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ORIGINAL ARTICLE

Health concerns of cancer survivors after primary anti-cancer treatment

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Abstract

Purpose Cancer survivors experience significant health concerns compared to the general population. Sydney Survivorship Clinic (SSC) is a multi-disciplinary clinic aiming to help survivors treated with curative intent manage side effects, and establish a healthy lifestyle. Here, we determine the health concerns of survivors post-primary treatment.

Methods Survivors completed questionnaires assessing symptoms, quality of life (QOL), distress, diet, and exercise before attending SSC, and a satisfaction survey after. Body mass index (BMI), clinical findings and recommendations were reviewed. Descriptive statistical methods were used.

Results Overall, 410 new patients attended SSC between September 2013 and April 2018, with 385 survivors included in analysis: median age 57 years (range 18–86); 69% female; 43% breast, 31% colorectal and 19% haematological cancers. Median time from diagnosis, 12 months. Common symptoms of at least moderate severity: fatigue (45%), insomnia (37%), pain (34%), anxiety (31%) and with 56% having ≥ 5 moderate-severe symptoms. Overall, 45% scored distress $\geq 4/10$ and 62% were rated by clinical psychologist as having 'fear of cancer recurrence'. Compared to population mean of 50, mean global QOL *T*-score was 47.2, with physical and emotional well-being domains most affected. Average BMI was 28.2 kg/m^2 (range 17.0–59.1); 61% overweight/obese. Only 31% met aerobic exercise guidelines. Overall, 98% 'agreed'/'completely agreed' attending the SSC was worthwhile, and 99% would recommend it to others.

Conclusion Distress, fear of cancer recurrence, fatigue, obesity and sedentary lifestyle are common in cancer survivors attending SSC and may best be addressed in a multi-disciplinary Survivorship Clinic to minimise longer-term effects. This model is well-rated by survivors.

Keywords Survivorship · Quality of life · Distress · Fear of cancer recurrence · Survivorship care plan

Background

Improvements in screening for and treatment of cancer, together with an ageing population, have resulted in rapidly increasing numbers of survivors of adult cancers. Cancer survivors are estimated to reach more than 21.3 million in the USA alone by 2026, and this number is projected to increase rapidly [1].

Research has consistently shown adults who have survived even early-stage cancer have poorer health than the general population, with an increased risk of cardiovascular disease, type II diabetes, metabolic syndrome, osteoporosis and risk of cancer recurrence [2, 3]. Many cancer survivors continue to suffer treatment-related side effects resulting in substantial distress, impacting quality of life (QOL), reducing their independent functional ability and decreasing productivity [4]. These issues are often multifactorial, complex and not always easily addressed by the patients' general practitioner (GP) or during routine oncology follow-up (e.g. with a medical or radiation oncologist, or surgeon). Furthermore, there is growing evidence of lifestyle risk factors, such as physical inactivity, obesity and excessive alcohol intake, increasing the risk of a new cancer or cancer recurrence [5]. A model of care consisting of multi-disciplinary health professionals with a

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good understanding of the disease trajectory and experience in treating cancer patients could address these health concerns in a coordinated and timely manner, and provide information to help cancer survivors modify their lifestyle risk factors to improve clinical outcomes.

The Sydney Survivorship Centre at Concord Cancer Centre, founded in 2013, included a new initiative with a multi-disciplinary Survivorship Clinic for survivors of adult cancers who had completed primary treatment (+/− surgery, chemotherapy, radiotherapy) for early-stage breast or colorectal cancer treatment. In 2014, the clinic expanded to include haematological malignancies, then other solid tumour types in 2015. At the initial clinic visit, survivors consulted a medical oncologist/haematologist, cancer nurse specialist, exercise physiologist, dietitian and clinical psychologist to develop a management plan based on current evidence and guidelines. Where appropriate, patients were referred to attached survivorship programmes promoting healthy lifestyles, such as the Survivorship gym, or other health services, such as a sexual health clinic. This paper aimed to describe the patient-reported outcomes (PROs) and health status of patients attending their initial visit at the Sydney Survivorship Clinic between September 12, 2013, and April 5, 2018, and their acceptance of the MDT clinic [6].

Methods

This was a single site, longitudinal study in which patient-reported outcome data were collected as part of standard care and for quality assurance. The current analysis reports baseline characteristics of clinic attendees, self-reported health issues and clinical data from the initial clinic visit, and satisfaction rating at the end of their first clinic.

Patients eligible for the Survivorship Clinic are survivors of adult cancers who have completed potentially curative primary treatment that includes chemotherapy, with no evidence of disease recurrence. Breast cancer patients may be receiving hormonal treatment and/or targeted treatment. Referrals from patients with complex survivorship issues who did not receive adjuvant chemotherapy are occasionally accepted [6].

Cancer survivors referred to the Sydney Survivorship Clinic were mailed a package of paper patient-reported outcome measures (PROM) prior to their appointment and asked to bring completed forms to clinic. These are described in full elsewhere [6] but, in brief, assessed aerobic exercise, food intake, distress [7], quality of life (QOL) [8] and symptoms [9] (outlined in Appendix Table 1). The 48 symptoms measured using the Patient's Disease and Treatment Assessment Form-General [9] were scored from 0 to 10 (from no trouble at all to worst I can imagine) with a score of 4 or above being classified as at least moderate intensity. From 2013 to 2016, the physical activity questionnaire sent to survivors was the Active Australia questionnaire [10], replaced in 2017 with the modified Godin Leisure-Time Exercise Questionnaire (LTEQ) [11]. Clinic staff performed anthropometric measurements (weight, body mass index). The clinical psychologist saw each survivor for at least 20 min, and as part of their clinical interview, provided brief psychoeducation about fear of cancer recurrence (FCR), describing its common features, prevalence and quality of life impact. Patients were encouraged to identify their own symptoms, or lack thereof, and then asked to compare their experience against this description, and, when appropriate, to self-rate the severity of their FCR. The psychologist diagnosed the presence, absence and level of severity of FCR symptoms based on both the reported self-rating and/or the psychologist's own observations about the patients' affective state when they described their experience, as well as the reported efficacy (or otherwise) of the patients' coping strategies and the impact of the FCR on their quality of life. Recommendations as to the benefits of further psychological follow-up were based on the outcome of this assessment. Demographic and disease information were accessed from the medical record. An individualised Survivorship Care Plan (SCP) was prepared by the oncologist, or Survivorship Nurse for haematology survivors, prior to clinic using medical records, and updated in consultation with the survivor. The SCP was a modified version of the disease-specific templates provided by the American Society of Clinical Oncology [12, 13]. The SCP contained a summary of medical information including treatment received, surveillance recommendations and personalised recommendations from the multi-disciplinary team. The SCP was mailed to survivors, their general practitioner and specialists involved in their care after being updated by the team. Survivors completed a written evaluation form at the conclusion of the clinic, which could be completed anonymously and placed in a box on the reception desk.

All data were entered into a custom designed REDCap™ database. Ethics approval was obtained from Concord Repatriation General Hospital Human Research Ethics Committee (HREC/14/CRGH/23). Survivors seen prior to July 17, 2014, had consent waived allowing use of their de-identified data unless they were returning to the Survivorship Clinic for follow-up, in which case consent was required to be obtained at that time.

Statistical analysis

Sample size was pragmatically determined by the number attending the Survivorship Clinic from September 2013 until April 2018. Descriptive statistics were used to report symptoms, exercise and dietary behaviour, with 95% confidence intervals (CI) reported where appropriate. The overall mean QOL and domain scores were converted to *T*-scores and compared with general Australian population data [14]. The number who completed an assessment is indicated in the manuscript and tables by the denominator. IBM SPSS Statistics version 24 was used for all analyses.

Results

A total of 410 new survivors attended their initial Sydney Survivorship Centre Clinic from September 2013 to April 2018, with data from 385 survivors included in the main analysis (Appendix Fig. 1). In total, 240/250 (96%) of cancer patients were referred to the MDT Survivorship Clinic by other medical oncologists or haematologists working in Concord Hospital. Referral for ongoing follow-up was made for a third (103/325) of the attendees but here we report only baseline data of all attendees. Consent was waived for 62 (15%) participants. In total, 25 (6%) survivors were excluded from the analysis as they either did not consent for their data to be used or their consent forms could not be located.

The overall response rate for PROM was 80–87%, except for the FACT-G, where due to an administrative error, the rate was 72%. Missing PROM responses were mainly due to insufficient English language skills.

Patients' characteristics and health concerns

The median age of survivors attending the clinic for the first time was 57 years (range 18–86); 69% of all attendees were women. Tumour types were breast 43%, colorectal 31%, haematological 19% and 7.5% other (mainly upper gastrointestinal) cancers. Most survivors previously had undergone surgery (81%) and chemotherapy (88%), and 44% radiation therapy. Survivors were a median of 12 months post cancer diagnosis or surgery, ranging from 1.6 to 327.8 months, including a small number of long-term haematology survivors. At the time of their initial Survivorship Clinic visit, 72% of breast cancer survivors were on adjuvant endocrine treatment, and 26% had or were currently receiving targeted therapy (see Table 1 for details).

Lifestyle risk factors—physical activity and obesity

Based on the Active Australia and Leisure Time Equivalent questionnaires, 31% of survivors met the recommended guidelines of at least 150 min/week of moderate-intensity aerobic activity, or 75 min/week of vigorous-intensity aerobic activity (Table 2). Information on resistance training was available for 90 survivors. Only 3/90 (3%) survivors met the current exercise guidelines for aerobic exercise plus two resistance training sessions per week. The mean body mass index (BMI) at time of their initial Survivorship Clinic visit was 28.2 kg/m^2 (range 17.0–59.1 kg/m^2); 233/368 (63%) survivors were overweight or obese (Table 2).

Stress and fear of cancer recurrence

The mean score on the distress thermometer was 3.5/10 (SD 2.8, range 0–10) with 151/335 (45%) rating their distress in the past week as 4 or above, meeting guidelines for further investigation [15] (Table 3). Our clinical psychologist classified 173/281 (62%) survivors as having fear of cancer recurrence based on their initial consultation. Severity was rated in 77, with 39 (51%) rated as moderate to severe. Overall, 135/329 (41%) were recommended psychological follow-up; of these, 29 (9%) were already receiving regular psychological care.

Quality of life

QOL scores as assessed by the FACT-G [16] showed a mean global score of 81.7 (SD 16.7) with physical (22.6, SD 4.9) and emotional well-being (18.0, SD 4.4) the domains most impacted. The mean *T*-scores for these domains were 42.6 and 41.5, respectively, which is almost one standard deviation below that seen in an Australian general population (expected mean 50, 1 SD = 10). The mean global QOL *T*-score was 47.2 (Fig. 1).

Symptoms and health concerns

Figure 2 illustrates the most common symptoms of at least moderate severity reported by cancer survivors by tumour groups. Common symptoms of at least moderate severity (rated 4+/10) were fatigue (45%), insomnia (37%), pain (34%), anxiety (31%), sore hands/feet (30%), numbness (30%) and trouble concentrating (27.5%). In total, 21.5% reported at least moderate problems with sex. Overall, 97/266 (36%) reported at least five symptoms of moderate severity or higher, with 21/44 (48%) at least 2 years post diagnosis or surgery having five or more symptoms. Approximately half of survivors self-rated their energy level as 'fair' to 'worst possible' (182/333, 55%) and one-third (116/333, 35%) rated their overall well-being as 'fair' to 'worst possible'.

In total, 38/113 (34%) had more than two lifestyle risk factors (overweight, not meeting exercise guidelines), in addition to psychological issues (distress thermometer score of 4+/10, and/or rated as having fear of cancer recurrence), and five or more symptoms of at least moderate severity.

Patient feedback on the MDT survivorship model

Overall, 98% (301/307) of participants 'agreed' or 'completely agreed' attending the Survivorship Clinic was worthwhile, and 98% (233/235) said they would recommend it to others.

Table 1 Patient characteristics of all cancer survivors attending the Sydney Survivorship Clinic (SSC) between 12 Sept 2013 and 5 April 2018 (*n* = 385)

	All	Breast	Colorectal	Haematology	Other
N (%)	385	165 (42.9%)	118 (30.6%)	73 (19.0%)	29 (7.5%)
Age, years, median with IQR	56.7 (IQR17.8)	52.3 (IQR12.5)	65.0 (IQR15.1)	46.1 (IQR32.1)	62.2 (IQR14.2)
(age range)	(18.2–86.4)	(29.6–74.8)	(32.4–86.4)	(18.2–83.0)	(43.3–79.2)
Aged 65 and older at the time of first clinic visit	108 (28.1%)	25 (15.2%)	59 (50%)	12 (16.4%)	12 (41.4%)
Female, *n* (%)	265 (68.8%)	165 (100%)	53 (44.9%)	34 (46.6%)	13 (44.8%)
Stage					
I	60 (15.6%)	41 (24.8%)	3 (2.5%)	9 (12.3%)	7 (24.1%)
II	125 (32.5%)	69 (41.8%)	26 (22.0%)	18 (24.7%)	12 (41.4%)
III	147 (38.2%)	46 (27.9%)	81 (68.6%)	11 (15.1%	9 (31.0%)
Not applicable*†	38 (9.9%)	7 (4.2%)	4 (3.4%)	27 (37.0%)	–
Unknown	15 (3.9%)	2 (1.2%)	4 (3.4%)	8 (11.0%)	1 (3.4%)
Treatment received					
Surgery	312 (81.0%)	165 (100%)	118 (100%)	2 (3.7%)	27 (93.1%)
Missing	4 (1.0%)	0 (0%)	0 (0%)	4 (5.5%)	0 (0%)
Chemotherapy	339 (88.1%)	144 (87.3%)	96 (81.4%)	73 (100%)	26 (89.7%)
Radiotherapy	171 (44.4%)	123 (74.5%)	20 (16.9%)	25 (34.2%)	3 (10.3%)
Missing	5 (1.3%)	0 (0%)	0 (0%)	5 (6.8%)	0 (0%)
Targeted therapy	44/234 (18.8%)	43/156 (27.6%)	1/78 (1.3%)	–	–
Currently on hormonal therapy	113	113/165 (68.5%)	–	–	–
Time from cancer diagnosis to 1st Survivorship Clinic, months Median (IQR) (range)	12 (IQR10.3) (1.6–327.8)	11.5 (IQR6.9) (2.3–149.8)	11.5 (IQR6.4) (1.6–90.9)	30.4 (IQR48.1) (5.8–327.8)	9.6 (IQR3.3) (1.9–21.4)
Comorbidities					
Hypertension (*n* = 283)	94 (33.2%)	34/103 (33.0%)	41/100 (41.0%)	7/54 (13.0%)	12/26 (46.2%)
Anxiety or depression (*n* = 263)	58 (22.1%)	22/93 (23.7%)	13/89 (14.6%)	15/56 (26.8%)	8/25 (32.0%)
Diabetes (*n* = 379)	52 (13.7%)	12/163 (7.4%)	23/116 (19.8%)	13/71 (18.3%)	4/29 (13.8%)
CVD (*n* = 257)	14 (5.4%)	3/87 (3.4%)	8/90 (8.9%)	3/55 (5.5%)	0
Autoimmune disease (*n* = 258)	11 (4.3%)	6/89 (6.7%)	2/89 (2.2%)	3/56 (5.4%)	0
‡Other (*n* = 377)	216 (56.1%)	89/163 (54.6%)	73/116 (62.9%)	31/69 (44.9%)	12/28 (42.9%)

IQR interquartile range, *SD* standard deviation

*Rated not applicable if patient had neo-adjuvant therapy and initial stage of disease was not clear; †or stage IV for haematology malignancies

∞ History of depression or anxiety at baseline and/or developed during the course of treatment

‡‡ Includes patients who have completed hormonal therapy

‡Other refers to comorbidities other than hypertension, anxiety or depression, diabetes, cardiovascular disease (CVD) and autoimmune disease

Most thought the timing of the first clinic visit (generally being seen 3–6 months after completion of primary adjuvant treatment) was 'right', but 22% (52/234) said they could have benefited from attending earlier in their cancer journey. Seeing a multi-disciplinary team was reported as the main strength of the clinic.

Discussion

Follow-up of cancer survivors is important in terms of surveillance for cancer recurrence or a second malignancy. However, with improved survival, the importance of identifying, treating and preventing longer-term physical and psychological side effects of the initial cancer diagnosis and treatment have received greater recognition.

The multi-disciplinary Sydney Survivorship Clinic for survivors of adult cancers is the first of its kind in Australia. Our results highlight the considerable burden of morbidity many survivors live with, long after completing cancer treatment with curative intent, with 36% reporting at least five symptoms of moderate severity or higher and 55% reporting sub-optimal energy levels. Fatigue was the most common symptom of at least moderate severity (45%), followed by sleep disturbance (37%), pain (34%) and symptoms of peripheral neuropathy (30%). Overall, 48% of breast cancer survivors were bothered by hot flushes. These results support the need for regular assessment and interventions to alleviate these

Table 2 Physical activity, body weight (kg) and body mass index (BMI, kg/m^2) for cancer survivors at first Sydney Survivorship Clinic (SSC) ($n = 371$)

	All	Breast cancer	Colorectal	Haematology	Others
Number of patients meeting recommended weekly guidelines for					
Aerobic exercise, *n* (%), $n = 332$	102 (30.7%)	50 (33.6%)	28 (27.2%)	19 (33.3%)	5 (21.7%)
Resistance exercise*, *n* (%), $n = 90$	13 (14.4%)	2/31 (6.5%)	5/32 (15.65)	3/15 (20%)	3/12 (25.0%)
Combined aerobic and resistance exercise, *n* (%), $n = 90$	3 (3.3%)	0	2 (2.2%)	0	1 (1.1%)
Average time spent per week[#] doing aerobic exercise of					
Light intensity minutes (SD) (range), $n = 93$	100 (SD 166) (0–840)	88.5 (SD140) (0–600)	117.5 (SD176) (0–700)	107 (SD 230) (0–840)	71 (SD102) (0–315)
Moderate intensity minutes (SD) (range), $n = 332$	63 (SD145) (0–840)	55 (SD123) (0–840)	68 (SD 155) (0–840)	63 (SD148.5) (0–840)	97 (SD215) (0–840)
Vigorous intensity minutes (SD) (range), $n = 333$	46 (SD113.5) (0–840)	41 (SD75) (0–480)	40 (SD101) (0–540)	75 (SD119) (0–840)	36 (SD117) (0–480)
Body weight and body mass index					
	$N = 371$	$N = 163$	$N = 117$	$N = 62$	$N = 29$
Weight, kg Mean (SD) (range) $N = 371$	77.6 (SD20.7) (43.9–158.8)	75.4 (SD20.5) (43.9–149.1)	79.6 (SD20.1) (48.4–140.9)	82.7 (SD23.4) (49.8–158.8)	71.0 (SD15.7) (46.3–109.9)
BMI, kg/m^2 Mean (SD) $N = 368$	28.2 (SD6.7) (17.0–59.1)	28.6 (SD7.8) (17.0–59.1)	28.2 (SD6.0) (17.6–46.5)	28.4 (SD5.8) (20.1–45.9)	25.8 (SD4.7) (18.0–36.3)
N (%) of survivors at first Survivorship Clinic visit					
Underweight	7 (1.9%)	4 (2.5%)	2 (1.7%)	0	1 (3.4%)
Normal weight	128 (34.8%)	55 (34.4%)	36 (30.8%)	22 (35.5%)	14 (48.3%)
Overweight	113 (30.7%)	42 (26.3%)	45 (38.5%)	17 (27.4%)	10 (34.5%)
Obese $N = 368$	120 (32.6%)	59 (36.9%)	34 (29.1%)	23 (31.5%)	4 (13.8%)

Number of patients completed Active Australia questionnaire = 242 (62.9%)

*LTEQ questionnaire = 90 (23.3%) and not completing either of the questionnaire = 53 (13.8%)

[#] Questionnaire caps upper limit of time at 840 min

Table 3 Distress and fear of cancer recurrence (FCR) of cancer survivors at first Sydney Survivorship Clinic (SSC) ($n = 335$)

	All $N = 335$	Breast cancer $N = 150$	Colorectal $N = 102$	Haematology $N = 58$	Others $N = 25$
Mean distress score^ (SD) (range), $N = 335$	3.5 (SD 2.8) (0–10)	4.3 (SD 2.8) (0–10)	2.7 (SD 3.2) (0–10)	3 (SD 2.5) (0–9)	3.6 (SD 3.2) (0–9)
Patients with distress score 4 and above, *n* (%)	151 (45.1%)	89 (59.3%)	30 (29.4%)	21 (36.2%)	11 (44.0%)
% of patients with FCR^^, *n* (%) $N = 281$	173/281 (61.6%)	94/133 (70.7%)	42/86 (48.8%)	24/36 (66.7%)	13/26 (50%)
Severity of FCR^^					
Mild	38/77 (49.4%)	8/31 (25.8%)	16/24 (66.7%)	9/13 (69.2%)	5/9 (55.6%)
Moderate	24/77 (31.2%)	11/31 (35.5%)	6/24 (25.0%)	4/13 (30.8%)	3/9 (33.3%)
Severe	15/77 (19.5%)	12/31 (38.7%)	2/24 (8.3%)	–	1/9 (3.4%)
N (%) recommended to have psychologist follow up	106 (32.2%)	56/153 (36.6%)	32/112 (28.6%)	12/36 (33.3%)	6/28 (21.4%)
n (%) of patients already seeing psychologist	29 (8.8%)	23/153 (15.0%)	2/112 (1.8%)	1/36 (2.8%)	3/28 (10.7%)

^ Distress was measured using the distress thermometer. The score ranges from 0 (no distress) to 10 (extreme distress) with a score of ≥ 4/10 being regarded as of clinical significance

^^ Fear of cancer recurrence (FCR) was rated by a clinical psychologist during the clinic visit

symptoms. Of note, while one-third of survivors reported at least moderately severe pain, the aetiology of the pain was unclear. Many concerns described by cancer survivors were psychosocial rather than physical, with a third of patients reporting poor overall well-being. In particular, we found high rates of fear of cancer recurrence and psychological distress warranting referral for further clinical support.

A British survey of 1425 early cancer survivors reported that 30% had five or more unmet needs at completion of treatment, with 60% of survivors still having unmet needs 6 months later [17]. Self-reported fear of cancer recurrence was the most common concern, with 30% rating this as moderate or severe immediately post treatment, and 26% 6 months later, with uncertainty about the future 26% and 20% respectively. The strongest predictors for unmet needs 6 months after completion of treatment were unmet needs immediately post treatment, receiving hormonal treatment, affective symptoms, fear of cancer recurrence, a comorbid condition and experiencing a significant event. An Australian cross-sectional study of 117 women also found self-reported fear of cancer recurrence and existential issues were the most common concerns (33%) 2–10 years after a breast cancer diagnosis, failing to find any association between increased time from diagnosis and lower needs [18].

Interestingly, the incidence of fear of cancer recurrence in our cohort was more than double that reported in either of the

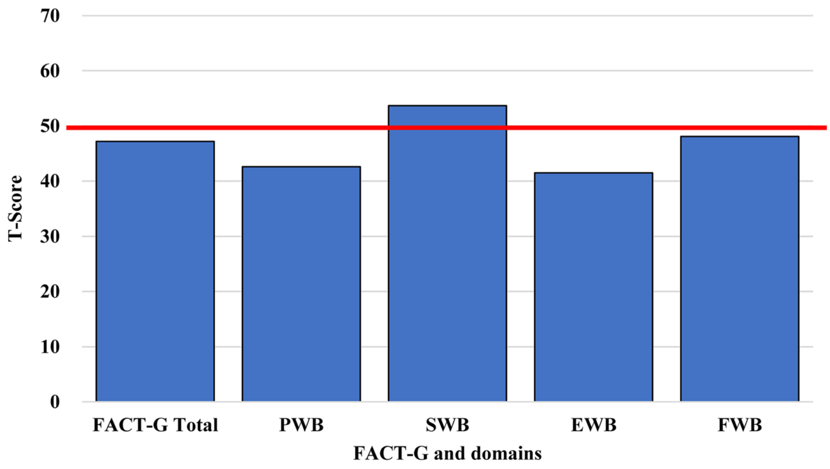

Fig. 1 Quality of life *T*-scores for cancer survivors compared to the general population ($n = 280$).

*Compared to age matched Queensland population[14] (mean 50, 1 SD =10)-red line.
Quality of life measured by Functional Assessment of Cancer Therapy – General (FACT-G)
PWB = Physical well being
SWB = Social/family well-being
EWB = Emotional well-being
FWB = Functional well-being

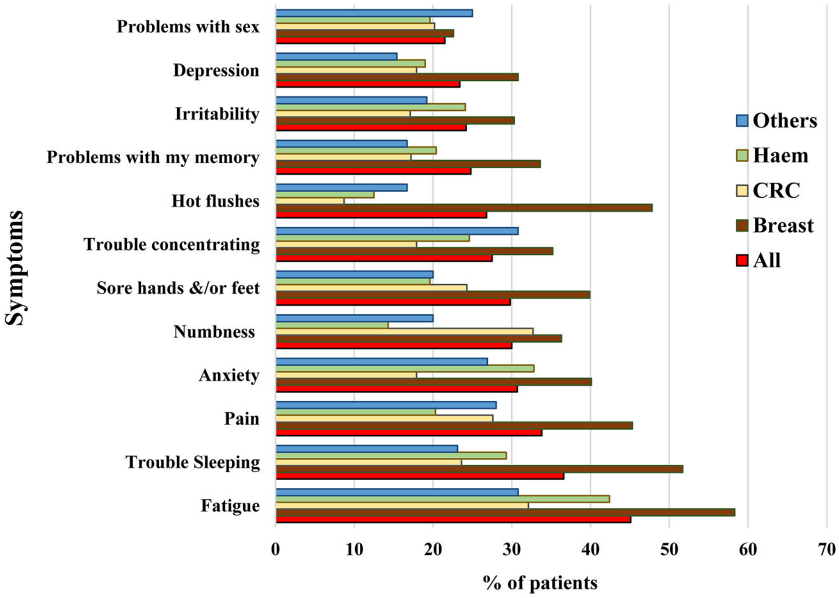

Fig. 2 Common symptoms of at least moderate severity reported by cancer survivors by tumour group

above studies. Rather than indicating a higher rate of fear of cancer recurrence amongst our survivors, the higher incidence may be due to survivors being assessed by a clinical psychologist rather than self-report questionnaire. This suggests that fear of cancer recurrence may be more prevalent than suggested by PROM, but unfortunately no specific fear of cancer recurrence PROM was included for comparison. Following this observation, the clinical psychologist in our Survivorship Clinic began to rate severity of fear of cancer recurrence; in more recent attendees, 24/77 (31%) were rated as having moderate severity of fear of cancer recurrence, and 15/77 (19%) as severe. The literature suggests little association between those at highest risk of a cancer recurrence and those with strongest fear of recurrence [19], but we have yet to formally evaluate this in our population. However, the link between high rate of fear of cancer recurrence and psychological distress and reduced QOL in other studies [19] highlights the importance of assessing fear of cancer recurrence and offering evidence-based treatment, such as a tailored psychological intervention [20].

Our study, and a number of others, reported QOL in cancer survivors to be similar to that of the general population [18], although QOL may vary depending on time from diagnosis and treatment. Compared to QOL from a large population study in Queensland, our patient group's mean *T*-scores were within 1 SD of the general population (mean 50; SD 10) [14]. It is important to note the age of our study cohort ranged from 18 to 86 years compared to the Queensland population study ($n = 2727$) aged 20–75 years. Physical and emotional well-being domains were the most affected, with *T*-scores of 42.6 and 41.5 respectively.

Despite mounting evidence that physical activity and a healthy body weight can reduce the risk of a recurrence of some common cancers [21–23], as well as decrease treatment-related side effects and improve function [24], population-based studies in the USA and Australia have shown up to 70% of cancer survivors do not meet recommended guidelines for physical activity, and 35% of breast cancer survivors are overweight or obese [2, 25–29]. Our cohort reflected these findings, reporting low compliance with guideline recommendations for aerobic and resistance exercise, and high rates of overweight and obesity. Actual compliance may be even lower, given evidence people overestimate their levels and intensity of physical activity [30]. In our study, 63% were overweight or obese. This highlights the need for healthy lifestyle programmes to facilitate cancer survivors' incorporation of physical activity and a healthy diet into their daily life, with weight loss where required [31–33]. The Sydney Survivorship Centre has developed a number of programmes with accredited health professionals to assist survivors in instituting and maintaining a healthy lifestyle [6]. Longitudinal follow-up of the cohort will determine the impact of these lifestyle and behavioural interventions.

Satisfaction with the clinic was high. Participants consistently reported the greatest benefit was being seen by a multidisciplinary team and having time to address their concerns with referral to support programmes as appropriate. These issues are often time-consuming to address, in routine follow-up cancer clinic appointments.

Strengths and limitations

There may be a selection bias with people with ongoing symptoms, or those more interested in self-management of their long-term health, more likely to be referred to, or to attend, the clinic. This is more likely to have occurred in the first couple of years when referral patterns were being established, particularly for haematology survivors. For the last 2 years, eligible oncology patients have been routinely referred to the Survivorship Clinic after completing chemotherapy. Missing data were an issue, either due to low English language literacy or survivors not completing questionnaires, despite attempts to overcome this barrier by using interpreters in the clinic, and encouraging survivors to complete questionnaires while waiting to be seen if they had not been completed in advance. This study evaluates 385 of 410 (94%) consecutive patients attending a Survivorship Clinic, with participants more generalisable to 'real world' cancer survivors than those in clinical trials.

Conclusion

Our results highlight that many cancer survivors experience concerning symptoms, mostly psychological, long after completion of their anti-cancer treatment. In particular, fatigue, sleep disturbance, symptoms of peripheral neuropathy, anxiety, distress and fear of cancer recurrence were common, highlighting the importance of a multi-disciplinary team to assess and address these concerns. The majority of survivors were overweight or obese and sedentary, indicating the need to address their weight and increase physical activity to reduce the risk of a new cancer or cancer recurrence. The Sydney Survivorship Clinic was rated highly by patients and has the potential to identify and address important concerns for cancer survivors.

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Compliance with ethical standards All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Conflict of interest The authors declare that they have no conflicts of interest.

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