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Assessing the needs of informal caregivers to cancer survivors: a review of the instruments

Short title: cancer caregiver needs assessment

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Abstract

Objective

Cancer may impact negatively on an informal caregiver's health long after treatment has ended. This review identifies the self-report measures currently in use to measure caregivers need for support, and determines their scientific soundness and clinical utility.

Method

A systematic electronic database search of Medline, CINAHL, PsychINFO, BNI and ProQuest was conducted. The psychometric properties and clinical utility of needs assessment tools for caregivers of cancer survivors (excluding advanced disease) was extracted and summarised.

Results

Seven cancer survivor caregiver needs assessment tools were identified. Data on instrument development was well reported, although variability was noted in their structure and content. The majority demonstrated some degree of reliability and validity; only two were evaluated for test-retest reliability (CaSPUN and SPUNS) with only the SPUNS showing a high degree of reliability over time. The HCNS, NAFC-C and CaTCoN have been validated at various stages of the cancer continuum. Minimal data was available on responsiveness.

Conclusion

All assessment tools identified require further psychometric analysis. For research purposes the use of the SPUNS (with its acceptable test-retest reliability) appears most appropriate; although its length may be of concern for clinical use, therefore the shorter SCNS-P&C is likely to be more suitable for use clinically. At present the NAFC-C demonstrates a great potential in both the research and clinical environments, however it requires further psychometric testing before it can be fully recommended. Further analysis is necessary on ideal response formats and the meaning of a total needs score.

Keywords: Cancer, Oncology, Caregivers, Needs Assessment, Review

Introduction

Informal care is that performed by family and/or friends as opposed to health care professionals [1]. The concerns of informal cancer caregivers can be estimated via various self-report outcome measures. Quality of life, satisfaction with care, strain, and health care needs assessment are distinct and separate domains of health [2]. Needs assessments identify specific needs (physical, psychological, social or spiritual) of an individual and can offer some insight into the magnitude of that need and whether or not the individual requires help or advice on that need. They can assist in the prioritisation of service needs so that resources can be allocated to the areas and individuals that require them most [3,4]. Needs assessment is crucial in order to develop the most cost effective interventions to improve care, consequently ensuring that patients and their families experience minimal unmet needs and improve or maintain their quality of life [5].

Health Related Quality of life (HRQoL) assessment measures an individual's functional status across various domains and their appraisal of how their health (or the health of the person they are caring for) affects their day-to-day life quality [6]. It has been argued that HRQoL measurement provides an indication of the well-being of a person, but does not distinguish between health problems and a desire to seek professional help [7,8]. Satisfaction with care questionnaires provide some understanding of patient or caregiver attitudes towards the health care they received. However, they provide little indication on how to ameliorate an individual's concerns [9]. The sensitivity and reliability of these measures to predict need in long term cancer caregivers is questionable, as HRQoL has been found to be a weak predictor of need in individuals caring for cancer survivors five years after the cancer diagnosis [10]. The direct assessment of an individual's perceived needs via a needs assessment rather than alternative measures leads to a more direct indication of needed resources [3]. HRQoL, satisfaction with care and needs assessment are inter-related [2] but one should not be used to predict the other. Need may have a direct effect on satisfaction with care but the direction of the relationship is not clear [11]. The challenge, as detailed by Asadi-Lori et al, [11] is to identify and target needs, and introduce resources/services/interventions to meet these needs, which should in turn improve satisfaction with care and quality of life.

Strain indices that measure the combination of stress and burnout and its impact on caregivers overall health, has previously been used as a method of identifying need (for example, the Modified Caregiver Strain Index [12]). Similar to HRQoL and satisfaction with care, it is acknowledged that strain contributes to the overall health of the caregiver, but these types of assessment do not identify the caregivers' needs for services, that is the gap between what the caregiver needs and what services are available to them.

There are a plethora of tools available to screen for caregiver burden/needs. A recent systematic review identified as many as seventy-four caregivers screening tools [13]. A disagreement has existed in the literature as to whether instruments should be specialised to specific disease states, or be devised to measure common factors affecting caregivers for patients with very different chronic conditions [14]. As some concerns, such as dealing with fear of recurrence, are of particular relevance to cancer caregivers, and may not be included in general measures, this review focuses on needs assessment tools devised specifically for cancer caregivers. It should be noted, however, that cancer is still a broad category, and that these instruments may not, on their own, be flexible enough to take account of needs arising from the specificities of neoplastic site.

There is a lack of an agreed standardised needs assessment instrument for informal cancer caregivers. Instruments that can demonstrate robust content validity are therefore required. This could be achieved through the use of a conceptual model to guide instrument development such as that developed by Swore-Fletcher et al [15]. It is however, unrealistic to presume that every caregiver needs assessment instrument will be based on the same model, and items included are dependent on how the scale was developed and whether or not they are theory based. Moreover, variations in need across time and across different types of caregiver/patient relationship require that instruments be sensitive to the types, intensity and extent of needs experienced by caregivers throughout the survivorship trajectory in order to facilitate the appropriate allocation of resources. Thus, it is imperative that needs assessment tools are sufficiently flexible to be able to measure chronological change and thus provide an accurate account of the level of need at various stages of cancer survivorship.

Profiling the needs of cancer caregivers is also complicated by the highly heterogeneous nature of the population [16]. For example, caregiving varies by ethnicity. North American studies have established that African-American and Hispanic caregivers are less likely to be a partner and more likely to be another family member [17], non-Caucasian caregivers provide care for more hours per week and report more caregiving tasks than other ethnic groups, and African Americans utilise less support services than Caucasians [18]. It is important that needs assessment are sensitive to the type of relationship between the caregiver and the individual with cancer in order to facilitate tailored support and increase the likelihood of identification of cancer caregivers who may be at risk of experiencing more unmet needs. Using instruments that are not sensitive to the type of caregiver/cancer survivor relationship may also lead to unnecessary participant burden. For example, the inclusion of sexuality-based questions may be inappropriate for those in a non-sexual relationship. Construct validity in terms of group differences is therefore a significant criterion in the selection of an appropriate tool.

In order to conduct valid and reliable cancer caregiver needs assessment, the selection of an appropriate needs assessment tool is paramount. The choice should be guided by the purpose for which the information is required and the psychometric properties of the particular instrument. This review aims to support researchers and clinicians in their choice of self-report tool for the assessment of cancer caregiver need by identifying the self-report measures currently in use, and determining their scientific soundness and clinical utility.

Methods

Relevant literature was identified through a systematic electronic database search of Medline (1966 –2013), CINAHL (1982 – 2013), PsychINFO (1872 – 2013), BNI (1985 – 2013), and ProQuest, using the keywords (cancer* or oncology* or neoplasm* or carcinom* or tumor* or malignan* or lymphoma or melanoma or leukemia or sarcoma) AND (family or families or parent\$2 or mother? or father? or friend? or relative? or spouse\$2 or partner? or husband? or wife or wives or son? or daughter? or offspring? or sibling? or brother? or sister?) OR (care* or caring) OR caregivers OR (carer* or caregiv* or care giv*) AND (assessment* or measur* OR psychometric* or reliab* or valid*). The reference list of each relevant study was searched for additional papers.

Inclusion/exclusion criteria

Included studies focused on the psychometric properties of needs assessment of caregivers of cancer survivors. Studies measuring HRQoL or satisfaction with care were excluded. Studies examining the needs of caregivers of advanced/terminal cancer patients or at bereavement were also excluded. This is because informal carers providing support to cancer survivors experience distinct issues from those caring for palliative patients [19]. Survivors and caregivers often experience fear of cancer recurrence, or anxiety around rehabilitation, for example, returning to work. These issues are likely to be redundant in a palliative or terminal population. Measuring need in a general manner regardless of prognosis may lead to misinterpretations in needs estimates and perhaps be deemed as insensitive.

Data extraction

Information on instrument development and the psychometric properties of each instrument were extracted from the studies retrieved. Evidence for internal consistency and test-retest reliability (stability) were summarised for each instrument. A Chronbach's alpha correlation coefficient of 0.7 was deemed as acceptable for internal consistency [20 - 22] and a minimal correlation coefficient of 0.7 was needed to support a measure's test-retest reliability [20]. For validity, face and content validity, criterion-related validity (concurrent validity) and construct validity were summarised. A correlation coefficient of above 0.6 was deemed acceptable to support construct

validity [20]. Responsiveness, that is, the ability of a measure to detect clinically significant change [21] was also extracted. One issue considered in the context of responsiveness was floor and ceiling effects which should be below 15% of the total sample [23], that is, less than 15% of the respondents should score the lowest (floor) and highest (ceiling) possible scores on the measure. Information on clinical usefulness, namely acceptability (percentage completion), length, response format and time for completion was also extracted.

Multidimensional measures are composed of subscales that assess various dimensions of the phenomenon of interest. The technique of factor analysis can be used to establish the internal structure of the scale and ensure that it is measuring the dimensions it purports to measure [20].

The final factor to consider is the clinical usefulness of the instrument. The tool must be short, not overburden or cause undue distress to the individual completing the questionnaire. Given the variation in caregiving by ethnicity the tool must be applicable cross-culturally, and not contain any colloquial or unfamiliar phrases.

Results

Seven self-report cancer survivor caregiver needs assessment tools were identified. A summary of each of the included scales is presented in Table 1. Details of the psychometric properties and clinical usefulness are included in Table 2. It should be noted that all instruments were validated via a mailed survey as opposed to telephone surveys or face-to-face interviews.

Summary of included scales

The Health Care Needs Survey (HCNS) which was developed based on the Lackey-Wingate model [24] in the United States, is a 90 item scale examining needs of home caregivers in six domains, with a completion time of thirty minutes. Each item has two likert scales to rate both the importance and satisfaction of each need statement. The survey generates an Importance Score, a Satisfaction Score and a Barrier Need Score. It has been designed for use across the entire cancer continuum. The scale has shown high internal consistency, concurrent validity and responsiveness in family caregivers (n = 14) of individuals diagnosed with breast, colon, lung and oesophageal cancer 3 months – 9 years previously [25]. It has also demonstrated a high internal consistency in a sample of 378 home caregivers, 75% of which lived with the individual with cancer [26].

The Cancer Survivors' Partners Unmet Needs (CaSPUN) scale is an Australian scale, developed to identify the needs of partners of long term cancer survivors. It consist of 35 unmet needs items, 6 positive change items and 1 open ended item, with a completion time of ten minutes. The CaSPUN asks caregivers to identify whether or not each issue is a need and if so to rate this need as low, moderate or high. Total needs are calculated by summing total met and unmet needs. The CaSPUN has been shown to have a high level of internal consistency, moderate test retest reliability and partial support for construct validity in a group of partners (n = 212) of patients diagnosed 1 – 11 years previously [27].

The Cancer Support Person's Unmet Needs Survey (SPUNS) is similar to the CaSPUN in that it was designed to identify the needs of caregivers of longer term cancer survivors. However, this measure was designed to determine the needs of a 'support person' regardless of their relationship to the survivor [28]. This 78 item survey asks respondents to identify unmet needs in the past

month. It assesses six domains of unmet needs. Although long (78 items) the developers report that it should take less than 15 minutes to complete [28]. The scale has undergone psychometric evaluation in Canadian support persons (n = 382) of patients diagnosed 1 – 5 years previously, 75% of which were the spouse of the individual with cancer. In this sample, the scale demonstrated high internal consistency and test retest reliability [28].

The Supportive Care Needs Survey-Partners and Caregivers (SCNS-P&C) was developed to assess the multidimensional needs of cancer caregivers across the illness trajectory. The 40 item survey assesses need in four domains. The psychometric analysis was conducted in Australia on respondents who were caregivers of cancer patients diagnosed 6-8 months previously (n = 574) [29]. The caregiver was a person nominated by the cancer survivor as most involved in supporting them through the illness [29]. Ninety percent of the sample identified themselves as the spouse or partner. In this sample, the scale demonstrated high internal consistency and construct validity. A floor effect was detected in four items and these were subsequently removed.

Comprehensive Needs Assessment Tool for Cancer-Caregivers (CNAT-C) [30] is a Korean needs assessment tool. The 41 items identify needs across seven domains. The scale has been validated in six hundred Korean speaking family caregivers (58% of which were the spouse of the cancer survivor) of individuals with cancer during or after cancer treatment. The individuals with cancer were a mean of 27.8 months since cancer diagnosis. In this group the scale demonstrated high internal consistency and partial construct validity (known group's validity). The low level of missing data (<1.8%) provided further support that it is an acceptable measure for this population group.

The Needs Assessment of Family Caregivers-Cancer (NAFC-C) was developed based the Need Fulfilment Theory [31], and was designed to identify caregiver needs across all phases of cancer survivorship from diagnosis through to the long term post five year follow up stage [5]. The 27 item survey measures need in terms of two dimensions: the importance of the need and how the need has been fulfilled, and consists of four factors. The scale has undergone limited psychometric evaluation in the United States in three cohorts of caregivers (family members or close friends) of patients; newly diagnosed with colon or rectal cancer (n = 162), two year (n = 896) and five years

(n = 608) since diagnosis with ten of the most common cancers and has shown to have moderate – high internal consistency [10].

The Cancer Caregiving Tasks Consequences and Needs Questionnaire (CaTCoN) is a Danish tool developed based on Lazarus and Folkman's stress-coping theory [32], and, as the name would suggest, was designed to measure caregiving tasks and consequences and caregiver's needs [33]. The tool contains 72 items (numbered 1 – 41 as some items contain several subsections), with the majority of items containing four ordinal response categories and a 'don't know/not relevant category [34]), and comprises nine subscales. The scale has been validated in 590 Danish caregivers of individuals diagnosed with various tumours across the cancer survivorship continuum (within the last six months – more than 5 years ago) (L Lund, personal communication). In this group the scale demonstrated moderate to high internal consistency, and convergent and discriminant validity due to correlations with existing caregiver assessment tools (FAMCARE and Family Inventory of Needs) [34]. No items had a response rate of >10% (range 0.5% - 10.0%) indicating that items could be understood by the target population [34]. The CaTCoN has been developed and validated in Denmark therefore studies evaluating its acceptability and cross-cultural validity are warranted [34].

Scale development

Four of the scales (CaSPUN, SPUNS, HCNS and the CaTCoN) had tangible support person input in the development of the scale. For the SPUNS support persons (n = 51, recruited from cancer registry) completed an open ended survey asking for their top six unmet needs, these needs were collated to develop the scale. With the HCNS cancer patients with a range of cancer diagnoses (diagnosed 3 month – 9 years previously) (n = 10) and their primary caregivers (n = 14) completed an 'Object Content Test' which involved them listing (up to) twenty needs of cancer patient and caregivers. A previous qualitative study of unmet needs in partners of cancer survivors alongside the current literature informed the CaSPUN. An initial scale of 47 unmet need items was reduced with items removed that were not endorsed by partners of disease free cancer patients (n = 212). Focus group interviews with 39 caregivers, cancer patients, clinicians and cancer counsellors supplemented a literature review for item identification for the CaTCoN. The questionnaire draft was then evaluated by cognitive interviews with 24 cancer caregivers.

The NAFC-C scale was developed from items from existing scales and new items that the lead researcher identified as missing. This produced an initial 60 item scale. Caregivers (n = 1666) completed the 60 item survey. The scale developers subsequently removed items that were not endorsed by the respondents. The items included in the SCNS-P&C were based on a literature review, existing tools assessing caregivers' unmet needs, and adaptation of the items from the SCNS. Caregivers (n = 547) completed the original 44 item scale, with four items being removed that were rated as 'no need' in more than 90% of respondents. A similar process to that of the SCNS-P&C was adopted with the CNAT-C, it was developed from literature review and existing current measures. The scale was piloted with caregivers to identify the need for additional items/elimination of redundant items.

All seven scales underwent factor analysis to identify subscales. The number of factors ranged from four (NAFC-C; SNCS-P&C) to nine (CaTCoN), with the percentage explanation of the variance ranging from 51% (CaSPUN) - 73.5% (SPUNS) (see table 2).

With reference to content validity, a reasonable degree of variability was noted in the structure and content of the needs assessments (table 3). Twenty seven different domains were measured by seven tools, with no scale measuring all 27, although the majority of tools assessed health care professionals, information, personal health, spiritual needs, and work and finance. There was a variation in the number of items dedicated to each dimension. Three scales, the SPUNS, CaSPUN and the CaTCoN asked respondents to identify positive aspects of caregiving.

Discussion

In this review, seven needs assessment instruments were identified that measure the needs of informal caregivers of cancer survivors. This result demonstrates that there has been a growth in instrument development targeting 'survivorship caregiving' since 2006, when none were identified [2]. The seven instruments identified are not site specific and therefore could be used to identify needs of caregivers of individuals with the most common solid tumours. However, general measures may not highlight certain issues that providing care for a specific cancer type may present, for example, stoma care in colorectal cancer or managing body image concerns in breast cancer. It may be necessary to develop 'add on' tumour specific modules similar to those used in HRQoL assessment.

Although there appeared to be similarities in the assessed domains across the scales, when each domain was examined at the individual item level there was variation (table 3). This finding suggests that items contained in a similarly named domain may be conceptually quite different. Thus two instruments could vary considerably on the needs they measure. This variability could be attributed to the subjective nature of instrument development both in the interpretation of qualitative data and factor analysis. This is reflected by the fact that only three of the seven instruments appear to be based on a conceptual model (HCNS, NAFC-C and CaTCoN).

The Swore Fletcher model highlights the cancer trajectory as an important element. According to the model [15] the stress process can occur at any point across the cancer trajectory, and it is likely to be experienced differently in different phases. A number of the current caregiver needs assessments have only been designed and validated for use in the phase following treatment completion. This poses difficulties when trying to track caregiver's needs across the whole trajectory and at times of transition (only the SPUNS had a high degree of test-retest reliability). However, the HCNS and the NAFC-C have been validated at various stages of the cancer continuum. Previous cancer survivor needs assessments [19] have argued the necessity for specific instruments in the post treatment phase due to the potential for items relating to the treatment phase, for example, medication use, to become redundant. However, this viewpoint may limit the potential to understand how the nature of need may change over time. Perhaps what may be most

helpful is for instrument developers to focus on generalizable wording of items to be used at any stage of the cancer trajectory and not the development of stage specific instruments.

The majority of measures demonstrated some degree of reliability and validity (HCNS, CaSPUN, SNCS-P&C, CNAT-C, CaTCoN), with all measures demonstrating an acceptable level of internal consistency. Only two of the measures were evaluated for test-retest reliability (CaSPUN and SPUNS) with only the SPUNS showing a high degree of reliability over time. This is crucial if the measure is to be used to determine the change in caregiver needs as there is limited evidence of how needs may change over time [35]. A cross sectional study by Kim et al [10] found that psychosocial needs were prevalent for cancer caregivers up to 5 years post diagnosis. Understanding need over time will inform the timing and content of support services [35]. There was minimal evidence of the examination of concurrent validity which is likely to be reflective of the fact that this is a relatively new area and hence little 'gold standard' measures available for comparison purposes. Four tools (CaSPUN, CNAT-C, SCNS-P&C and the CaTCoN) showed evidence of group differences validity. More information is required on the validity of the SPUNS and the NAFC-C. Minimal attention was given by any of the instruments to responsiveness, that is, the ability to detect meaningful change. Only the HCNS reported on responsiveness and only the SCNS-P&C described the removal of items with a floor effect (with caregivers scoring the minimum possible scores). Failing to identify whether or not a measure has a floor effect could have serious implications in intervention research. This is imperative if these measures are to be used in intervention studies that are designed to produce a reduction in need. Minimal information was also provided on missing data, with only the SPUNS, CaTCoN and the CNAT-C reporting on data quality. Making a measure applicable to the participant will obviously increase response rate, reduce the percentage of missing data and improve the quality of the research project or clinical evaluation of the individual(s) [20].

Psychometric evaluation in the reported studies was carried out on samples that were mainly English speaking, white, middle class, working individuals (with the exception of the CNAT-C (Korean) and the CaTCoN (Danish)). As already alluded to, evidence exists that suggests significant variations in caregiving exists between cultures, thus measures developed and tested in one country or culture may require retesting and possible revision before they are utilised in

another. Another key issue with psychometric analysis is that values for reliability or validity are not an inherent property of the measure [20], but the psychometric data are specific to the sample studied [36]. Therefore a number of studies are needed before it can be concluded that a measure is scientifically sound. However, four of the scales recruited respondents from a cancer registry, and hence sampled from all cancer diagnosis in a given population, increasing the likelihood of a representative sample, which could increase the generalizability of the psychometric properties (SPUNS, SCNS-P&C, NAFC-C and CNAT-C).

Some of the scales facilitate the calculation of a total needs (e.g. CaSUN). This requires further consideration as to what this indicates, that is, do more unmet needs (or a higher unmet needs score) equate to more distress or a poorer HRQoL or satisfaction with care. It is plausible that one unmet need could cause as much distress as a number of 'less severe' needs. Needs assessments must translate a clinically meaningful outcome in order to examine the degree to which services or supports are achieving their aims. In patient needs assessment, it is becoming more commonplace for a needs assessment or problem checklists to be combined with a distress thermometer [37]. This can be used as a triage tool to identify patients with severe distress and as a needs assessment tool to identify issues that require discussion and further support, for example, signposting to local support services, psychological support, work and finance concerns etc. For cancer caregivers, it would appear that a needs assessment should be used in conjunction with an indicator of distress.

Conclusion

The purpose of this review was to provide a recommendation on the choice of informal cancer caregiver needs assessment tool. For research purposes, given its rigorous psychometric testing, and the fact it has demonstrated test-retest reliability and hence would be effective in tracking changing needs with time, the SPUNS is considered the most appropriate at this time. However, given that it consists of 78 items it may be considered lengthy for clinical use. If a needs assessment is used to assist clinicians to triage caregivers and refer them to appropriate services, the shorter 40 item CaSPUN or the 41 item SCNS-P&C may be more acceptable, although the population to be assessed should be taken into account. The CaSPUN has been developed for partners only, while the SCNS-P&C is designed for both partners and other types of caregivers, and therefore

would be considered the most useful. However, it has only been validated in individuals 6-8 months post cancer diagnosis. Given that it takes 30 minutes to complete, the authors consider the HCNS too burdensome for use in the research or clinical setting. Two of the tools have been developed in non-English speaking populations (CaTCoN and CNAT-C; Danish and Korean respectively). As these instruments were developed and validated in Denmark and Korea, studies evaluating feasibility and cross-cultural validity are warranted before using them in other cultures, although it is accepted that this reasoning could be applied to all of the measures that have been validated in English. The authors recommend that the most potentially beneficial tool for both research and clinical use would be the NAFC-C as it is short, based on a conceptual framework and has been shown to be acceptable across all three phases of cancer survivorship, however recommending it for use currently is hindered by its limited psychometric analysis. If this tool undergoes rigorous testing in the future, it has the potential to be a very useful cancer caregiver needs assessment measure.

Conflict of interest statement

There are no conflicts of interest to declare.

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Table 1: Summary of included scales

Measure	Description	Conceptual Model	Psychometric soundness	Additional comments
Health Care Needs Survey (HCNS) [34,35]	90 item Six domains: Information; Household; Patient Care; Personal; Spiritual; Psychological Each item has two likert scales to rate both the importance and satisfaction of each need statement. Generates an Importance Score, a Satisfaction Score and a Barrier Need Score	Lackey-Wingate Model	High internal consistency, concurrent validity and responsiveness	Validated in family caregivers of individuals diagnosed with breast, colon, lung and oesophageal cancer 3 months – 9 years previously. Items generated from an Object Content Test asking about primary caregiver needs.
Cancer Survivors' Partners Unmet Needs (CaSPUN) [27]	40 item 35 unmet needs items, 6 positive change items, 1 open ended item. Five factors: Relationships, Information, Partner Issues, Comprehensive Care and Emotional Support.		High degree of acceptability, internal consistency, construct validity and mod-low test retest reliability	Validated in male and female caregivers of individuals with varying cancer diagnoses 1- 11yrs previously. Developed to identify the needs of long term cancer survivors.
The Cancer Support Person's Unmet Needs Survey (SPUNS) [36]	78 item Unmet needs in the past month Six domains of unmet needs: Information and relationship needs, Emotional needs, Personal needs, Work and finance, Health care access and continuity and Worries about the future.		High internal consistency and test retest reliability	Validated in male and female caregivers of individuals with varying cancer diagnoses who are 12-60 months post diagnosis. Participants recruited via the cancer registry which should increase generalizability
Needs Assessment of Family Caregivers-Cancer (NAFC-C) [10]	27 item Measures need in terms of two dimensions: importance of the need; how the need has been fulfilled. Four factors: Psychosocial Unmet Needs, Medical Unmet Needs, Financial Unmet Needs, Daily Activity Unmet Needs	Need Fulfilment Theory	Very limited psychometric data. Moderate to high internal consistency.	Validated in three cohorts: newly diagnosed, 2 and 5 years since diagnoses of the ten most common cancers. Includes the caregiver's needs for self-care and care

				for other family members.
Supportive Care Needs Survey– Partners and Caregivers (SNCS-P&C) [37]	40 item Four domains: Health Care Service Needs; Psychological and Emotional Needs; Work and Social Needs; Information Needs.		High internal consistency and construct validity. Cross sectional study therefore could not examine test retest reliability or predictive validity. No other needs measure administered concurrently so convergent validity was not assessed.	Validated in English speaking male and female caregivers of individuals diagnosed with the eight most incident cancers in Australia 6-8 months post diagnosis.
Comprehensive Needs Assessment Tool for Cancer-Caregivers (CNAT-C) [29]	41 item Seven domains: Health and psychological problems; family and social support; healthcare staff; information; religious/spiritual support; hospital facilities and services; practical support		High internal consistency and partial construct validity (known groups validity) Cross sectional study therefore could not examine test retest reliability or predictive validity. The lack of other needs assessment measure validated in Korean meant that concurrent validity could not be established. Only four point Likert scale tested.	Validated in Korean family caregivers of individuals with cancer during or after cancer treatment. Mean of 27.8 months since cancer diagnoses (mixed).
Cancer Caregiving Tasks Consequences and Needs Questionnaire (CaTCoN)	71 items Nine subscales 'caregiving workload', 'lack of attention from HCPs on the caregivers wellbeing', 'lack of personal growth', 'lack of privacy during conversations with HCPs', 'need for help from HCPs', 'problems with the quality of information and communication from HCPs', 'lack of information from HCPs', 'lack of time for social relations' and 'need for contact to other caregivers'.	Lazarus and Folkman stress-coping theory (Lazarus and Folkman 1984)	Acceptable internal consistency across all nine subscales. The hypothesised convergent CaTCoN and FAMCARE/Family Inventory of Needs subscales positively correlated, and the hypothesised divergent CaTCoN and FAMCARE/Family Inventory of Needs scales negatively correlated.	Validated in Danish caregivers of individuals diagnosed from six months to more than five years previously.

Table 2 Psychometric properties of included scales

	HCNS [34,35]	CaSPUN [27]	SPUNS [36]	NAFC-C [10]	CNAT-C [29]	SNCS-P&C [37]	CaTCoN
Scientific soundness							
Internal consistency	0.93, 0.98 (0.85-0.97)	0.94	0.99 (0.98 – 0.946)	0.56 – 0.86	0.96 (0.79 – 0.95)	0.88 – 0.94	0.65 – 0.95
Test-retest reliability	-	0.60	95% CI contained 0.70 for all items	-	-	-	-
Content validity	Statements from patients and home caregivers. Input from experts.	Research panel and partners of cancer survivors	Input from support persons and health professionals	-	Input from experts and patients	Experts, general public and cancer caregivers	Literature; cancer patients, caregivers, clinicians and counsellors.
Criterion-related/concurrent validity	Correlated with KPSS	-	-	Extent to which unmet needs predicted QOL	No gold standard in Korean for comparison	-	-
Construct (convergent/discriminant/group differences)	-	Group differences (partially supported)	-	-	Group differences	Group differences (partially)	Convergent and discriminate
Factor analysis	Six factors	Five factors (51% of the variance)	Six factors (73.5% of the variance)	Four factors (58% of the variance)	Seven factors (66.4% of the variance)	Four factors	Nine factors
Responsiveness	Detected changing caregiver needs at 3 time points	-	-	-	-	Floor effect (4 items deleted)	-
Data quality (missing data)	-	-	5/118 items (<10%)	-	<1.8%	-	0.5 – 10.0%
Clinical usefulness							
Brief – time for completion	90 items 30 minutes	10 minutes	78 items <15 minutes	27 item <10 minutes	41 items	? 40 items	71 items
Simple response format	Two 7 point Likert scales	Indicate if they have need and a Likert scale on strength of need.	5 point likert (0 no unmet need – 4 very high unmet need)	5 point likert scale (0 = not at all; 4 = extremely)	4 point Likert scale	4 point Likert scale (1 = no need; 4 = some need-high)	4 point Likert scale, don't know/not relevant
Self report	✓	✓	✓	✓	✓	✓	✓

Table 3: Item distribution across measures

	SPUNS	NAFC-C	SCNS-P&C	CaSPUN	CNAT-C	HCNS	CaTCoN
Information in general							6
Information on who to contact							2
Understandable/up to date information	1			2			
Information for partners				1			
Information on Disease and treatment	5	1	3		2		7
Patient symptom management/experience		2	6	4	2		3
Involved in decision making/patient care		1	3		1		
Health care professionals	9	2	7	3	7	14	8
Health services/availability	5				7	16	9
Support services	4		3	2	1		3
Practical/Instrumental support				1	3		
Relationships	4	4	2	5	2		
Caregiver role	5	3	5	2	1		6
Communication with family and friends	2		2	2	1		
Work	5	1	1	1		12	
Finance	4	4	3	1	2		2
Personal	11	1	1	1	2	11	8
Help around the house	2						
Help for caregiving from others		1	1		2		
Help in everyday life							1
Help in personal care							2
Socialising	1	2	1				3
Psychological						30	3
Emotional distress	8	3	2		3		2
Spiritual	1	2	2	1	2	6	
Worries about the future	4		2	2			
Finding the positives	7			1			3