

## Research Article

# Supportive Care Needs following Cancer Treatment: A Comparison of Breast and Brain Cancer in an Australian Cohort

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**Objective.** To assess and identify patient-reported supportive care needs following definitive treatment in persons with breast cancer (BC) and primary brain tumours (gliomas) (BT) in an Australian community cohort and to assess the commonalities and/or discrepancies of the reported needs in these oncological populations. **Methods.** A prospective cross-sectional survey of persons with BC ( $n = 85$ ) and BT ( $n = 106$ ) using questionnaires for supportive care needs, psychological morbidity, and quality of life. **Results.** BT participants were younger than BC patients (mean ages 51 and 57 years). The median time since diagnosis for both groups was over 2 years. The level of psychological morbidity, mainly depression, was high in both groups: BC (22%) and BT (20%). Participants in both groups reported at least one need (“met” or “unmet”). The BC patients reported higher numbers of “needs” and “unmet” needs compared with BT patients (mean 13.7 versus 11.6 needs; “unmet” needs mean 6.0 versus 4.1). The common “met” and “unmet” needs highlighted by both groups were comparable; the domain for most “met” needs included comprehensive cancer care, while “unmet” needs related to existential survivorship issues. **Conclusion.** Despite successful treatment many cancer survivors experience unmet supportive care needs in longer term. Understanding the impact of these beyond the acute phase is important as care shifts to community settings. More research in existential survivorship issues is needed.

## 1. Introduction

Cancer is a leading cause of death worldwide [1]. Breast cancer (BC) is the most common malignancy in women [1], comprising up to 16% of all cancers in women [2]. Primary brain tumours (BT), a comparatively rare and diverse group of neoplasms, account for 2% of all cancers [3] and affect 7 per 100,000 population annually worldwide [4]. The overall incidence of BC and BT is on increase worldwide [2]. In Australia, by 2015, 1 in 9 women will develop BC [5]. It is estimated that in 2009, there were 22,070 new cases of BT in United States [6, 7]. In Australia, a similarly high incidence rate is reported, with approximately 1400 new cases and more than 1200 deaths annually [8]. The World Health Organisation (WHO) promotes the integration of prevention, early detection, diagnosis and treatment [9], rehabilitation and palliative care [2] in the management of BC and BT within the national cancer control programs.

With recent therapeutic advances, survival rates of persons with cancers have improved [10–12]. However, recovery and treatment options after BC or BT can be challenging, and many survivors experience transient and/or persistent physical, functional, and psychosocial morbidities impacting everyday activities, participation (work, social activities), and quality of life (QoL) [12–14]. In the community, various issues may surface during transition: adjustment (self-worth, self-image), coping with new demands associated with increased care needs, inability to return to driving and work, financial constraints, marital stress, and restriction in participation. Further, treatment regimens can be associated with complications and/or side-effects [14–16]. After treatment, many BC and BT patients report a range of psychological sequelae across the survivorship continuum (e.g., anxiety, depression, and sexual dysfunction) [17–19]. These disabilities can have a cumulative effect over time and cause considerable distress to the cancer survivors and their families and reduce QoL.

There are significant costs and socioeconomic implications of increased demand for health care, social and vocational services, and caregiver burden [15].

A number of studies assessed QoL, psychosocial variables and patient satisfaction in cancer cohorts [20, 21]. These studies largely evaluated problems experienced by these patients but not whether help is required to manage these problems and if patients actually received the help required. This has resulted in the development of specific measures to more broadly assess cancer patients' needs and unmet needs by directly measuring the gap between a person's experience of a service and the actual service required [22]. Some studies have attempted to use this needs-based research approach in various oncological conditions, such as BC, gynaecological, prostate, and colorectal cancers, to evaluate the problems and "needs" cancer survivors experience [23–26]. These studies were conducted in the acute care settings (hospital oncology clinics) and none address the extent of assistance/need experienced by the cancer survivors living in the community in Australian context. To our knowledge no studies compare the care needs amongst diverse cancer populations such as BC and BT. The *primary objectives* of this study therefore were to assess and identify supportive care needs in patients following definitive treatment for BC and BT in an Australian community cohort and to assess the commonalities and/or discrepancies of the reported needs in these oncological populations. The findings from this study will identify the needs from patients' perspective and will inform healthcare providers for potentially important factors impacting patients' everyday activities to facilitate optimal delivery of limited health care resources.

## 2. Methods

**2.1. Participants and Setting.** This cross-sectional study was part of a prospective rehabilitation outcomes oncological research program at the Royal Melbourne Hospital (RMH), a tertiary referral centre in Victoria, Australia and approved by its Human Research Ethics Committee (numbers 2010.203 and 2010.216). The recruitment process has been reported previously [27–29]. All consecutive patients with BC or BT (main diagnosis, *first* admission only) discharged to the community following acute treatment at RMH between 2007 and 2011 were identified. The RMH Access Database was used for cross-indexing of diseases from the Patient Administrator System of Hospital Information Systems, Department of Health, Victoria, Australia. Information in the database was from a pool of persons residing in the community, referred to the RMH from public and private medical clinics across greater Melbourne in Victoria. All participants were aged >18 years and fulfilled standard diagnostic criteria for BC as defined by the American Joint Committee on Cancer [30] and for BT using the grading system (grades I–IV) for gliomas as outlined by the WHO for Central Nervous System Tumours [31] and assessed by a surgeon/oncologist. Exclusion criteria included survival rate less than 4 months, benign and metastatic tumours, significant comorbidities or medically unstable, or psychiatric disorders (such as

uncontrolled schizophrenia, actively suicidal/self-harm or physical aggressiveness (based on clinical judgment)) limiting participation in rehabilitation, and bed-bound and/or institutionalized in nursing homes.

**2.2. Procedure.** All 450 patients identified on the RMH Database ( $n = 298$  BC and 152 BT patients) were invited by mail to participate in the study and a total of 191 participants ( $n = 85$  BC and 106 BT patients) who consented were recruited. These participants undertook rehabilitation program, which provided acute surgical/oncological and rehabilitative care for inpatients and in ambulatory setting to minimize activity limitation and enhance participation.

**2.2.1. Assessment.** All assessments were completed in hospital clinics (or participants' homes) in a 6-week period, using a structured format, by three independent assessors. These assessors (two physicians, one research officer) were trained in cognitive and functional ability assessments (examined and accredited by a national body—the Australian Rehabilitation Outcomes Centre). They were not in contact with the acute surgical/oncological services or the rehabilitation treating teams and received separate clinical record forms. They completed demographic, functional assessments and health-related QoL measures using standardized instruments (see measures). These assessment interviews took approximately 30 minutes. The assessors did not prompt participants but provided assistance for those who had difficulty completing the questionnaires. All assessments were secured and filed and opened only at the time of entry into the database by an independent data entry officer.

### 2.3. Measurement

**2.3.1. Demographic Characteristics.** A self-reported questionnaire was used to gather basic demographic information and disease related data (surgery, pathology, treatments received, signs and symptoms, etc.).

**2.3.2. Supportive Care Needs.** Cancer survivor unmet needs measure (CaSUN) [22] assessed and identified needs experienced by cancer survivors within the preceding month. This included 35 need items: 6 positive change items and one open-ended question. Need items were scored as: no need (0), "met" need (1), or "unmet" need (2); "unmet" needs were further rated as weak, moderate, or strong. The total scores were derived by summing responses in that category. The "needs" items were in five domains: existential survivorship (14 items), comprehensive care (6 items), information (3 items), QoL (2 items), and relationships (3 items), as well as six positive change items. This scale has good acceptability, internal consistency, and validity [22].

**2.3.3. Measures for Participation and Quality of Life.** The cancer rehabilitation evaluation system—short form (CARES-SF) [32], a self-administered 59-item questionnaire, the cancer specific rehabilitation needs, and QoL. Global scores indicate QoL with summary scores for 5 domains (physical,

psychosocial, medical interaction, and marital and sexual function). The participant rated the degree to which a given problem applied during the 4 weeks before the survey. Scoring was based on a four-point Likert scale, with higher scores indicating more difficulty or impairment.

The depression anxiety stress scale-21 (DASS) [33], a set of three 7-item self-report scales, measured the negative emotional states of depression, anxiety, and stress. Participants rated the extent to which they experienced each state over the past week on a 4-point Likert rating scale. Subscale scores were derived by totalling and multiplying by two to ensure consistent interpretation with the longer DASS 42-item version, as per the manual.

**2.4. Statistical Analysis.** All statistical analysis was conducted using SPSS for Windows software version 16 (SPSS, Chicago, IL). Kolmogorov-Smirnov tests were used to test for normality. For the CaSUN measure all 35 items were included in the calculation of the sum of total “met,” total “unmet” and total needs. Factor analysis for each domain of the CaSUN was conducted. The responses format of the positive change items was interpreted descriptively. A complete case analysis strategy was used; hence, cases with missing values on a variable were excluded from the analyses of that particular variable.

### 3. Results

**3.1. Sample Characteristics.** Mean age of BC participants was 57 years (all female), with median time since definitive diagnosis of 2.2 years (IQR 1.4, 4.9), while mean age of the BT participants was 51 years (range 21–77 years), and the majority were female (56%) with median time since diagnosis of 2.1 years. More than a third (39%) of the BT patients had high grade gliomas (grade IV) and underwent surgery; two-thirds had radiotherapy (64.2%) and less than half had chemotherapy (43%). Over half of the BC patients had Bloom-Richardson-Elston (BRE) grade 3 tumours (54%), were estrogen-receptor positive (85%) and with lymph node involvement (66%). More than a third (37%) of BC patients had breast conservation surgery (lumpectomy) with axillary clearance (Table 1).

**3.2. Current Symptoms.** Both patient groups reported various condition-related symptoms. The main symptoms in BT patients were pain/headache (56%), ataxia (44%), seizures (43%), paresis (37%), cognitive dysfunction (36%), and visual impairment (35%). Three quarters of the BC patients reported some degree of breast related pain (75%), with 39% ( $n = 24$ ) rating the pain as  $>5$  on a 10-point scale. Other symptoms in BC patients included upper limb weakness (32%), pain limiting shoulder movement (31%), and lymphedema (29%) (Table 1).

**3.3. Current Level of Psychological Wellbeing and QoL.** Compared with a normative sample of the Australian population (13%) [33], a substantial number of participants reported high levels of depression: BC (22%); BT (20%) (measured

by DASS). Although the stress scores were almost similar (12% each), higher level of anxiety was expressed only by BC participants (19%) (Table 2).

The highest median scores (indicating greatest distress or disability) in the CARES-SF for BT participants were found on subscales for “physical” (median (Md) = 1.0, IQR = 0.5, 1.5) (evaluating problems with daily activity) and “psychological” factors (evaluating communication and relationship) (Md = 0.6, IQR = 0.4, 1.1), while for BC participants highest scores were in “marital” (Md = 1.0, IQR = 0, 2) and “physical” factors (Md = 0.5, IQR = 0.3, 1.3) (Table 2).

**3.4. Supportive Care Needs.** Except for one participant in each group, both BT (99.1%,  $n = 105$ ) and BC groups (98.8%,  $n = 84$ ) reported at least one need (“met” or “unmet”). BC patients had slightly higher numbers of reported needs (“met” or “unmet”): mean 13.7 needs (range 0–31) compared to mean 11.6 needs (range 0–29) in BT patients (Table 2).

**3.4.1. “Unmet” Needs.** The majority of participants in the BC group (85%,  $n = 72$ ) endorsed at least one “unmet” need, with an average of  $6.0 \pm 6.3$  “unmet” needs (range 0–28). More than one-third of these participants (41.2%) rated their “unmet” needs as severe. The ten most frequently endorsed “unmet” needs by BC patients are shown in Table 3.

Compared to BC participants slightly fewer BT participants endorsed at least one “unmet” need ( $n = 81$ , 76%), with an average of  $4.1 \pm 4.9$  (range 0–26) “unmet” needs. Similar to the BC group, more than one-third of the participants (41.2%) rated their “unmet” needs as severe. The ten most frequently endorsed “unmet” needs by BT patients are shown in Table 4.

Both patient groups had similar “unmet” needs with the highest needs related to dealing with fears of cancer spreading, making decision about life, stress, need for complementary medicine, and hospital parking. Additional “unmet” needs in the BC group included adjusting the body image, managing ongoing side effects, and concern about the coordinated care from treating clinicians. The BT group’s additional “unmet” needs included communication with health care professionals, peers, finance, and family support.

**3.4.2. “Met” Needs.** Of the total BC participants, 96.5% ( $n = 82$ ) reported at least one “met” need, with an average of  $7.7 \pm 4.6$  (range 0–27) “met” needs. Similarly, most of the BT participants 98.1% ( $n = 104$ ) reported at least one “met” need, with an average of  $7.3 \pm 4.0$  (range 0–24) “met” needs. The ten most frequently endorsed “met” needs by BC patients are shown in Table 5 and by BT patients in Table 6.

Most common “met” needs were similar in both patient groups, the highest number of “met” needs relating to medical care, information, local health services, communications with treating medical team and healthcare professionals, and emotional support. Additional “met” needs in the BC group included communication with peers and overall help and support. The BT group’s additional “met” needs included managing side effects and financial support.

TABLE 1: Sociodemographic characteristics of participants ( $n = 85$ ).

	<i>n</i> , (%) (unless otherwise stated)	
	Breast cancer ( $n = 85$ )	Brain tumour ( $n = 106$ )
<i>Demographic factors</i>		
Age (years)		
(Mean (SD), range)	57.6 (10.6), 34.8–81.8	52.6 (13.6), 22.1–78.5
Sex		
Female	85 (100)	61 (57.5)
Marital status		
Married/partner	53 (62.4)	81 (76.4)
Living with		
Partner/family	68 (80.0)	81 (76.4)
Education		
Secondary	37 (43.5%)	55 (51.9)
Tertiary	43 (50.6%)	47 (44.3)
Smokers	13 (15.3%)	17 (16.0)
Consumes alcohol	46 (54.1%)	45 (42.5)
<i>Clinical characteristics</i>		
Disease duration (years)		
(Md, (IQR))	2.2 (1.4–4.9)	2.1 (0.8, 4.0)
Tumour grading	BRE* ( $n = 83$ )	WHO** ( $n = 96$ )
Grade 1	10 (12.0%)	14 (14.6)
Grade 2	28 (33.7%)	30 (31.3)
Grade 3	45 (54.2%)	15 (15.6)
Grade 4	N/A	37 (38.5)
Surgery	85 (100%)	105 (99.1)
$\geq 2$ surgery episodes	36 (42.4%)	33 (31.4)
Chemotherapy	63 (74.1%)	45 (42.5)
Multiple episode	54 (96.4%)	19 (42.2)
Side effects	60 (70.6%)	31 (68.9)
Radiotherapy	63 (74.1%)	68 (64.2)
Multiple episode	48 (76.2%)	44 (64.7)
Side effects	47 (55.3%)	45 (66.2)
Currently on treatment	55 (64.7%)	
Comorbidities		
Hypertension	27 (31.8%)	30 (28.3)
Diabetes	5 (5.9%)	5 (4.7)
Depression	28 (32.9%)	12 (11.3)
Pain	63 (74.1%)	59 (55.7)
VAS pain score (0: no pain; 10: extreme pain)		
Mean (SD), range	3.8 (2.1), 1–8	3.0 (2.0, 5.0)

IQR: interquartile range, Md: median,  $n$ : total number, SD: standard deviation, VAS: visual analogue scale.

\*BRE: Bloom-Richardson-Elston grading.

\*\*WHO: World Health Organisation classification of brain tumours (gliomas).

TABLE 2: Descriptive statistics for subscales of the depression anxiety stress scale, cancer rehabilitation evaluation system-short form and cancer survivor unmet needs measure.

Scales	Statistics	
	Breast cancer ( <i>n</i> = 85)	Brain tumour ( <i>n</i> = 106)
DASS (Md, IQR)		
Depression (0–42)	2 (0, 12)	4 (0, 10)
Anxiety (0–42)	4 (2, 8)	2, (0, 6)
Stress (0–42)	8 (4, 14)	6 (2, 14)
DASS group: ( <i>n</i> , %)		
Depression		
Normal/mild (0–13)	66 (77.6%)	85 (80.2)
Moderate/severe/extreme severe ( $\geq 14$ )	19 (22.4%)	21 (19.8)
Anxiety		
Normal/mild (0–9)	69 (81.2%)	93 (87.7)
Moderate/severe/extreme severe ( $\geq 10$ )	16 (18.8%)	13 (12.3)
Stress		
Normal/mild (0–18)	75 (88.2%)	93 (87.7)
Moderate/severe/extreme severe ( $\geq 19$ )	10 (11.8%)	13 (12.3)
CARES-SF (global scores) (Md, IQR)		
Physical (0–4)	0.5 (0.3, 1.3)	1.0, (0.5, 1.5)
Psychological (0–4)	0.4 (0.3, 1)	0.6 (0.4, 1.1)
Medical (0–4)	0 (0, 0.5)	0 (0, 1.0)
Martial (0–4)	1 (0, 2)	0.2 (0, 0.8)
Sexual (0–4)	0.3 (0.1, 0.6)	0.3 (0, 1.5)
Overall (0–4)	0.5 (0.4, 1)	0.6 (0.4, 1.0)
CaSUN (mean (SD), range)		
Total needs	13.7 (6.5), 0–31	11.6 (5.9), 0–29
Total “unmet” needs	6.0 (6.3) 0–28	4.1 (4.9), 0–26
Total “met” needs	7.7 (4.6), 0–27	7.3 (4.0), 0–24

CARES-SF: cancer rehabilitation evaluation system-short form; CaSUN: cancer survivor unmet needs measure; DASS: depression anxiety stress scale; *n*: total number; Md: median; IQR: interquartile range.

TABLE 3: Breast cancer survivors’ most frequently endorsed ten “unmet” needs (*n* = 85).

Rank*	CaSUN need items	<i>n</i>	%
1	I need help to manage my concerns about the cancer coming back	35	41.2
2	I need help to adjust to changes to the way I feel about my body	29	34.1
3	I need help to reduce stress in my life	29	34.1
4	I need help to manage ongoing side effects and/or complications of treatment	29	34.1
5	I need access to complementary and/or alternative therapy services	26	30.6
6	I need to know that all my doctors talk to each other to coordinate my care	22	25.9
7	I need more accessible hospital parking	21	24.7
8	I need to feel like I am managing my health together with the medical team	18	21.2
9	I need any complaints regarding my care to be properly addressed	18	21.2
10	I need help to try to make decisions about my life in the context of uncertainty	18	21.2

CaSUN: cancer survivors’ unmet needs measure; *n*: total number.

\* All items also reported by BT participants are bolded.

TABLE 4: Brain tumour survivors' most frequently endorsed ten "unmet" needs ( $n = 106$ ).

Rank*	CaSUN need items	<i>n</i>	%
1	I need help to try to make decisions about my life in the context of uncertainty	28	26.4
2	I need help to manage my concerns about the cancer coming back	26	24.5
3	I need help to reduce stress in my life	25	23.5
4	I need to talk to others who have experienced cancer	25	23.5
5	I need more accessible hospital parking	23	21.7
6	I need an ongoing case manager to whom I can go to find out about services whenever they are needed	22	20.8
7	I need access to complementary and/or alternative therapy services	18	17.0
8	I need help to know how to support my partner and/or family	18	17.0
9	I need help to find out about financial support and/or government benefits to which I am entitled	17	16.0
10	I need help to adjust to changes in my quality of life as a result of my career	16	15.1

CaSUN: cancer survivors' unmet needs measure; *n*: total number.

\* All items also reported by BC participants are bolded.

**3.4.3. Domains of Needs.** The domains of highest "met" needs for both BC and BT patients were very similar. The most frequently endorsed "met" needs by the BC group were in "comprehensive cancer care" (mean  $2.6 \pm 1.3$ ), followed by "existential survivorship" (mean  $2.5 \pm 2.6$ ). Likewise, the most frequently endorsed "unmet" needs in the BC group were in "existential survivorship domain" (mean  $2.7 \pm 3.5$ , range 0–13) followed by "comprehensive cancer care" domain (mean  $1.1 \pm 1.4$ , range 0–6) (Table 7, Figure 1).

The most frequently endorsed total "met" needs by the BT patients were also in "comprehensive cancer care" (mean  $2.8 \pm 1.3$ ), followed by "information" domain (mean  $1.7 \pm 1.2$ ) and existential survivorship (mean  $1.6 \pm 1.9$ ). Similar to the BC group, the most frequently endorsed "unmet" needs by BT group were in "existential survivorship" (mean  $1.9 \pm 2.6$ ) followed by "comprehensive cancer care" (mean  $0.8 \pm 1.1$ ) (Table 7, Figure 1).

## 4. Discussion

To our knowledge, this cross-sectional study is the first to report comparative ongoing "needs" in two diverse groups of cancer populations (BC and BT) in the community following successful completion of their treatment. The BT and BC survivors in this study are similar to those in other studies in terms of age, gender, disease severity, and treatment [10, 34–38]. The median time since diagnosis was just over 2 years with established impairments and functional disability. Although most cancer survivors in this study seem to have adjusted well, a significant proportion experienced transient and/or persistent physical and psychosocial morbidities which necessitated some form of care. Almost all participants from both BC and BT groups reported at least one need ("met" or "unmet") and over two-thirds reported that one or more of their needs were unmet. BC patients reported a slightly higher number of "unmet" needs compared to BT patients (85% versus 76%). Of these "unmet" needs, over 40% in both groups reported that their "unmet" needs were severe.

As expected, there were commonalities and overlap amongst the supportive care needs endorsed by BT and BC survivors. Highest levels of "met" needs across the survivorship continuum reported by both groups were in the "comprehensive care," "existential survivorship," and "information" domains, consistent with those in other oncological cohorts such as gynaecology, prostate, and colorectal cancers [24, 26]. Remarkably, the highest levels of the "unmet" needs in both groups were similar, in the domains of "existential survivorship" and "comprehensive care." Further, a substantial number of participants in both groups reported high levels of depression, anxiety, and stress (measured by DASS), compared with only 13% in an Australian normative sample [33].

Advanced medical management in cancer has significantly improved survival rate both in BC and BT populations, and there is growing recognition of these conditions as a long-term illnesses impacting psychological functioning and QoL [39, 40]. However, the physical and psychological morbidity and needs associated with these impairments, as in other cancer patients, can be underestimated [15, 41]. Understanding the long-term posttreatment impact of cancer and the needs of these patients is important as followup moves from acute settings to community health services.

This study provides an overview of the commonalities and discrepancies of the needs from the perspective of BC and BT patients across the survivorship trajectory. The findings of this study not only validate the ongoing challenges of survivorship reported by studies in other oncological groups [24–26, 42–44], but also are an important step towards understanding the problems with which a growing number of cancer survivors require assistance in the community. This information will assist in evidence-based planning and management and can improve clinical service delivery in identified areas for improved patient outcomes [26, 45].

This study has some potential limitations. First, this is a cross-sectional study, which limits the ability to draw causal relationships between the many domains of reported needs

TABLE 5: Breast cancer survivors' most frequently endorsed "met" needs ( $n = 85$ ).

Rank*	CaSUN need items	<i>n</i>	%
1	I need the very best medical care	71	83.5
2	I need up-to-date information	50	58.8
3	I need to feel like I am managing my health together with the medical team	50	58.8
4	I need information provided in a way that I can understand	46	54.1
5	I need local health care services that are available when I require them	45	52.9
6	I need to know that all my doctors talk to each other to coordinate my care	43	50.6
7	I need emotional support to be provided for me	42	49.4
8	I need to talk to others who have experienced cancer	32	37.6
9	My family and/or partner needs information relevant to them	27	31.8
10	I need help to move on with my life	24	28.2

CaSUN: cancer survivors' unmet needs measure; *n*: total number.

\* All items also reported by BT participants are bolded.

TABLE 6: Brain tumour survivors' most frequently endorsed "met" needs ( $n = 106$ ).

Rank*	CaSUN need items	<i>n</i>	%
1	I need the very best medical care	89	84.0
2	I need local health care services that are available when I require them	70	66.0
3	I need to feel like I am managing my health together with the medical team	67	63.2
4	I need up-to-date information	62	58.5
5	I need information provided in a way that I can understand	61	57.5
6	My family and/or partner needs information relevant to them	57	53.8
7	I need to know that all my doctors talk to each other to coordinate my care	57	53.8
8	I need help to manage ongoing side effects and/or complications of treatment	38	35.8
9	I need emotional support to be provided for me	36	34.0
10	I need help to find out about financial support and/or government benefits to which I am entitled	33	31.1

CaSUN: cancer survivors' unmet needs measure; *n*: total number.

\* All items also reported by BC participants are bolded.

TABLE 7: Participants' endorsement of the cancer survivor unmet needs measure ranked by total "met" needs.

Rank	CaSUN factor	Brain tumour ( $n = 106$ )				Breast cancer ( $n = 85$ )			
		Total met need		Total unmet need		Total met need		Total unmet need	
		Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range	Mean (SD)	Range
1	Comprehensive cancer care	2.8 (1.4)	0–5	0.8 (1.1)	0–5	2.6 (1.3)	0–5	1.1 (1.4)	0–6
2	Existential survivorship	1.6 (1.9)	0–11	1.9 (2.6)	0–12	2.5 (2.6)	0–13	2.7 (3.5)	0–13
3	Information	1.7 (1.2)	0–3	0.3 (0.7)	0–3	1.5 (1.1)	0–3	0.4 (0.7)	0–3
4	Quality of life	0.5 (0.6)	0–2	0.3 (0.6)	0–2	0.3 (0.6)	0–2	0.5 (0.7)	0–2
5	Relationship	0.1 (0.4)	0–2	0.4 (0.8)	0–3	0.2 (0.6)	0–3	0.5 (0.9)	0–3

CaSUN: cancer survivor unmet needs measure; *n*: total number; SD: standard deviation.

and functional improvements. Second, as this study utilized relatively small selective cohorts listed on a database held at single tertiary institution, with strict inclusion criteria who volunteered to participate, which may limit generalizability of findings. The study cohorts, however, are similar to cohorts reported in other studies and represent a wide sample of BT and BC survivors in the community. Participants in this study were complex in terms of disease severity, symptoms, and comorbidities (reflective of those seen in clinical practice). In an attempt to reduce recall and information bias, the assessors worked individually with each participant and all questions were limited to the person's current situation. Thirdly, we acknowledge that we were not able to capture and evaluate

various other needs and problems (such as spiritual and religious needs) beyond those included within the domains of the CaSUN, this was beyond the scope of this study. The CaSUN measure, however, was broad and expansive.

## 5. Conclusions

BT and BC are complex and challenging conditions, with multifaceted physical, psychological, and cognitive disabilities and participatory limitations that require an integrated interdisciplinary approach [39, 40]. Understanding the impact of BT and BC in the longer term (beyond the acute phase) is important, as current medical advances have

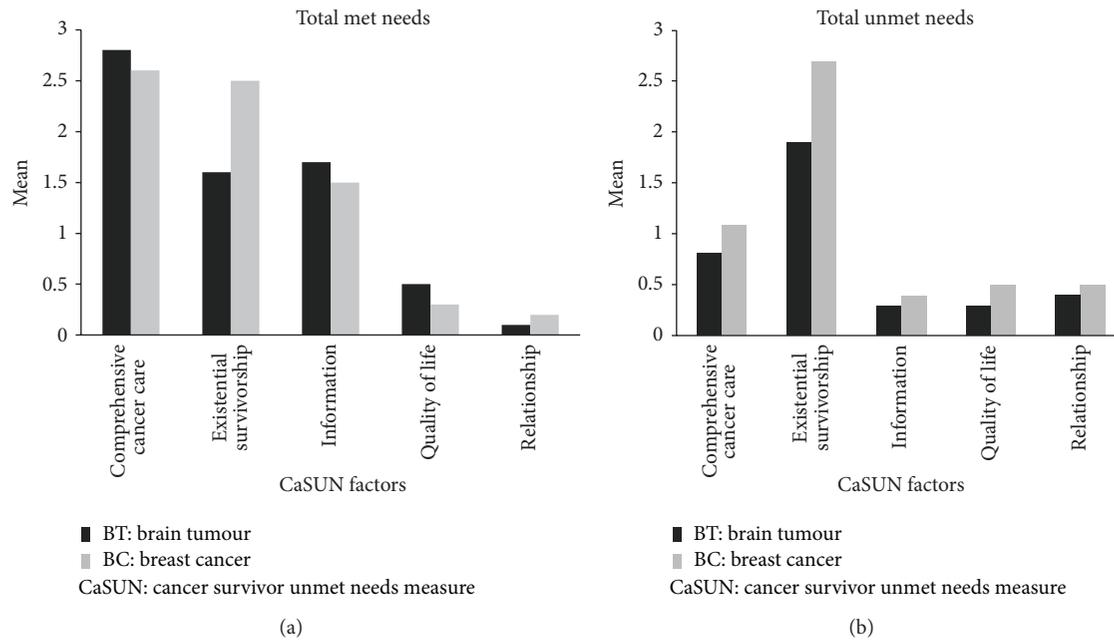


FIGURE 1: Participants' endorsement of the cancer survivor unmet needs measure factors. BT = brain tumour; BC = breast cancer; CaSUN = cancer survivor unmet needs measure.

improved patient survival and shifted care patient management to the ambulatory care sector. Supportive care needs were frequently reported by both BT and BC survivors in the longer term along the disease-survivorship continuum, with over two-thirds reporting one or more of their needs not unmet. The most frequently reported needs were in domains of “existential survivorship” and “comprehensive care.” The specific needs experienced by these survivors were similar many years after apparently successful cancer treatment. Findings from this study highlight the multifaceted needs and problems reported by these complex patient populations, which needs to be assessed and addressed by all healthcare professionals involved in the follow-up care. These findings, however, need to be confirmed in robust clinical trials with larger study samples in multiple settings.

## Abbreviations

BC:	Breast cancer
BT:	Brain tumour
BRE:	Bloom-Richardson-Elston grading
CaSUN:	Cancer survivor unmet needs
CARES-SF:	Cancer rehabilitation evaluation system—short form
DASS:	Depression anxiety stress scale
IQR:	Interquartile range
VAS:	Visual analogue scale
WHO:	World Health Organisation.

## Ethical Approval

The study was approved by the Royal Melbourne Hospital Ethical Committee and informed consent was obtained from all the subjects.

## Disclosure

The corresponding author has the right to grant on behalf of all authors and does grant on behalf of all authors an exclusive license to the ISRN Rehabilitation.

## Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of the paper.

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