

SCORING MANUAL

**The Cancer Survivors' Unmet Needs
Measure (CaSUN)**

**The Cancer Survivors' Partners Unmet
Needs
Measure (CaSPUN)**

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Scoring and Interpretation

Items on the CaSUN and CaSPUN can be scored in terms of *items* or *domains* of *met*, *unmet* and *total need*, and/or *strength* of need. Total scores consist of the sum of all need items. Higher scores indicate greater needs (range 0-35). *Domains* are scored by summing all items in that domain; as domains contain different numbers of items, the average number of needs in that domain is reported.

Data elicited from the positive change items and the open-response item are considered qualitatively.

Met needs are scored as follows:

NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
0	1	0	0	0

Unmet needs are scored as follows:

NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
0	0	1	1	1

Total needs are scored as follows:

NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
0	1	1	1	1

Strength of need is scored as follows:

NO UNMET NEED		NEED IS CURRENTLY UNMET How strong is your need?		
No need, or is not applicable	Have need, but need is being met	Weak	Moderate	Strong
0	0	1	2	3

CaSUN: Domains of need

CaSUN item number

Domain

Factor 1 Existential Survivorship (14 items)

10	reduce stress in my life
19	concerns about the cancer coming back
20	emotional support for me
23	new relationships
24	talk to others
25	handle social/work situations
26	changes to my body
29	move on with my life
30	changes to beliefs
31	acknowledging the impact
32	survivor expectations
33	decisions about my life
34	spiritual beliefs
35	make my life count

Factor 2 Comprehensive Cancer Care (6 items)

4	best medical care
5	local health care services
6	manage health with team
7	doctors talk to each other
8	complaints addressed
18	accessible hospital parking

Factor 3 Information (3 items)

1	up to date information
2	information for others
3	understandable information

Factor 4 Quality of Life (2 items)

11	manage side effects
12	changes to quality of life

Factor 5 Relationships (3 items)

21	support partner/family
22	impact on my relationship
27	problems with sex life

CaSPUN: Domains of need

CaSPUN item number

Domain

Factor 1 Relationships (12 items)

8	reduce stress in partners life
9	manage treatment side effects
18	concerns about the cancer coming back
20	communicate with others
21	how to support partner
23	talk to others
26	changes to partner
27	impact on relationship
28	adjust to changes to body
29	problems with sex life
31	partner needs to move on
32	acknowledge impact on life

Factor 2 Information (3 items)

1	up to date information
2	information for partners
3	understandable information

Factor 3 Partner Impact (9 items)

10	help with own health
12	hospital parking
13	changes to partners life
14	impact on my working life
15	financial support
25	additional responsibilities
33	deal with uncertainty
34	explore spiritual beliefs
35	make my life count

Factor 4 Comprehensive Cancer Care (4 items)

4	local health care services
5	manage health with team
6	doctors talk to each other
7	complaints addressed

Factor 5 Emotional Support (2 items)

19	emotional support for me
22	support for loved ones

Relevant Publications by Authors

K Hodgkinson , P Butow , GE Hunt , S Pendlebury , KM Hobbs , SK Lo, G Wain. The development and evaluation of a measure to assess cancer survivors' unmet supportive care needs: The CaSUN (Cancer Survivors' Unmet Needs measure). *Psycho-oncology* 2007; 16:796-804.

Background: Many cancer survivors experience ongoing morbidity over the survivorship continuum and their supportive care needs have yet to be comprehensively assessed.

Methods: This study aimed to develop and empirically evaluate a self-report measure of cancer survivors' supportive care needs. In Phase I, questionnaire items were generated based upon previous qualitative research that identified both unique and shared needs in survivors and their partners; items were constructed into the Cancer Survivors' Unmet Needs measure (CaSUN). In Phase 2, the CaSUN was completed by 353 cancer survivors who had been diagnosed with cancer between 1 and 15 years earlier and were currently disease-free.

Results: After modification, the CaSUN included 35 unmet need items, 6 positive change items and an open-ended question. Good acceptability, internal consistency and validity were demonstrated, although test-retest reliability was low. Maximum likelihood factor analysis identified five discrete factors: Existential Survivorship, Comprehensive Care, Information, Quality of Life and Relationships.

Conclusions: Preliminary data indicates that the CaSUN meets the majority of psychometric criteria for assessment measures, although its low test-retest reliability awaits further investigation. The CaSUN will facilitate the evaluation of supportive care services and generation of service delivery recommendations for cancer survivors.

K Hodgkinson, P Butow, KM Hobbs, GE Hunt, SK Lo, G Wain. Assessing unmet supportive care needs in partners of cancer survivors: The development and evaluation of the Cancer Survivors' Partners Unmet Needs measure (CaSPUN). *Psycho-oncology* 2007; 16:805-813.

Background: Partners of cancer patients typically provide the majority of patients' emotional and physical care. Partners may be profoundly affected by the cancer and may experience ongoing supportive care needs across the survivorship continuum. Research has been restricted by a lack of psychometrically evaluated measures and in this study, a self-report measure of partners' needs was developed and empirically evaluated.

Methods: Questionnaire items generated from a qualitative study were constructed into a 47- item unmet need measure (Cancer Survivors' Partners Unmet Needs measure, CaSPUN). The psychometric properties of the CaSPUN were evaluated in 212 partners of patients who had been diagnosed with cancer 1-11 years earlier and were currently disease-free.

Results: The CaSPUN was modified to include 35 unmet need items, 6 positive change items and an open ended item. The CaSPUN demonstrates a high level of acceptability, internal consistency and construct validity, although test-retest reliability was moderate. Factor analysis identified five discrete

factors: (1) Relationships, (2) Information, (3) Partner Issues, (4) Comprehensive Care and (5) Emotional Support.

Conclusions: The CaSPUN permits the identification of long-term supportive care needs in generic populations of cancer survivors' partners and will assist with the formulation of recommendations regarding required supportive care services

K Hodgkinson, P Butow, G Hunt, S Pendlebury, K Hobbs, G Wain. Breast cancer survivors' supportive care needs 2-10 years after diagnosis. *Supportive Care in Cancer* 2006; Nov 21; DOI 17120068

GOALS OF THE WORK: A significant proportion of breast cancer patients experience psychosocial morbidity after treatment, although their longer-term outcomes and supportive care service needs have not been comprehensively documented. The aim of this study was to identify longer-term outcomes and supportive care needs in disease-free breast cancer survivors.

MATERIALS AND METHODS: One hundred seventeen patients who had been diagnosed with breast cancer 2-10 years earlier completed questionnaires to assess psychosocial outcomes including supportive care needs, psychological distress, and quality of life (QoL).

MAIN RESULTS: QoL and depression scores were consistent with community rates although anxiety scores were higher. Approximately two thirds of survivors reported at least one unmet need, most frequently concerning existential survivorship issues, thereby highlighting the unique needs of survivors. Years since diagnosis was not correlated with need levels. Survivors classified as clinically anxious reported over three times as many unmet needs and survivors classified as depressed reported over two and a half times as many unmet needs. Positive outcomes were frequently reported.

CONCLUSIONS: The findings have direct clinical relevance: irrespective of years since diagnosis, comprehensive and extended supportive care services are required to identify breast cancer survivors in need of supportive care interventions and remediate high levels of anxiety.

K Hodgkinson, P Butow, G Hunt, R Wyse, K Hobbs, G Wain. Life after cancer: Couples' and partners' psychological adjustment and supportive care needs. *Supportive Care in Cancer* 2007; 15(4):405-415.

GOALS OF WORK: Partners of cancer patients may experience significant distress at the time of treatment and many may experience persistent difficulties, although little research has examined their longer term psychosocial outcomes or supportive care needs.

MATERIALS AND METHODS: One hundred and fifty-four cancer survivors who were 1-11 years post diagnosis and disease-free and their partners completed mailed questionnaires.

MAIN RESULTS: A positive relationship was found between psychological distress and supportive care needs both within and between partner and survivor samples. Partners reported high levels of anxiety and supportive care needs, most frequently concerning relationships and the impact of the

cancer illness. Partners within couples reported both shared and unique needs, although agreement on ratings of shared needs was low. Needs did not diminish over time although partners demonstrated psychological resilience and reported positive outcomes. Predictors of distress and unmet needs were explored: physical QOL, relationship satisfaction, and total needs contributed to variability in partners' distress; relationship satisfaction and total needs were associated with survivors' distress. Distress and relationship satisfaction were associated with partners' unmet needs; only distress was associated with survivors' unmet needs. **CONCLUSIONS:** Partners are not merely providers of support, but need support themselves many years after a cancer diagnosis and in the context of apparently cured disease. The quality of the dyadic relationship may be critical in determining both partner and survivor distress and needs, and may prove a useful target for psychosocial interventions.

K Hodgkinson, P Butow, A Fuchs, GE Hunt, A Stenlake, KM Hobbs, A Brand, G Wain. Long-term survival from gynecologic cancer: Psychosocial outcomes, supportive care needs and positive outcomes. *Gynecologic Oncology* 2007; 104:381-389.

OBJECTIVES.: To assess the long-term psychosocial outcomes and supportive care needs of gynecologic cancer survivors.

METHODS.: Women who had received care in a tertiary-based gynecologic cancer center 1-8 years earlier and who were disease-free were invited to complete a mailed self-report questionnaire to assess psychosocial outcomes and supportive care needs.

RESULTS.: In total, 199 survivors participated in the study. Survivors reported normal quality of life and relationship adjustment although functioning was at the lower end of the range; over two-thirds (68%) reported positive outcomes. However, nearly one-third (29%) reported clinical levels of anxiety and the most frequently endorsed need concerned fear of disease recurrence (24%). About one-fifth (19%) reported symptoms that indicated posttraumatic stress disorder (PTSD) and this rose to close to one-third (29%) for survivors of advanced stage disease. Nearly 90% of survivors reported supportive care needs and the diagnosis of anxiety or PTSD resulted in a four-fold increase in unmet needs. Needs most frequently concerned "existential survivorship" (e.g., spiritual beliefs, decision making, the meaning of life) and "comprehensive cancer care" (e.g., team care, communication, local health care services). Years since diagnosis was not related to distress or need levels.

CONCLUSIONS.: All members of the care team need to be aware that significant psychosocial morbidity may occur many years after the successful treatment of a gynecologic malignancy and may be associated with elevated supportive care needs. Comprehensive and extended supportive care services are required to address anxiety and trauma responses and investigate strategies to meet ongoing needs in order to improve long-term psychosocial outcomes.

K Hodgkinson, P Butow, KM Hobbs, G Wain. After cancer: The unmet supportive care needs of survivors and their partners. *Journal of Psychosocial Oncology* 2007, 24(5); 89-104.

Cancer patients and their partners experience elevated distress and unmet supportive care needs at the time of treatment, however, their ongoing needs have not been adequately described. This qualitative study explores the needs of disease-free cancer survivors and their partners using semi-structured telephone interviews. A convenience sample of 25 key informants identified needs in the domains of: *information, health care, physical functioning, relationships, emotions, socio-economic issues, expectations* and *life perspective*; positive outcomes were widely reported. The identification of unique needs in survivors and partners supports the development of supportive care measures to specifically assess ongoing care need in these populations.