**.50**
2 Information prognosis	1.44(.87)	10.8	13.5	.50			**.33**
3 Information support services	1.27(.68)	10.0	7.1				**.60**
4 Information alternative therapies	1.26(.67)	8.4	7.5				**.30**
5 Information patient physical needs	1.36(.75)	10.9	11.4				**.53**
6 Information for decision making	1.47(.89)	10.8	15.1	.49			**.46**
7 Best medical care patient	1.46(.99)	5.6	14.7	**.72**			
8 Access local health services	1.28(.77)	4.8	9.3	**.50**			
9 Involved in patient care	1.37(.87)	4.3	13.0	**.66**			
10 Discuss concern with doctor	1.43(.90)	9.1	13.4	**.73**			
11 Doctor coordinated care	1.40(.92)	5.2	13.3	**.95**			
12 Case manager coordinated services	1.40(.91)	6.1	13.0	**.83**			
13 Complaints regarding care addressed	1.32(.82)	5.5	9.9	**.82**			
14 Reduce stress for patient	1.61(1.01)	14.2	18.1	**.52**			
15 Look after own health	1.41(.81	11.5	12.8				
16 Pain control for patient	1.28(.79)	4.4	8.9	**.70**			
17 Fears about patient deterioration	1.48(.91)	12.2	14.3	**.51**			
18 Fertility problems in patient	1.13(.53)	2.8	4.2	-	-	-	-
19 Practical caring tasks	1.11(.46)	3.9	3.0	-	-	-	-
20 Accessible hospital parking	1.48(.98)	5.7	15.9	**.42**			
21 Changes to patient’s life/work	1.38(.80)	11.7	10.7			**.45**	
22 Life/work changes for carer	1.41(.81)	13.0	11.9			**.38**	
23 Financial/government support	1.14(.84)	6.1	12.0				**.32**
24 Insurance for patient	1.14(.55)	4.3	3.7	-	-	-	-
25 Access legal services	1.06(.31)	3.5	1.1	-	-	-	-
26 Communicate with patient	1.29(.75)	6.9	8.5			**.82**	
27 Communicate with family	1.22(.64)	6.3	6.0			**.73**	
28 Support from family	1.23(.66)	7.2	6.3			**.53**	
29 Talk to other cancer carers	1.26(.67)	10.4	6.5			**.39**	
30 Discuss cancer at work/socially	1.17(.51)	8.5	3.5			**.50**	
31 Concerns about recurrence	1.61(.99)	14.7	18.6		**.47**		
32 Impact on relationship with patient	1.43(.83)	12.6	12.6		**.53**	.33	
33 Understand patient experience	1.51(.91)	12.8	16.1		**.53**	.33	
34 Balancing own and patient’s needs	1.46(.86)	10.9	15.0		**.53**	.38	
35 Changes in patient's body	1.42(.83)	10.9	13.7		**.59**		
36 Problems with sex life	1.42(.85)	9.5	13.6		**.53**		
37 Emotional support for self	1.41(.79)	12.8	12.4		**.68**		
38 Emotional support for loved ones	1.34(.75)	11.7	9.5		**.64**		
39 Feelings about death	1.42(.83)	12.8	12.3		**.88**		
40 Not acknowledging impact of caring	1.43(.82)	14.5	11.7		**.65**		
41 Recovery not as expected	1.33(.74)	10.5	9.7		**.67**		
42 Decision making in uncertainty	1.40(.81)	13.1	11.1		**.89**		
43 Own spiritual beliefs	1.18(.58)	6.1	5.0		**.48**		.31
44 Meaning in patient’s illness	1.33(.77)	8.9	9.5		**.63**		

Table 2 Proportion of Participants Identifying at Least One Unmet Moderate or High Need by Age Group, Sex, Anxiety and Depression Level ($N_{age/sex}$=546; $N_{anxiety/depression}$=540; $N_{cancer\ type}$=399)

SCNS-P&C Domains	**Anxiety**		**P**	**Depression**		**P**	**Age**		**P**	**Sex**		**P**	**Cancer Type**							**P**
	< 8 (%)	**≥ 8 (%)**		**< 8 (%)**	**≥ 8 (%)**		**≤60 (%)**	**>60 (%)**		**Male (%)**	**Female (%)**		**Colo-rectal (%)**	**Breast (%)**	**Pros-tate (%)**	**Mela-noma (%)**	**Lung (%)**	**NHL (%)**	**HN (%)**	
Health Care Service	**24.9**	**50.2**	**<.01**	**29.6**	**59.3**	**<.01**	37.4	33.1	.30	35.2	34.9	.96	**37.0**	**33.3**	**23.7**	**21.3**	**55.2**	**40.4**	**45.7**	**<.01**
Psycho-logical and Emotional	**22.5**	**59.4**	**<.01**	**29.8**	**70.3**	**<.01**	**43.3**	**31.8**	**<.01**	35.2	37.5	.60	41.3	31.5	29.8	25.5	48.3	42.1	37.1	0.23
Work and Social	**11.4**	**37.7**	**<.01**	**16.3**	**47.3**	**<.01**	**26.9**	**16.9**	**<.01**	18.8	22.3	.36	17.4	14.8	15.3	14.9	27.6	31.6	28.6	.08
Information	**18.0**	**41.1**	**<.01**	**21.6**	**52.8**	**<.01**	31.1	24.0	.07	27.3	27.0	.95	**21.7**	**22.2**	**20.6**	**14.9**	**34.5**	**38.6**	**34.3**	**.04**