

Psychometric properties of the Dutch extended Cancer Survivors' Unmet Needs measure (CaSUN-NL)

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Information and support needs increase emotional distress and can impede cancer survivors' adjustment. To investigate the information and support needs of Dutch cancer survivors, the Cancer Survivors' Unmet Needs measure (CaSUN) was translated into Dutch and applied in two Dutch studies with cancer survivors ($N = 255$; $N = 467$). The CaSUN-NL entailed the original five CaSUN scales, extended with respectively a returning to work and lifestyle scale. This study aimed to determine the psychometric properties of the CaSUN-NL. To assess validity, a maximum likelihood factor analysis was employed. Construct validity was analysed using Pearson's and Spearman's correlation coefficients. To assess reliability, test-retest (Kappa coefficient) and internal consistency (Cronbach's alpha) values were determined. Factor analysis revealed the original five factors. Test-retest reliability was low ($r \leq .15$, 93% retest response). Internal consistency values were high (Cronbach's alpha = 0.92–0.94), except for lifestyle. Significant correlations were found between total number of unmet needs with anxiety ($r = .55$), depression ($r = .49$), negative adjustment ($r = .50$), quality of life ($r = -.52$) and age ($r = -.24$). The CaSUN-NL is valid and reliable to investigate the unmet information and support needs of Dutch cancer survivors.

KEYWORDS

cancer survivors, CaSUN, reliability, unmet needs, validity

1 | INTRODUCTION

Cancer survivors can experience physical and psychosocial problems, which are most prevalent during the first year after cancer treatment completion, but may endure for many subsequent years (Andrykowski, Lykins, & Floyd, 2008; Duijts et al., 2014; Hodgkinson, Butow, Fuchs, et al., 2007; Hodgkinson, Butow, Hunt, et al., 2007; Mehnert & Koch, 2008). Many cancer survivors also report having

unmet information and support needs in dealing with these issues (Geller, Vacek, Flynn, Lord, & Cranmer, 2014; Hodgkinson, Butow, Fuchs, et al., 2007; Hodgkinson, Butow, Hunt, et al., 2007; Willems et al., 2016a). The greater the number of unmet information and support needs, the greater the depressive feelings, fear of recurrence and distress, and the lower the quality of life of cancer survivors (Smith et al., 2013). Insight into these unmet needs may help agenda-setting in health policy addressing cancer survivors unmet

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needs, tailoring information provision and development of tailored interventions. Therefore, it is important to assess possible unmet needs of cancer survivors.

Several valid and reliable questionnaires assess the unmet needs of cancer survivors. However, they were all in English.

The Cancer Survivors' Unmet Needs measure (CaSUN) is a 35-item self-report questionnaire, assessing the need for psychosocial support in several domains, such as existential survivorship, comprehensive cancer care, information, quality of life and relations. It also consists of one open question for possible additional needs, and six items on positive changes, unrelated to unmet needs (Hodgkinson et al., 2007). The validation study of the original CaSUN revealed that the number of unmet needs significantly correlated with quality of life, anxiety and depression. Internal consistency of all items was high (Cronbach's $\alpha = 0.96$), and test-retest reliability was low (average Kappa Coefficient = 0.13). Factor analysis revealed five factors (existential survivorship, comprehensive cancer care, information, quality of life and relations) with Cronbach's alphas between 0.78 and 0.93. Despite the low test-retest reliability, the CaSUN was regarded as a valid questionnaire to measure unmet needs of cancer survivors (Hodgkinson et al., 2007). The 89-item Survivors Unmet Needs Survey (SUNS) has strong psychometric properties and five subscales (emotional health needs, access and continuity of care, relationships, financial concerns and information needs; Cronbach's alphas 0.94–0.98; Campbell et al., 2011). The 60-item Supportive Care Needs Survey (SCNS) also has five subscales (psychologic needs, health system and information, physical and daily living, patient care and support and sexuality needs; Cronbach's alphas 0.87–0.97; Bonevski et al., 2000). The 34-item short form SCNS-SF34, recently translated and validated for the Dutch cancer population (Jansen et al., 2016), is reliable but not a cancer survivor-specific questionnaire, and therefore unsuitable for use in the two Dutch studies that underlie the current validation study. The SUNS and the CaSUN are survivor-specific questionnaires; however, while the SUNS has a relatively large quantity of items on financial issues, it lacks items on quality of life.

In the Netherlands, only a few studies have identified the unmet needs of cancer survivors (Jansen, van Uden-Kraan, van Zwieten, Witte, & Verdonck-de Leeuw, 2015; Kanera, Bolman, Willems, & Mesters, 2016; Pauwels, Charlier, De Bourdeaudhuij, Lechner, & Van Hoof, 2013; Willems et al., 2016a,b). For our two studies (Kanera, Bolman, Mesters, et al., 2016; Willems et al., 2016a), the validated CaSUN was regarded as the most appropriate general questionnaire to specifically investigate the unmet needs of cancer survivors (Bender et al., 2012; Brennan, Butow, Spillane, & Boyle, 2016; Geller et al., 2014; Harrison et al., 2011; Hodgkinson, Butow, Fuchs, et al., 2007; Hodgkinson, Butow, Hunt, et al., 2007; Rowlands, Janda, McKinnon, Webb, & Beesley, 2015; Smith et al., 2013; Urbaniec, Collins, Denson, & Whitford, 2011). Therefore, the CaSUN was translated into Dutch. In order to estimate its value for broader use in the Netherlands but also in other non-English-speaking countries, it is important to test the CaSUN-NL on its psychometric quality.

The aim of this study was to determine the psychometric properties of the CaSUN-NL in two substantial patient samples. Construct validity was determined by assessing correlations of unmet needs with psychological, demographic and disease-related variables. Several hypotheses were formulated a priori (Cohen, 1992; Terwee et al., 2007). It was expected that unmet needs would correlate positively with anxiety, depression and negative adjustment, and negatively with quality of life, positive adjustment and personal control (Rowlands et al., 2015; Smith et al., 2013; Urbaniec et al., 2011). Furthermore, we studied associations of unmet needs with age and marital status and with type of cancer and time since treatment (Pauwels et al., 2013; Rowlands et al., 2015; Urbaniec et al., 2011). In addition, factor analysis, test-retest reliability and internal consistency were determined.

2 | METHODS

2.1 | CaSUN-NL

The CaSUN—developed for the Australian cancer survivor population—was independently translated from English into Dutch by two investigators. These translations were combined to one new version, critically reviewed and translated back by an English native speaker. This led to a second version, which was adapted to the Dutch health care situation. Feedback from a pilot study among eight cancer survivors, primarily concerning scoring instructions, led to a definitive version of the CaSUN-NL. During this process, the CaSUN-NL was extended with five items on return to work and four on lifestyle, because return to work and lifestyle are prominent issues among cancer survivors and cancer survivors may also experience unmet needs in these domains (Demark-Wahnefried & Jones, 2008; Duijts et al., 2014; Harding, 2012; Küsters, Lechner, Willems, Bolman, & Mesters, 2012; Stergiou-Kita et al., 2014; Wolin & Colditz, 2013). The CaSUN-NL was subsequently applied in the two Dutch studies (hereafter called “first study” and “second study”; Kanera, Bolman, Mesters, et al., 2016; Kanera, Bolman, Willems, et al., 2016; Kanera, Willems et al., 2016; Willems et al., 2015, 2016a,b).

The CaSUN-NL measures the information and support needs of Dutch cancer survivors in the past month, categorised into five original domains: existential survivorship (14 items, e.g. “emotional support”), comprehensive cancer care (six items, e.g. “best medical care”), information (three items, e.g. “comprehensible information”), quality of life (two items, e.g. “help with side effects and complications”) and relations (three items, e.g. “help to manage effects of cancer on relationship with my partner”) and the added domains: lifestyle (four items, e.g. “help to quit smoking”) and return to work (five items, e.g. “help to return to work”). As in previous validation study (Hodgkinson et al., 2007), the open question, six items on positive change (e.g. “I grew as a person”) and seven complementary items (fertility issues, employment, financial support, insurance, legal services, case manager and reduce alcohol use) were not included in the current validation analysis. The focus was on the items that might reveal a correlation between unmet needs and demographic, disease-related and psychological characteristics. Items are scored with *no need/not applicable*, a

met need or an *unmet need* and the strength of unmet need as *weak* (1), *moderate* (2) or *strong* (3). In accordance with the CaSUN manual, sum scores were calculated to *total unmet needs*, *total met needs* and *total needs*. Higher sum scores indicate a greater number of (un)met needs.

2.2 | Respondents and procedure

Participants were recruited by hospital staff during regular control visits or through case findings in medical files. Inclusion criteria were minimum age of 18 years, diagnosed with cancer, 4 weeks to a year after primary treatment completion, no signs of recurrence, able to speak and read Dutch and absence of severe physical or mental disorders.

The first study, a paper-and-pencil cross-sectional survey explored the information and support needs of cancer survivors, and its relationships with demographic, disease-related and psychosocial characteristics, with a follow-up after 6 weeks (Kanera, Bolman, Mesters, et al., 2016; Willems et al., 2016a). Of the 455 invited cancer survivors, 255 (58.9%) were eligible and consented to participate, and 237 (93%) participated again after 6 weeks. The questionnaires included demographic items, the CaSUN-NL, the Hospital Anxiety and Depression Scale (HADS), the Mental Adjustment to Cancer Scale (MAC), the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) and the Brief Illness Perception Questionnaire Revised (IPQ-R). The study was approved by the Ethical Review Board on Research of the Open University of the Netherlands.

The second study was a randomised controlled trial to evaluate the effectiveness of an e-Health intervention for cancer survivors on quality of life, anxiety, depression and fatigue (Kanera, Willems et al., 2016; Willems et al., 2015, 2016b). The inclusion criterion (4 weeks to a year after primary treatment) was somewhat longer than in the first study. Baseline data were used in this study. Of 1,303 invited patients, 467 (35.8%) were eligible and consented to participate. The online questionnaires included the CaSUN-NL, the EORTC QLQ-C30, the HADS, the MAC, the IPQ-R, the Checklist Individual Strength, demographic and disease-related items. This study was approved by the Medical Ethics Committee Zuyderland-Zuyd (NL41445.096.12).

2.3 | Construct validity measurements

Variables included demographic characteristics (age, gender, marital status (with/without partner), education (low/middle/high) and employment situation (working/not working)) and disease-related characteristics (type of cancer (breast/colon/other type) and time since treatment).

The HADS (Bjelland, Dahl, Haug, & Neckelmann, 2002) measures anxiety (HADS-A) and depression (HADS-D); both seven items, range 0–21 and is frequently used to measure anxiety and depressive symptoms of cancer patients.

The MAC (Braeken et al., 2009; Watson & Homewood, 2008) includes two higher order scales, positive adjustment (MAC-PA, 17 items, range 17–68) and negative adjustment (MAC-NA, 16 items,

range 16–64) and is used to measure cancer patients' adjustment to their illness. Higher scores mean higher positive or negative adjustment (Watson & Homewood, 2008).

The 30-item EORTC QLQ-C30 (Aaronson et al., 1993) measures the quality of life of cancer patients. In the current validation study, the two-item global health scale was included. A higher mean score means having a better global health/quality of life.

The 38-item IPQ-R (Weinman, Petrie, Moss-Morris, & Horne, 1996) measures the perception of patients' illness. In the first study, the third item on personal control ("How much control do you feel you have over your illness?") of the Brief IPQ-R (Broadbent, Petrie, Main, & Weinman, 2006) was used. In the second study, the six items on personal control from the IPQ-R (Weinman et al., 1996) were included. Higher scores mean higher personal control.

2.4 | Statistical analyses

For this validation study, the baseline and second measurement of the first study, and the baseline measurement of the second study, were included. Missing data in the first study were handled according to the instrument-specific manuals (Hodgkinson et al., 2007; Kanera, Bolman, Mesters, et al., 2016; Willems et al., 2016a). In the second study, no data were missing because the online assessment was programmed to avoid non-response.

Analyses were kept similar to the original validation study (Hodgkinson et al., 2007), but with less demographic and disease-related categories and with return to work, lifestyle and personal control items. The quality criteria (e.g. construct validity, internal consistency and test-retest reliability) for measuring properties of health status questionnaires were used to evaluate the quality of the psychometric properties (Terwee et al., 2007).

Construct validity was analysed with Pearson's correlation coefficients with (sub)scales of the CaSUN-NL with the HADS, MAC, EORTC QLQ-C30, the IPQ-R, age and time since treatment. Correlations with marital status and type of cancer were analysed with Spearman's correlation coefficients.

Factor analyses on the original five factors were conducted, with maximum likelihood, oblique rotations, Kaiser normalisation and minimum factor loads of 0.30.

Test-retest reliability was evaluated with Kappa coefficients with the two measurements of the first study (Sim & Wright, 2005). Analyses were conducted with *total needs*, *total met needs*, *total unmet needs* and the subscales *existential survivorship*, *comprehensive cancer care*, *information*, *relations*, *quality of life* and *return to work*.

Internal consistency was analysed with Cronbach's alphas. Analyses were conducted with the same scales as for the Kappa coefficients and with the separate lifestyle items.

3 | RESULTS

3.1 | Study participants

Demographic and disease-related characteristics of the participants are shown in Table 1. The mean age of the participants for the first

TABLE 1 Patient characteristics

Variable	First study (N = 255), n (%)	Second study (N = 467), n (%)
Age (years)		
Mean (SD)	60.6 (10.74)	55.8 (11.49)
Range	25–88	21–82
Female	176 (69.0)	372 (79.7)
Breast cancer	150 (58.8)	329 (70.4)
Colon cancer	51 (20.0)	65 (13.9)
Other type of cancer	54 (21.2)	73 (15.6)
Married/living together	217 (86.5)	380 (81.4)
Low education	137 (54.6)	175 (37.6)
Middle education	47 (18.7)	147 (31.5)
High education	67 (26.7)	144 (30.9)
Paid employment	89 (36.0)	235 (50.3)

and second study was 60.6 ($SD = 10.74$) and 55.8 ($SD = 11.49$), respectively, the majority were female (69.0%; 79.7%) and mostly survivors of breast cancer (58.8%; 70.4%).

3.2 | Construct validity

Table 2 shows the correlations between the *unmet* needs, *met* needs and *total* needs of the CaSUN-NL with demographic, disease-related and psychological variables. In both studies, a significant correlation was found between *unmet* needs and age ($r = -.24$; $r = -.23$), indicating that younger patients had more unmet needs. In the second study, a significant correlation was found between marital status and *unmet* needs ($r = .15$), indicating that people living without a partner had more unmet needs. In both studies, there

was no significant correlation between unmet needs and time since treatment or type of cancer.

Anxiety ($r = .52$; $r = .55$), depression ($r = .49$; $r = .49$) and negative adjustment ($r = .50$; $r = .56$) were significantly positively correlated, in both studies, with *unmet* needs; the higher the unmet needs, the higher the scores on anxiety, depression or negative adjustment. Positive adjustment was significantly negatively correlated, in the second study, with unmet needs ($r = -.16$); the lower the unmet needs, the higher the score on positive adjustment. Positive adjustment was significantly positively correlated with *met* needs in the first study ($r = .14$). In both studies, there was a significant negative correlation between global health and *unmet* needs ($r = -.52$; $r = -.45$), indicating that more unmet needs lower the score on global health. Personal control correlated significantly negatively with *unmet* needs in the second study ($r = -.18$). Higher scores on personal control indicate lower numbers of unmet needs.

3.3 | Factor analyses

The items of the original CaSUN not loading over 0.03 were excluded from factor analyses, in accordance with the study of Hodgkinson et al. (2007). The items on *existential survivorship* (ES) in both studies fell in two different factors (partly in a separate factor; partly together with quality of life). The items on *quality of life* (QL) fell, in both studies, in the factor *existential survivorship*. The items on *comprehensive cancer care* (CC) formed one factor. The items on *information* (IN) were included in the factor *comprehensive cancer care* in the first study, but in the second study, the items constituted a separate factor. The items on *relations* (RE) formed a separate factor in both studies. The total variance explained in the first study was 51% and in the second study 45%, both concerning the baseline measurement (see Tables S1 and S2 for more details).

TABLE 2 Correlations between CaSUN-NL and variables

Variable	First study			Second study		
	Total needs	Total met needs	Total unmet needs	Total needs	Total met needs	Total unmet needs
Age	-.25**	-.08	-.24**	-.24**	-.05	-.23**
Marital status	.04	.01	.04	.16**	.01	.15**
Type of cancer	-.04	-.04	-.00	-.06	-.03	-.04
Time since treatment	-.10	-.11	-.06	-.05	-.06	-.03
Anxiety (HADS)	.55*	.18**	.52**	.57*	.15**	.55**
Depression (HADS)	.52**	.19**	.49**	.51**	.12**	.49**
Positive adjustment (MAC)	.03	.14*	-.04	-.18**	-.08	-.16**
Negative adjustment (MAC)	.50**	.12	.50**	.55**	.08	.56**
Global Health (EORTC)	-.54**	-.17**	-.52**	-.50**	-.17**	-.45**
Personal control (IPQ)	.03	.15*	-.05	-.14**	.04	-.18**

The CaSUN-NL included the original 35 items (in the first study minus 1 double), four items on lifestyle and five items on return to work.

* $p \leq .05$; ** $p \leq .01$.

TABLE 3 Kappa coefficients first study

Variable	Original list	Extended list
Met and unmet needs per factor		
Existential survivorship (ES)	0.22**	
Comprehensive cancer care (CC)	0.24**	
Information (IN)	0.28**	
Quality of life (QL)	0.41**	
Relations (RE)	0.37**	
Return to work (RW)		0.46**
Total unmet needs	0.15**	0.12**
Total met needs	0.11**	0.12**
Total needs	0.13**	0.14**

Interpretation: 0–0.20 slight, 0.21–0.40 fair, 0.41–0.60 moderate, 0.61–0.80 substantial, 0.81–1 almost perfect.

**Correlation is significant at $p \leq .01$.

3.4 | Test–retest reliability

The data of the first study, a test and retest measurement after 6 weeks, including the original questionnaire and the extended questionnaire, were used to analyse test–retest reliability (Table 3). All Kappa coefficients were significant, ranging from 0.22 to 0.46 for the original factors and return to work (RW) and from 0.11 to 0.15 for *total unmet needs*, *total met needs* and *total needs*.

3.5 | Internal consistency

As displayed in Table 4, Cronbach's alphas ranged from 0.73 to 0.94, except for quality of life (QL, $\alpha = 0.63$) and relations (RE, $\alpha = 0.68$) in the second study. The items on lifestyle had low alphas ranging from 0.38 to 0.52.

4 | DISCUSSION

The present study determined the psychometric properties of the CaSUN-NL, the Dutch translated and extended Cancer Survivors Unmet Needs measure, using data from two substantial Dutch cancer survivor samples. Overall, sufficient evidence was found that supports the construct validity and reliability (Terwee et al., 2007). Test–retest reliability proved to be low for the overall CaSUN, but fair to moderately strong for the six factors.

The added scales on lifestyle and return to work proved to be valuable extensions. Both studies show that many cancer survivors had unmet needs in these domains (Kanera, Bolman, Willems, et al., 2016; Willems et al., 2016a). This is in line with the conclusion of Duijts et al. (2014) that cancer survivors experience problems that may cause serious difficulties at work, as well as that of Harding (2012), suggesting that cancer survivors may need support to engage in healthy lifestyle behaviours.

Regarding construct validity, data showed that there were significant correlations in the expected directions: moderate to strong significant positive correlations of *unmet* needs with anxiety, depression and negative adjustment; strong significant negative correlation of global health with *unmet* needs; and a weak significant negative correlation with age (Cohen, 1992). A weak significant negative correlation between *unmet needs* and personal control was only found in the second study, which may be caused by the difference in used items. No significant correlations were found for type of cancer and time since treatment. Hodgkinson et al. (2007) found comparable correlations. In the literature, different associations were found for time since treatment with unmet needs (Pauwels et al., 2013; Urbaniec et al., 2011). However, shortly after treatment completion, many cancer survivors have more and/or stronger unmet needs (Boyes, Girgis, D'Este, & Zucca, 2012; Willems et al., 2016a). More research is needed to resolve these contradictory findings.

The factor structure was, for the most part, comparable with the factor structure found by Hodgkinson et al. (2007). Both quality of life items (manage side-effect, changes to quality of life) fell in both studies in the existential survivorship factor. As the data confirm, the items of existential survivorship and quality of life may be associated with each other. Shin et al. (2009) conclude that existential well-being of breast cancer survivors is critical for their quality of life. However, a clear explanation for not finding completely matching factor structures remains unclear. Difference in factor structure between the first and second study might be explained by a difference in the characteristics of respondents. Most importantly, the

TABLE 4 Internal consistency

	First study		Second study Baseline
	First measurement	Second measurement	
CaSUN-NL (met needs, unmet needs)			
Original list	0.93	0.94	0.91
Extended list	0.94	0.94	0.92
Existential survivorship (ES)	0.90	0.90	0.89
Comprehensive cancer care (CC)	0.81	0.80	0.78
Information (IN)	0.84	0.87	0.80
Quality of life (QL)	0.73	0.75	0.63
Relations (RE)	0.74	0.75	0.68
Return to work (RW)	0.84	0.87	0.72
Lifestyle	0.38	0.44	0.52

The original list of the first study contained 34 items and of the second study 35 items. The extended list of the first study contained 43 items and of the second study 44 items. The six items on positive change were not included in the analyses. For research, a Cronbach's alpha of ≥ 0.70 is sufficient.

percentage of women and breast cancer survivors was higher in the second study. The respondents of the second study chose to be part of an intervention study and therefore may have had more or stronger unmet needs than the respondents of the first study, who were just asked for their opinion, independent from any intervention. The participants in the second study may, to a larger degree, represent the target group of cancer survivors seeking information and support care for their unmet needs.

For reliability, the test-retest correlations of the original five factors and the return to work factor were fair to moderate. As in the study of Hodgkinson et al. (2007), test-retest correlations of *total unmet needs*, *total met needs* and *total needs* were low. Contrary to Hodgkinson et al., there was a high test-retest response. Although test-retest reliabilities were not very different, in Hodgkinson's study, test-retest moments were 3 weeks apart and respondents were short-term to long-term female survivors of breast or gynaecological cancer. In the current study, test-retest moments were 6 weeks apart and respondents were male and female survivors of many types of cancer—although females and breast cancer survivors were over-represented—and the period since their treatment completion was shorter. The explanation for the low test-retest reliability is unclear and judging test-retest reliability needs to be done with caution. Cronbach's alphas were sufficient and comparable to those found by Hodgkinson et al. (2007).

4.1 | Study limitations

This study for the psychometric properties of the CaSUN-NL, with 722 respondents divided over two Dutch studies, makes a reasonably robust conclusion possible. However, some shortcomings of the current study need to be addressed. There were small differences between the questionnaire of the first and the second study. The items that were considered complementary or abundant were removed in the second study, making the questionnaire shorter and more appropriate. However, this did not lead to major differences in the results. Furthermore, although there were clear selection criteria, there was a risk of selection bias, because respondents were selected by medical staff. This selection resulted in respondents who were mainly female survivors of breast cancer, which is not representative of the average Dutch cancer survivor population, hampering generalisation of research findings.

For future research into the specific unmet needs of cancer survivors, the extended CaSUN-NL is applicable. However, further research into the validity and reliability of the CaSUN-NL is recommended, specifically for factor structure and test-retest reliability, and preferably with a more balanced sample in terms of demographic and disease-related characteristics.

4.2 | Conclusion and clinical implications

This study provides evidence for the construct validity and reliability of the CaSUN-NL. Because of differences in factor structure compared to the original CaSUN, further research into the factor

structure and the underlying dimensions is recommended. The CaSUN-NL can be used to gain insight into the information and support needs of cancer survivors of different demographic and disease-related characteristics. Ongoing attention of healthcare professionals to cancer survivors' needs—regardless of time since treatment—and tailored interventions can help improve their health and quality of life.

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SUPPORTING INFORMATION

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