

# Development and validation of the Short-Form Survivor Unmet Needs Survey (SF-SUNS)

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## Abstract

**Purpose** The Survivor Unmet Needs Survey (SUNS) is one of the only unmet needs measures that was developed and evaluated utilising a population-based sample of cancer survivors. At 89 items, the current scale is quite burdensome. The current study aimed to develop a valid and reliable short version of this survey.

**Methods** A heterogeneous sample of 1,589 cancer survivors, aged 19 years or over at diagnosis, diagnosed with a histologically confirmed cancer in the previous 12 to 60 months, completed the SUNS. Using these data, we

employed a combined theoretical and statistical method of reducing the number of items in the SUNS. The shortened survey was examined for construct validity, internal consistency, discriminant validity and floor and ceiling effects.

**Results** Fifty-nine items were removed. Construct validity closely reflected the original structure of the SUNS. However, all items from the *Emotional health* and *Relationships* domains loaded onto one factor. Cronbach's alpha for the final four domains were 0.85 or above, demonstrating strong internal consistency. Intra-class correlations of the three domains from the original survey (*Financial concerns*, *Information* and *Access and continuity of care*) and shortened survey were high (>0.9). Discriminant validity illustrated the short-form SUNS' ability to discriminate between those who had recently received treatment and those who had not.

**Conclusions** This study describes the development and psychometric evaluation of the short-form SUNS (SF-SUNS). Future studies should confirm the test–retest reliability and predictive validity of the SF-SUNS utilising large, independent, population-based samples of cancer survivors.

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## Introduction

The number of people living with cancer continues to increase [1]. In 2008, it was estimated that 25 million people were alive with cancer, and by 2030 it is expected

that this number will rise to 75 million [1]. According to the World Health Organization, the worldwide burden of cancer has more than doubled in the previous three decades [1]. Survival rates have also improved for a number of cancer types across multiple countries [2–4]. Although more people are living longer with cancer, the impact of the disease may continue long after treatment has ended [5–8].

Addressing cancer survivor needs is central to the aims of achieving patient-centred care [9, 10]. Unlike other patient-centred outcomes, such as quality of life and satisfaction of care, unmet needs provide an opportunity to assess the gap between patient concerns and the level of assistance they require [11–13]. A standardised needs assessment measure that is specific to identifying the unmet needs of cancer survivors would be considerably useful as it would provide an opportunity to accurately identify and summarise the collective unmet needs of cancer survivors on a large scale [12]. Data collected from such measures can be used to inform resource allocation and service provision [12, 14]. Alternatively, a standardised measure has the potential to be incorporated into standard cancer care practices [15], whereby clinicians can identify the highest area of concerns and tailor health care to the needs of individual survivors [15]. To maximise the clinical and research value of a standardised measure, it is important that the measure is short and concise to reduce respondent burden [15–17], while maintaining strong psychometric properties [16–18].

One standardised measure that has the potential to be routinely used as an unmet needs measure for cancer survivors is the Survivor Unmet Needs Survey (SUNS). Despite a variety of cancer-specific unmet needs measures [11, 15, 19, 20], the SUNS is one of the only unmet needs measure developed and psychometrically evaluated with a population-based sample of cancer survivors [12]. The SUNS has acceptable test–retest reliability, strong internal consistency (all Cronbach's alphas above 0.90) and has evidence of face, content and construct validity [12]. In addition, the SUNS has been found to be highly acceptable to cancer survivors [12]. The development of the SUNS and the initial psychometric evaluation is reported elsewhere [12].

However, the SUNS is a considerably long measure with a total of 89 items, which potentially increases response burden and decreases its acceptability as a measure for adoption into routine clinical care [15, 16]. A shorter version of the SUNS that illustrates strong psychometric properties would be ideal for the progression of needs assessment in cancer survivorship. In order to strengthen the applicability of the SUNS for use in routine clinical practice and large-scale research studies, this study aimed to reduce the length of the current version of the SUNS and assess its psychometric properties.

## Methods

### Design

A cross-sectional survey, utilising three population-based cancer registries, was conducted in three Canadian provinces.

### Sample

A stratified sample (12 to 24, 25 to 36, 37 to 48, and 49 to 60 months post-diagnosis) of 1,600 cancer survivors ( $n=400$  per stratum) was randomly selected from one registry and a simple random sample was used to select 850 and 1,300 survivors from two other registries. In all three studies, eligible persons were those 19 years of age and over at diagnosis, alive, with a histologically confirmed cancer diagnosis in the preceding 12 to 60 months. In situ, neurological and non-melanoma skin cancers were excluded as were survivors who had previously told the Cancer Registry they did not want to participate in research.

### Recruitment procedure

On behalf of the researchers, the cancer registries sent eligible survivors a study package, including a self-report questionnaire containing the SUNS, an information letter and a pre-paid return envelope. Two registries sent pre-notification letters 7 to 10 days prior to the survey package. Non-responders were sent a mailed reminder from the registry after 3 to 4 weeks and a second reminder after a further 10 to 14 days. Completed surveys were returned directly to the researchers. Return of a completed survey was taken as informed consent to participate in the study. For all three of the cancer registries, responder's age at diagnosis, sex, cancer type and time since diagnosis were available for comparison with the entire population of cancer survivors from the registry. This research was approved by the relevant ethics committees prior to undertaking this research with human participants.

### Shortening of the SUNS

The SUNS assesses cancer survivor's unmet needs over the last month utilising 89 items, across five domains: *Financial concerns* (11 items), *Emotional health* (33 items), *Access and continuity of care* (22 items), *Information* (8 items) and *Relationships* (15 items) [12]. Each of the five domains illustrated high internal consistency with all Cronbach's alphas above 0.9: Financial concerns (0.936), Emotional health (0.983), Access and continuity of care (0.967), Information (0.932) and Relationships (0.973). Response options range from 0 to 4, with 0 representing 'no unmet need' and 4 representing a 'very high unmet need' [12]. Any items that were uncodeable were treated as missing. Scores for each item

within the domain were summed to provide a domain score. Respondents were also asked to provide self-reported data on their demographic characteristics, cancer history, health care visits and any current treatment.

As suggested by Coste et al. [16] and utilised by previous research [15, 21, 22], we employed an approach that combined theoretical and statistical methods to reduce the number of items in the SUNS. Three researchers independently assessed all 89 items. Items assessed as confusing or vague were identified for removal. Items assessing similar areas of need were identified and compared, with the item narrower in scope considered for removal. The three researchers then discussed their results and any discrepancies were resolved. Once consensus was reached, the agreed upon items were removed.

Once these items were removed, the Cronbach's alpha for each of the five domains was assessed. If a domain still had very high internal consistency (i.e. Cronbach's alpha >0.9), indicating redundancy within the domain [16], further items were removed using combined theoretical and statistical methods. For each domain, the item that reduced the Cronbach's alpha the least was identified and the level of perceived clinical relevance to cancer survivors was assessed. Items were initially reviewed by two researchers: one with statistical expertise and a psycho-oncology researcher with experience in assessing the supportive care needs of cancer survivors. Items perceived by the researchers as clinically or theoretically relevant to cancer survivors based on the literature or previous research were retained and the next item which reduced the Cronbach's alpha the least was identified and assessed. This process was repeated so that the Cronbach's alpha for the overall domain was 0.85 or above. The final items were reviewed by two other psycho-oncology researchers.

#### Statistical analysis

##### *Construct validity*

Participants missing 21 or more responses to the 89 items were not included in the factor analysis, leaving 1,498 participants for the factor analyses. All 89 items had less than 5 % missing data and were therefore retained for the analysis. To ensure that the short-form SUNS was assessing similar constructs as the original SUNS, factors analysis using principal axis factoring and forcing five factors was used. Varimax rotation was used to reduce the complexity of the factor structure. Comparison of the factor loadings of the SUNS-SF were compared to the theoretical constructs from the original SUNS.

##### *Internal consistency*

Cronbach's alpha was calculated for each domain to provide a measure of internal consistency. Intra-class correlation

coefficients (ICC) were calculated for all domains that were consistent between the original SUNS and short-form. ICCs provided an indication of the level of agreement between mean domain scores on the original SUNS and the shortened version of the SUNS.

##### *Floor and ceiling effects*

The percentage of survivors with the lowest and highest possible scores on each subscale were calculated.

##### *Discriminant validity*

Known-groups validity for the shortened scale was assessed by comparing the median unmet need scores for each of the domains between survivors who had received treatment in the last month (including surgery, chemotherapy, radiation (radiotherapy), bone marrow transplant, stem cell transplant, complementary or alternative therapies or other) to those who had not received treatment in the last month. Median scores were compared using the Mann–Whitney *U* test. It was expected that survivors who had received treatment in the last month would report a higher level of unmet needs in all domains.

## Results

### Consent rate

A total of 3,750 cancer survivors were identified by the cancer registries as eligible to participate and were sent a study package. Three hundred ninety-six were later deemed ineligible as they had died (3.2 %) or were unable to be contacted (6.8 %). Of the 1,712 eligible survivors who returned a survey, 1,589 were completed (47.6 % consent rate).

### Participant characteristics

As shown in Table 1, there were almost equal proportions of male and female participants (51 %) and almost one third were aged between 60 and 69 years at diagnosis (31 %). Almost half of participants were retired (48 %) and had up to secondary schooling (48 %). The most common cancer types were breast (22 %) and prostate (21 %) followed by colorectal (14 %). Other cancers (including but not limited to brain, gynaecological, head and neck, kidney, liver, multiple myeloma and connective tissue) accounted for 32 % of all cases. There were no statistically significant differences between responders and the entire population of cancer survivors from the three cancer registries, except for one of the registries where age and cancer type were found to be statistically significantly different between the two groups. For this one

**Table 1** Participant demographic and disease characteristics

Characteristics	Survivors ( <i>n</i> =1,589)	
	<i>N</i>	%
Sex		
Male	775	49
Female	814	51
Age group at diagnosis		
20–39	58	3.7
40–49	170	11
50–59	391	25
60–69	491	31
70–79	396	25
80+	83	5.2
Cancer diagnosis		
Breast	356	22
Prostate	338	21
Colorectal	230	14
Lung	67	4.2
Non-Hodgkin's lymphoma	84	5.3
Other	514	32
Highest level of education		
Secondary school or less	733	48
Trade, vocational, college or other	403	26
University or higher	390	26
Employment status		
Retired	727	48
Paid work	563	37
Other	220	15

Columns may not equal total sample size due to missing values

registry, a higher percentage of responders were diagnosed with prostate cancer and a lower percentage were diagnosed with breast cancer, while a higher percentage of responders were aged between 50 and 59 years.

#### Item reduction

Original assessment of the SUNS by the three researchers resulted in a total of 23 items being removed: 16 due to item similarity, 4 due to items assessing similar areas of need and 3 due to confusing or vague wording. Correlation coefficients between items assessing similar areas of unmet need ranged from 0.57 to 0.89. Table 2 details the 23 items removed.

After removing the 23 items, internal consistency was still very high, with Cronbach's alpha for each domain above >0.9 (Information, 0.94; Financial concerns, 0.91; Access and continuity of care, 0.95; Relationships, 0.96; Emotional health, 0.98). A further 36 items were removed based on reductions in the domain's Cronbach's alpha from that item. During this process, 16 items were identified as reducing the Cronbach's

alpha the least but were included in the final scale based on perceived clinical or theoretical relevance to survivors. Such items included those which reflect areas of need that have previously been identified as frequently endorsed by cancer survivors, including: “finding information about complementary or alternative therapies” [12, 23, 24], “finding car parking that I can afford at the hospital or clinic” [25], “finding someone to talk to who understands and has been through a similar experience” [23–26] and “dealing with feeling tired” [11, 12, 25, 27]. Items that may be particularly important to a majority of cancer survivors from specific subgroups of survivors were also retained. For instance “having access to cancer services close to my home” was retained as this issue may be particularly relevant to many cancer survivors who reside in rural and remote areas. This resulted in a total of 30 items for the final shortened version of the SUNS: three from the Information domain, eight from Financial concerns, six from Access and continuity of care, five from Relationships and eight from the Emotional health domain.

#### Construct validity

As shown in Table 3, all eight items retained from the Financial concerns domain loaded on factor 3. Similarly, all six items from the Access and continuity of care domain loaded on factor 2. One item from the Information domain “finding information about complementary or alternative therapies” loaded highest on factor 2, but did load similarly on factor 4. The remaining two items from the Information domain loaded on factor 4. All items from the Emotional health and Relationships domains (five items in the Relationships domain and eight in the Emotional health domain) loaded together on factor one, suggesting that these two factors be combined into one domain.

#### Internal consistency

For the final shortened version of the SUNS, all Cronbach's alphas were 0.85 or above, indicating strong internal consistency for all four domains (as shown in Table 4). Intra-class correlations between the mean domain scores of the original SUNS that corresponded to the domains in the shortened SUNS were all above 0.9 (see Table 4), indicating a high level of agreement. ICCs between the original Emotional health and Relationships domains were not compared between the short and long form SUNS as they were combined into one domain in the short-form.

#### Floor and ceiling effects

Over a quarter of participants obtained the lowest possible score on all four domains of the short-form SUNS (Table 4). There were few ceiling effects

**Table 2** Items removed from the original Survivor Unmet Needs Survey (SUNS) during step one of the item removal process

Items assessing similar unmet needs		
Item selected for removal	Item remaining	Correlation coefficient
Adapting to living on a pension or disability allowance	Having to take a pension or disability allowance	0.80
Paying non-medical costs related to my cancer (travel, accommodation, special foods, etc.)	Paying household bills or other payments	0.66
Doing yard work (cutting grass, snow shovelling etc.)	Doing work around the house (cooking, cleaning, home repairs, etc.)	0.79
Finding information about cancer and its effects in a way I can understand	Understanding the information I was given	0.62
Making sure my family doctor could get information from specialists	Making sure all my health care workers had all the medical files related to my cancer care	0.67
Getting appointments with my family doctor quickly enough	Getting appointments with specialists quickly enough (oncologist, surgeon, etc.)	0.65
Getting follow-up tests quickly enough	Getting test results quickly enough	0.88
Feeling comfortable in the waiting room	Making sure I was treated in a hospital or clinic that was as physically pleasant as possible	0.57
Finding health care professionals who were friendly and could have a laugh with me	Making sure I was treated like a person, not just another case	0.80
Making sure the health care team understood and was aware of my feelings and emotional needs	Making sure I was treated like a person, not just another case	0.85
Dealing with the way other people react to my new priorities and my different outlook on life	Dealing with people accepting that having cancer has changed me as a person	0.70
Dealing with strains in relationships	Dealing with losses and changes in my relationships	0.72
Dealing with people not understanding how my physical abilities have changed	Dealing with people accepting that having cancer has changed me as a person	0.72
Dealing with feeling like I am a burden to my family and friends	Dealing with feeling guilty about what I have put others through	0.68
Dealing with feelings of isolation	Dealing with feeling lonely	0.78
Coping with things not going back to how they were before I had cancer	Coping with feeling like a different person	0.75
Items where area of need is captured by several broader items		
Item selected for removal	Items remaining	Correlation coefficient
Dealing with feelings about death and dying	Dealing with grief and loss	0.74
	Dealing with not being able to set future goals or make long-term plans	0.73
	Dealing with a loss of control	0.66
	Coping with feelings of despair	0.69
	Trying to keep a sense of hope	0.67
	Finding someone to talk to who understands and has been through a similar experience	0.62
Dealing with people not understanding what I'm going through	Dealing with people who expect me to be back to normal	0.76
	Dealing with people accepting that having cancer has changed me as a person	0.78
	Dealing with feeling stressed	0.89
Dealing with feeling worried (anxious)	Knowing how to relax	0.69
	Dealing with people who expect me to be “back to normal”	0.75
Dealing with people who expect me to feel happy or relieved when treatment has ended	Dealing with people accepting that having cancer has changed me as a person	0.80
Items expressed in a confusing or vague manner		
Being told I had cancer		
Wanting to reflect on what I have achieved		
Dealing with missing important events like holidays		



**Table 3** Item factor scores for the shortened version of the SUNS

Domains	Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Information	Finding information about complementary or alternative therapies		0.461		0.404	
	Dealing with fears about cancer spreading				0.591	
	Dealing with worry about whether the treatment has worked				0.598	
Financial concerns	Worry about earning money			0.786		
	Having to take a pension or disability allowance			0.728		
	Paying household bills or other payments			0.822		
	Finding what type of financial assistance is available and how to obtain it			0.660		
	Finding car parking that I can afford at the hospital or clinic			0.454		
	Understanding what is covered by my medical insurance or benefits			0.597		
	Knowing how much time I would need away from work			0.640		
Access and continuity of care	Doing work around the house (cooking, cleaning, home repairs etc.)			0.454		
	Having access to cancer services close to my home		0.572			
	Getting appointments with specialists quickly enough (oncologist, surgeon etc.)		0.757			
	Getting test results quickly enough		0.762			
	Having access to care from other health specialists (eg dietitians, physiotherapists, occupational therapists)		0.603			
	Making sure I had enough time to ask my doctor or nurse questions		0.664			
Relationships	Getting the health care team to attend promptly to my physical needs		0.716			
	Telling others how I was feeling emotionally	0.617				
	Finding someone to talk to who understands and has been through a similar experience	0.465				
	Dealing with people who expect me to be “back to normal”	0.551				
	Dealing with people accepting that having cancer has changed me as a person	0.607				
Emotional health	Dealing with reduced support from others when treatment has ended	0.541				
	Dealing with feeling depressed	0.824				
	Dealing with feeling tired	0.755				
	Dealing with feeling stressed	0.831				
	Dealing with feeling lonely	0.738				
	Dealing with not being able to feel ‘normal’	0.708				
	Trying to stay positive	0.702				
Coping with having a bad memory or lack of focus	0.639					
	Dealing with changes in how my body appears	0.608				

### Discriminant Validity

As illustrated in Table 5, survivors who had received treatment in the last month had significantly higher median scores for all four domains of the short-form SUNS, compared to survivors who had not received treatment in the last month.

**Table 4** Cronbach's alpha, ICC coefficients and percentage of survivors reporting the lowest and highest possible domain score for the four shortened domains of the SUNS

Domain	Cronbach's alpha	ICC	Lowest score % ( <i>n</i> )	Highest score % ( <i>n</i> )
Information	0.85	0.96	44 (683)	1.6 (25)
Financial concerns	0.90	0.99	53 (816)	0.5 (7)
Access and continuity of care	0.90	0.95	53 (811)	0.5 (7)
Relationships and Emotional health	0.95	–	36 (559)	0.3 (4)

### Discussion

We shortened the SUNS from 89 to 30 items, while maintaining strong internal reliability, evidence of validity and encompassing similar domains as the original measure. A copy of the SF-SUNS and original SUNS can be obtained, free-of-charge, from one of the authors.

**Table 5** Median domain scores for survivors who have received treatment in the last month compared to survivors who have not received treatment in the last month

Domain	Median score (min, max)		<i>P</i> value
	No treatment ( <i>n</i> =1,273)	Treatment ( <i>n</i> =181)	
Information	0.3 (0.0, 4.0)	0.7 (0.0, 4.0)	<0.001
Financial concerns	0.0 (0.0, 4.0)	0.4 (0.0, 4.0)	<0.001
Access and continuity of care	0.0 (0.0, 4.0)	0.2 (0.0, 3.8)	0.008
Relationships and Emotional health	0.2 (0.0, 4.0)	0.6 (0.0, 4.0)	<0.001

### Construct validity

The construct validity of the shortened survey corresponds closely with the original SUNS. In addition, the substantially larger sample size that was used for the factor analysis in this study ( $n=1,498$ ) compared to the original development of the SUNS ( $n=550$ ), provides greater power to the current factor analysis. However, items from two separate domains, the Relationships and Emotional health domains, loaded together on the same factor. This finding is not surprising given the relatively high correlation ( $r_s=0.848$ ) that was found between these two domains during the original development of the scale [12]. In addition, the item relating to getting information about complementary and alternative therapies, originally from the Information domain loaded more highly on the factor pertaining to Access and continuity of care. Theoretically, this makes sense since complementary therapies are considered along with more conventional health care services [28]. However, as this item loaded similarly on both factor 4 and factor 2, and the item specifically relates to finding information about complementary and alternative therapies, we included this item in the Information domain. It also ensures that three items are maintained within the information domain, which is the recommended minimum number of items to ensure a stable factor [29].

### Internal consistency

With Cronbach's alphas of 0.85 or above for all four domains, the shortened version of the SUNS displays high internal consistency. Furthermore, the exceptionally high intra-class correlation coefficients between the original measure and the short-form on the Financial concerns, Information and Access and continuity of care domains provides evidence that the short-form SUNS will identify cancer survivors' level of unmet needs on these domains as reliably as the original version. We did not find it appropriate to measure the ICCs between the original and short-form measure for the Emotional health

and Relationships domains as they have been combined into one domain in the short-form SUNS.

### Floor and ceiling effects

The short-form SUNS illustrates possible floor effects for each of the four domains. This is evident by more than 15 % of participants [30] obtaining the lowest possible score for each domain. Floor effects may impact on the ability to observe reductions in individual's level of unmet needs using the short-form SUNS [30]. This is not uncommon with more than 15 % of participants having reported the lowest possible domain score in other needs assessment measures [15, 31]. This finding is consistent with data from the original full-length SUNS, which when examined illustrated significant floor effects for all five of the original domains (Information, 37 %; Financial concerns, 51 %; Access and continuity of care, 42 %; Relationships, 47 %; Emotional health, 33 %). Although not ideal, floor effects may not be a significant limitation of the SF-SUNS as they reflect a positive outcome for this sample of cancer survivors, with the results indicating that the majority of these samples are experiencing few unmet needs across all domains of the SF-SUNS. It is possible that most cancer survivors are faring relatively well after their diagnosis, with only a few requiring additional intensive assistance. For instance, 280 survivors in the current study provided an open-ended response to the question "are there any other problems or needs that you needed help with in the last month?" Of these 280 survivors, over 100 indicated that they had no additional problems, few unmet needs and/or that the SUNS was not applicable or relevant to their situation.

### Discriminant validity

The shortened SUNS was also successful in differentiating between groups of cancer survivors who are thought to experience different levels of unmet needs. The data from this study illustrates that cancer survivors who have recently received treatment reported significantly higher levels of unmet needs across all four domains of the short-form SUNS, compared to survivors who have not had treatment in the last month. This finding was expected as a recent review reported that the unmet needs of people diagnosed with cancer appeared to be highest during treatment [32]. The ability of the shortened SUNS to identify survivors who theoretically should report higher unmet needs further supports the validity of this measure as well as its clinical usefulness.

The original SUNS had high acceptability [12] and took an average of 24 min (95 % CI=0.±72) to complete. With only 30 items, the shorter version will require less time to complete, reducing respondent burden and making it more feasible to administer in clinical and research settings.

## Limitations

There is no standard protocol for reducing the length of a standardised measure [16], which may raise questions about the procedures used in this study and the joint consideration of theoretical relevance with our statistical approach. In a review conducted by Coste et al. [16], it was suggested that an expert-based approach to shortening a standardised measure was more preferable to a statistical approach when no gold-standard measure is available [16]. In addition, prior studies, which have aimed to reduce the length of previously developed psychometric measures, have also relied upon a combination of theoretical and clinical judgment with statistical methods [15, 21, 22]. As a result of keeping items based on clinical relevance and a theoretical basis, we kept three items with factor loadings lower than the cut-point of 0.5, which was used to exclude items in the original development of the SUNS [12].

Despite high internal reliability and consistency between the domains that were the same in the original SUNS and the shortened version, we were not able to establish the test–retest reliability, predictive validity or face validity of the shortened measure. However, given the extensive iterative process that was involved in the original development of the SUNS, including consultation with survivors, health care professionals and researchers in the area, we believe the face validity of the measure is sound. The factor analysis of the short-form SUNS did not coincide exactly with the original factor structure of the long-form SUNS. Notably, all items from the original Relationships and Emotional health domains loaded together on one factor, resulting in a combined Relationships and Emotional health domain in the short-form SUNS. However, based on the high correlation between these two domains in the original development of the measure and the increased sample size and power of the current study, it is arguably warranted that the items from both domains are combined to form one domain in the short-form scale. Unfortunately, due to combining the Emotional health and Relationships domains in the short-form SUNS, we were unable to assess the intra-class correlations between the original two domains and the new combined domain in the short-form. However, the high Cronbach's alpha and evidence of adequate discriminant validity of the combined domain in the short-form SUNS provides some support for the reliability and validity of the new domain. We did not validate the shortened measure with a sample of survivors who were independent from the shortening process as recommended by Coste et al. [16]. Consequently, we suggest that future studies aim to assess the predictive validity, cross-cultural validity and test–retest reliability, and reconfirm the construct validity of the short-form SUNS, using an independent sample of cancer survivors.

Finally, at 47.6 %, the overall response rate was relatively low, which may affect the generalisability of the current findings to the wider population of cancer survivors. In addition,

responders from one registry differed from the entire population of survivors in terms of cancer type and age at diagnosis. Unfortunately, low response rates are not uncommon in registry-based studies, with several previous studies recording response rates below 50 % [27, 33]. Caution should be made when generalising the current results to the wider population of cancer survivors, particularly in relation to cancer type and age at diagnosis.

## Conclusion

As the number of cancer survivors increases, it is imperative that we understand and address the unmet needs of this population. However, to do this we require a valid and reliable unmet needs measure that is short and concise and can easily be adopted into routine clinical and research practices. Currently, the SUNS is one of the only unmet needs measure developed using a population-based sample of cancer survivors. However, with a total of 89 items, the SUNS in its original form is relatively long and burdensome. With strong reliability and evidence of validity, the shortened version of the SUNS presented in this paper offers a reasonable alternative as an unmet needs measure for cancer survivors. Future studies should further explore the reliability and validity of this measure.

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## References

- Boyle P, Levin B (2008) World cancer report. International Agency for Research on Cancer, Lyon
- Verdecchia A, Francisci S, Brenner H, Gatta G, Micheli A, Mangone L, Kunkler I, EURO CARE-4 Working Group (2007) Recent cancer survival in Europe: a 2000–02 period analysis of EURO CARE-4 data. *Lancet Oncol* 8:784–796. doi:10.1016/S1470-2045(07)70246-2
- Welch HG, Schwartz LM, Woloshin S (2000) Are increasing 5-year survival rates evidence of success against cancer? *JAMA* 283:2975–2978



4. Coleman MP, Forman D, Bryant H, Butler J, Rachet B, Maringe C, Nur U, Tracey E, Coory M, Hatcher J, McGahan CE, Turner D, Marrett L, Gjerstorff ML, Johannesen TB, Adolfsen J, Lambe M, Lawrence G, Meechan D, Morris EJ, Middleton R, Steward J, Richards MA, ICBP Module 1 Working Group (2011) Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *Lancet* 377:127–138. doi:10.1016/S0140.6736(10)62231-3
5. Haylock P, Mitchell S, Cox T, Vogt Temple S, Curtiss CP (2007) The cancer survivor's prescription for living: nurses must take the lead in planning care for survivors. *Am J Nurs* 107(4):58–70
6. Aziz NM (2009) Long-term cancer survivors: research issues and care needs in a key phase of the survivorship spectrum. *Am J Hematol* 84(12):782–784. doi:10.1002/ajh.21579
7. Aziz NM (2007) Cancer survivorship research: state of knowledge, challenges and opportunities. *Acta Oncol* 46:417–432. doi:10.1080/02841860701367878
8. Harrington CB, Hansen JA, Moskowitz M, Todd BL, Feuerstein M (2010) It's not over when it's over: long-term symptoms in cancer survivors—a systematic review. *Int J Psychiatr Med* 40(2):163–181. doi:10.2190/PM.40.2.C
9. Hanna A (2010) Patient-centred care. *Ontario Medical Review* June: 34–49
10. Australian Commission on Safety and Quality in Health Care ACSQHC (2010) Patient-Centred Care: Improving quality and safety by focusing care on patients and consumers: Discussion paper draft for public consultation. Australian Commission on Safety and Quality in Health Care ACSQHC, Sydney
11. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P, The Supportive Care Review Group (2000) The unmet supportive care needs of patients with cancer. *Cancer* 88:225–236
12. Campbell HS, Sanson-Fisher R, Turner D, Hayward L, Wang XS, Taylor-Brown J (2011) Psychometric properties of cancer survivors' unmet needs survey. *Support Care Cancer* 19:221–230. doi:10.1007/s00520-009-0806-0
13. Richardson A, Sitzia J, Brown V, Medina J, Richardson A (2005) Patients' needs assessment tools in cancer care: principles & practice. King's College London, London
14. Wen KY, Gustafson D (2004) Needs assessment for cancer patients and their families. *Health and Quality of Life Outcomes* 2(11)
15. Boyes A, Girgis A, Lecathelinais C (2009) Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *J Eval Clin Pract* 15:602–606. doi:10.1111/j.1365-2753.2008.01057.x
16. Coste J, Guillemin F, Pouchot J, Fermanian J (1997) Methodological approaches to shortening composite measurement scales. *J Clin Epidemiol* 50(3):247–252
17. Muhlan H, Bullinger M, Power M, Schmidt S (2008) Short forms of subjective quality of life assessments from cross-cultural studies for use in surveys with different populations. *Clin Psychol Psychother* 15:142–153. doi:10.1002/cpp.573
18. DeVellis RF (2003) Scale development theory and applications. 2nd edn. SAGE, London
19. Hodgkinson K, Butow P, Hunt GE, Pendlebury S, Hobbs KM, Lo SK, Wain G (2007) The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: the CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-Oncology* 16: 769–804. doi:10.1002/pon.1137
20. Richardson A, Medina J, Brown V, Sitzia J (2007) Patients' needs assessment in cancer care: a review of assessment tools. *Support Care Cancer* 15:1125–1144. doi:10.1007/s00520-006-0205-8
21. Schag CAC, Ganz PA, Heinrich RL (1991) CAncer Rehabilitation Evaluation System-Short Form (CARES-SF). *Cancer* 68:1406–1413
22. Boyer L, Simeoni MC, Loundou A, D'Amato T, Reine G, Lancon C, Auquier P (2010) The development of the S-QoL 18: a shortened quality of life questionnaire for patients with schizophrenia. *Schizophr Res* 121:241–250. doi:10.1016/j.schres.2010.05.019
23. Hodgkinson K, Butow P, Fuchs A, Hunt GE, Stenlake A, Hobbs KM, Brand A, Wain G (2007) Long-term survival from gynecologic cancer: psychosocial outcomes, supportive care needs and positive outcomes. *Gynecol Oncol* 104(2007):381–389
24. Lobb EA, Joske D, Butow P, Kristjanson LJ, Cannell P, Cull G, Augustson B (2009) When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. *Patient Educ Couns* 77:103–108. doi:10.1016/j.pec.2009.02.005
25. Hall AE, Campbell HS, Sanson-Fisher R, Lynagh M, D'Este C, Burkhalter R, Carey M (2013) Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. *Psycho-Oncology* 22(9):2032–2038. doi:10.1002/pon.3247
26. Molassiotis A, Wilson B, Blair S, Howe T, Cavet J (2011) Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. *Psycho-Oncology* 20(1):88–97
27. Boyes AW, Girgis A, D'Este CA, Zucca AC (2012) Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: a population-based cross-sectional study. *BMC Cancer* 12 (150). doi:10.1186/1471-2407-12-150
28. Verhoef MJ, Trojan L, Armitage GD, Carlson L, Hilsden RJ (2009) Complementary therapies for cancer patients: assessing information use and needs. *Chron Dis Canada* 29(2):80–88
29. Costello AB, Osborne JW (2005) Best practices in exploratory factor analysis: four recommendations for getting the most from your analysis. *Practical Assess Res Eval* 10(7)
30. Terwee CB, Bot SDM, de Boer MR, van der Windt DAWM, Knol DL, Dekker J, Bouter LM, de Vet HCW (2007) Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol* 60:34–42. doi:10.1016/j.jclinepi.2006.03.012
31. Clinton-McHarg T, Carey M, Sanson-Fisher R, D'Este C, Shakeshaft A (2012) Preliminary development and psychometric evaluation of an unmet needs measure for adolescents and young adults with cancer: the Cancer Needs Questionnaire—Young People (CNQ-YP). *Health and Quality of Life Outcomes* 10 (13). doi:10.1186/1477-7525-10-13
32. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ (2009) What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer* 17:1117–1128. doi:10.1007/s00520-009-0615-5
33. Hall AE, Sanson-Fisher RW, Lynagh MC, Threlfall T, D'Este CA (2013) Format and readability of an enhanced invitation letter did not affect participation rates in a cancer registry-based study: a randomized controlled trial. *J Clin Epidemiol* 66(1):85–94. doi:10.1016/j.jclinepi.2012.07.016