ACTA ONCOLOGICA
2019, VOL. 58, NO. 5, 782–789
https://doi.org/10.1080/0284186X.2018.1562209

ORIGINAL ARTICLE

A longitudinal study of four unique trajectories of psychological distress in cancer survivors after completing potentially curative treatment

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ABSTRACT

Background: Many survivors report short-term, transient psychological distress after cancer treatment. Some experience severe, worsening or persistent psychological morbidity which impairs functioning and warrants intervention. Using Bonanno's trajectories model, this study aimed to distinguish distress trajectories and to identify demographic, medical or psychosocial characteristics that differentiate those at risk of ongoing, clinically significant psychological distress.

Methods: One-hundred and twenty-five cancer survivors of breast, prostate, colorectal or haematological cancers (response rate: 72%) completed measures of psychological distress (BSI-18), unmet needs (CASUN), social support (ESSI), coping styles (Mini-MAC), symptom prevalence (MSAS-SF) and benefit finding (PTGI) immediately after treatment and three and six months later. Distress and its predictors were investigated using linear mixed models. Groups based on Bonnano's trajectories were also compared on demographic, medical and psychosocial characteristics.

Results: Changes in psychological distress over time were not statistically significant. Using BSI-18 clinical cut-off scores, most survivors ($n = 65$, 80%) were 'resilient', with stable, low distress levels. Almost one-tenth of survivors ($n = 7$, 9%) reported persistent, 'clinically significant' distress. Compared with the 'resilient' group, this 'chronic' group reported higher unmet needs, benefit finding, physical symptoms and poor coping styles, as well as lower social support immediately after treatment. They were also more likely to have a documented history of psychiatric illness. A 'recovered' group ($n = 5$, 6%) experienced high levels of distress that quickly returned to non-clinical levels and a delayed group ($n = 4$, 5%) reported initial low distress which worsened after treatment completion.

Conclusions: Most survivors experience low distress (resilience) over time and may not require intense follow-up care. Screening for distress at the end of treatment may help to identify patients with more physical symptoms and unmet needs, less social support and higher use of maladaptive coping styles who are at risk of experiencing non-resilient trajectories of distress for further management of these symptoms.

ARTICLE HISTORY
Received 7 September 2018
Accepted 12 December 2018

Introduction

With earlier detection and improved treatments, more people are surviving cancer, either through cure or effective long-term management [1]. The period immediately after treatment can be distressing for survivors, due to physical and psychosocial consequences such as ongoing treatment side-effects, fear of recurrence, difficulties making decisions, existential and mortality concerns, relationship/family problems, changes in employment status, redefining one's sense of self, and making lifestyle changes as a result of cancer and treatment [2,3]. For the purposes of this research, the term 'survivor' refers to individuals who have completed potentially curative treatment for cancer and are living 'cancer free'.

Although many adjust well [2], some survivors report short-term, transient psychological distress which dissipates over time. Others experience severe, worsening or persistent psychological morbidity which impairs functioning and requires assistance to resolve [4–6]. Two recent, large, studies have measured overall low levels of survivor distress using the HADs and BSI-18 after treatment have suggested that there are different trajectories of distress, and there is an increasing recognition of the need to look 'beyond the mean' [7] to identify the small, subgroup of survivors most in need [7,8]. However, there is little empirical literature which identifies and characterizes these different psychosocial experiences, particularly during the time immediately after treatment completion as most studies to date have included patients undergoing active treatment. Evidence on how to identify at-risk survivors following the end of treatment is critical to ensure the provision of high-quality survivorship care to those who need it, including

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interventions that can improve psychosocial outcomes after treatment [2,3].

Theoretical framework

Drawing from the literature on adjustment after loss or traumatic events, Bonanno [9,10] developed a trajectories model which describes four unique trajectories for how people adjust to adversity over time: *chronic distress* (severe distress from which an individual is unable to recover), *delayed distress* (individuals recover quickly from a traumatic event, but begin to experience problems or difficulties later on), *recovery* (initial disturbance which dissipates over time, returning to normal function and *resilience* (despite experiencing stress, individuals manage with minimal disruptions to their physical, emotional and social functioning). The model asserts that most individuals experience resilience and that it is more appropriate to target interventions only towards those actively struggling with the most severe levels of distress [9]. This approach was therefore selected to highlight a clinically important way of defining psychological distress using a trajectories approach and serves as a useful framework to guide this research.

Several empirical studies have explicitly tested Bonanno's framework in a cancer setting [4–6,11]. Most have identified the four trajectories in their sample, however, prevalence for each group has varied and there has been less investigation on how to predict membership to any given trajectory. The majority were conducted exclusively with women with breast cancer, and all except one [11] included patients still having active treatment, ranging from six months to four years after diagnosis. Further evaluation is needed specifically in the early survivorship phase with samples that represent a variety of demographic and clinical backgrounds.

This study, therefore, aimed to:

1. Describe the course and predictors of psychological distress in cancer survivors during the first 6 months after treatment completion.
2. Apply Bonanno's trajectories model to identify and describe different trajectories of psychological distress in cancer survivors.

Method

Study design and setting

This paper reports data collected at two metropolitan cancer centers in Melbourne, Australia between 2009 and 2011 as part of a prospective, longitudinal study examining psychological morbidity in cancer survivors after completing potentially curative treatment. The study was approved by the Human Research Ethics Committee at both sites.

Participants

A consecutive sample of patients completing treatment was identified from treatment lists at each site. Eligible survivors were (a) diagnosed with breast, prostate, colorectal or haematological cancer (Hodgkin's disease or Diffuse Large B-Cell Lymphoma), (b) completing primary treatment with curative intent (surgery, chemotherapy, radiotherapy or combination), (c) over 18 years old, and (d) able to speak sufficient English to complete questionnaires and provide informed consent. Patients were excluded if they were receiving treatment for recurrent/second cancers or with palliative intent, or if they had current severe cognitive or psychological impairment which would preclude involvement, determined by the treating clinician. Survivors participating in other research projects with similar measures or time points were also excluded to prevent patient burden or questionnaire learning.

Procedures

One researcher (KLJ) approached eligible survivors during the final two weeks of their treatment, described the study and provided written information. Written, informed consent was obtained. Reasons for refusal were recorded.

Participants completed self-report measures within two weeks of finishing cancer treatment (T1), then three and six months later (T2 and T3, respectively). Phone calls were made to participants who had not submitted their questionnaires within the first week, to encourage timely completion and provide assistance if any difficulties were experienced. Study measures took approximately 20 minutes to complete. The current analysis only includes participants who were cancer-free at T3 ($n = 116$).

Measures

Demographic and medical variables (T1 and T3)

Demographic and medical data were collected from medical records and directly from participants in the T1 questionnaire. Data included gender, age, marital status, education, employment, location (metropolitan/regional), country of birth, language spoken, cancer type, stage, treatment type and treatment duration and psychiatric history. Cancer status (cancer free, progression/early recurrence, second cancer) was collected from participants' medical records at T3 to ensure that only survivors who remained cancer-free were included in the analysis.

Primary outcome: psychological distress (T1, T2, T3)

The primary outcome, psychological distress, was measured using the 18-item Brief Symptom Inventory (BSI-18). The BSI-18 has demonstrated reliability, validity and acceptability in both cancer and healthy populations [12,13]. It is a robust screening tool, with good sensitivity (91.2%) and specificity (92.6%) [13]. Cut-off scores are separated by gender; cases of 'clinically significant distress' are identified with a score of 10 for men and a score of 13 for women [13].

Psychosocial variables (T1, T2, T3)

Several other psychosocial factors were assessed. These are listed below. Each measure was selected for its brevity and relevance to the construct, as well as its acceptability, reliability and validity in cancer survivor populations.

Unmet needs were assessed using the Cancer Survivors Unmet Needs Scale (CaSUN). The 35-item CASUN assesses five domains—existential survivorship (14 items), comprehensive cancer care (6 items), information (3 items), quality of life (2 items) and relationships (3 items)—using a 4-point scale [14]. A total unmet needs score may be calculated. Respondents receive a score of ‘0’ or ‘1’ for each item where there is no unmet need or unmet need respectively; in this case, higher scores indicate more needs.

Physical symptoms were assessed using the physical subscale of the Memorial Symptom Assessment Scale Short Form (MSAS-SF) [15]. This survey asks respondents whether they have experienced each of 28 included symptoms (Yes/No). Respondents receive a score of ‘1’ for each symptom experienced. Total number of symptoms is the sum of these scores, with higher scores indicating more physical symptoms.

Benefit finding was assessed using the Posttraumatic Growth Inventory (PTGI). The 21-item PTGI assesses positive changes after cancer across five subscales using a six-point scale ranging from 0 (no change) to 5 (a very great degree of change as a result of my cancer) [16]. The total benefit finding score is calculated by summing the scores across all items, with higher scores reflecting greater benefit finding.

Coping styles were assessed using the Mini-Mental Adjustment to Cancer Scale (Mini-MAC) [17]. The 29-item Mini-Mac assesses fighting spirit (four items), cognitive avoidance (four items), fatalism (five items), anxious preoccupation (eight items) and helplessness-hopelessness (eight items) using a four-point scale ranging from ‘definitely does not apply to me’ to ‘definitely applies to me’. Higher subscale scores indicate strong use of the coping strategy. Only the anxious preoccupation and helplessness-hopelessness subscales were included in this analysis, as these two factors are categorized as the ‘maladaptive coping styles’ [18], and may be associated with higher psychological distress.

Social support was measured using the ENRICHD Social Support Instrument (ESSI) [19]. The seven-item survey assesses perceived social support in different contexts ranging from 1 (none of the time) to 5 (all of the time). Items are summed, with higher scores indicating greater perceived social support.

Statistical analysis

Mean scores were substituted for missing item values when a participant had completed more than 50% of the items on a domain or subscale, by adding the total score for the subscale and then dividing it by the number of items answered on that subscale, or as recommended in the relevant scoring manuals. Independent samples t-tests and chi-squared tests were used to compare the characteristics of study participants and decliners, and participants who completed all three assessments and those who did not.

Descriptive statistics were used to summarize demographic, clinical and psychosocial variables at T1. Analysis of the primary outcome, psychological distress, was carried out by fitting a linear mixed model to all available data. A fixed effect for time and a random subject effect were included in the model. Mixed models account for the influence of participants on their repeated observations [20]. A linear mixed model was also used to investigate associations between psychological distress and other psychosocial factors at T1. In addition to the fixed effect for time and random subject effect, this model included fixed effects for age (re-scaled to represent 5-year increases), gender, psychiatric history, as well as physical symptoms, anxious-preoccupation, helplessness-hopelessness, benefit findings, social support and unmet needs.

To describe the distress trajectories developed by Bonanno [9], participants were first assigned to one of four trajectory groups based on their BSI scores at T1 and T3. If both scores reached the cut-off for ‘clinically significant distress’, the participant was assigned to the ‘chronic’ group. If neither score reached the cut-off, they were assigned to the ‘resilient’ group. Those whose scores only reached the cut-off at T1 were assigned to the ‘recovered’ group and those whose scores only reached the cut-off at T3 were assigned to the ‘delayed’ group. Then, the T1 demographic, medical and psychosocial characteristics of groups were compared (in all cases, the Resilient group was used as the reference group). Cohen’s *d* was calculated to provide an estimate of the size of group differences and interpreted as follows: 0.2, small-; 0.5, medium-; and 0.8, large-sized difference.

IBM SPSS Statistics Version 24 (Armonk NY, USA) was used for exploratory analysis, scoring and descriptive analysis, the analysis of recruitment and attrition bias, and the analysis trajectory group differences based on Bonanno’s model. Mixed model analyses were performed in R Version 3.5.1 (Vienna, Austria), using the ‘lme4’ package (available from https://cran.r-project.org/web/packages/lme4/lme4.pdf).

Results

Sample characteristics

The flow of participants is presented in Figure 1. Of the 1303 patients screened, 173 eligible survivors were approached for the study. Of these, 125 survivors (72%) provided written informed consent and completed the T1 questionnaire. One hundred and four participants completed the T2 questionnaire, and 91 completed the T3 questionnaire. Notably, 23 individuals were deemed ineligible because their treating clinician advised that they lacked the cognitive or psychological capacity to participate. Nine survivors with early recurrence, second cancer or disease progression at T3 were excluded. Although no significant differences were found across the demographic, medical or psychosocial factors between this group and the rest of the sample, it was determined that they could be experiencing very different

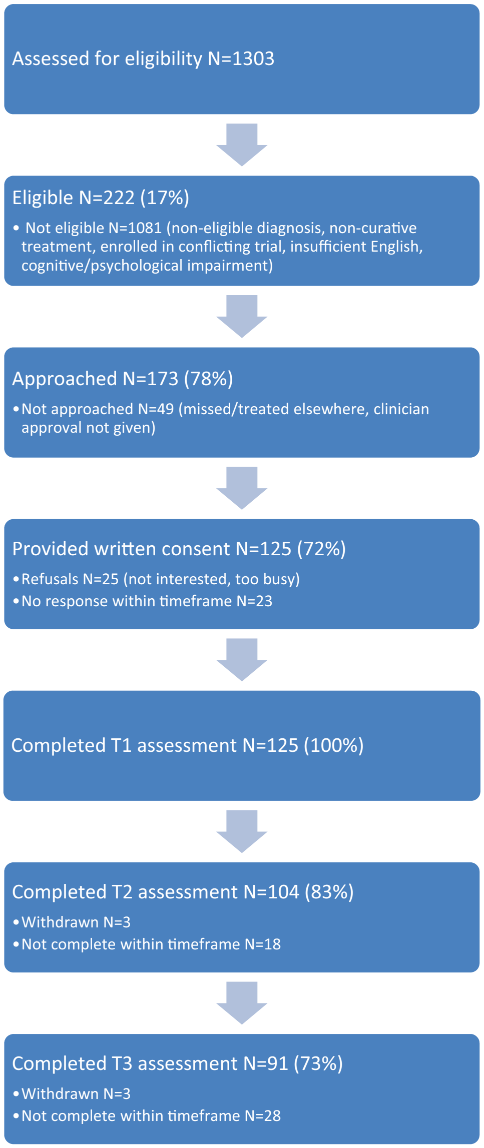

Figure 1. Summary of recruitment and data collection throughout study. Note: N refers to the number of participants at each phase of recruitment and data collection. Percentages for the number of 'eligible', 'approached' and 'consenting' survivors are calculated using the previous stage to track the flow of participation. Several participants completed the T3 assessment, but not the T2 assessment, and vice versa. Therefore $N = 91$ completing T3 reflects 125 participants minus six people who withdrew throughout the study, minus 28 participants who did not complete T3 (but who may have completed T2) Percentages of assessments completed at each time point are therefore calculated as a percentage of the total number of participants ($N = 125$).

circumstances to those survivors who considered themselves 'cancer free'.

There were no significant differences on key demographic or clinical variables between those who chose to participate and those who did not (all $p > .05$). However, fewer colorectal cancer survivors completed all three assessments than did those with other cancer types ($p = .04$), as did those with a history of psychiatric illness ($p = .04$).

Sample characteristics are presented in Table 1. The average age of survivors was 61 years. Slightly higher proportions were diagnosed with breast or prostate cancer. Most had early-stage disease and received multiple treatment modalities. Inspection of medical records revealed that 16 participants (13%) had a previous history of anxiety, depression or both; all 16 were included in the analysis as this did not impact their capacity to participate.

Table 1. Demographic, medical and psychosocial characteristics of sample.

Characteristic	*n* (%)	Mean (SD)
Gender		
Male	71 (57)	
Female	54 (43)	
Age		
Years		61.2
Range		24–83
Marital status		
Married or defacto	87 (70)	
Never married, divorced or widowed	38 (30)	
Employment		
Working (full time or part time)	31 (25)	
Sick leave, retired or not working	94 (75)	
Education		
Primary or secondary	67 (54)	
Post-secondary	58 (46)	
Location		
Metropolitan	94 (75)	
Regional	31 (25)	
Country of birth		
Australia	87 (70)	
Not Australia	38 (30)	
First language		
English	114 (91)	
Not English	11 (9)	
Psychiatric history		
Anxiety and/or depression	16 (13)	
None	109 (87)	
Tumor type		
Breast	34 (27)	
Prostate	41 (33)	
Colorectal	23 (18)	
Haematological	27 (21)	
Cancer stage		
1	28 (22)	
2	59 (47)	
3	35 (28)	
4 (hematological only)[a]	3 (2)	
Treatment type		
Surgery	69 (55)	
Chemotherapy	64 (51)	
Radiotherapy	101 (81)	
Previous/ongoing hormone treatments	22 (18)	
Multimodal treatment (two or more of above)	99 (79)	
Treatment duration		
Days		131
Range		1–332
Cancer status[b]		
Cancer free	86 (95)	
Progression/early recurrence	8 (4)	
Second cancer	1 (1)	
Psychosocial variables at T1		
Unmet needs (0–35)		4.7 (6.2)
Helplessness-Hopelessness (1–4)		1.3 (0.4)
Anxious Preoccupation (1–4)		1.9 (0.6)
Benefit finding (0–105)		36.7 (23.9)
Social support (0–24)		19.6 (4.9)
Physical symptoms (0–28)		8.7 (4.7)

[a] Several survivors had Stage 4 hematological cancers, however, these were being treated with curative intent, and were therefore eligible for inclusion.
[b] Survivors who experienced early recurrence, second cancer or disease progression requiring further treatment were excluded from the longitudinal analysis.

Changes over time in overall psychological distress

One hundred and sixteen participants were included in the mixed model analysis. Results for the primary outcome, psychological distress, are provided in Table 2. In the six months

Table 2. Effects of time and other predictors of psychological distress.

	Model 1			Model 2		
Variable	Estimate	95% CI	*p*-Value	Estimate	95% CI	*p*-Value^a
BSI-18			.24			.25^b
Intercept	6.6	(5.2 to 8.0)		2.6	(−4.8 to 9.9)	
Time 2	−1.1	(−2.3 to 0.2)		−1.0	(−2.3 to 0.2)	
Time 3	−0.5	(−1.9 to 0.8)		−0.2	(−1.6 to 1.1)	
Age (per 5-year increase)				−0.2	(−0.5 to 0.1)	.26
Gender (reference: female)				−1.0	(−2.7 to 0.6)	.22
Psychiatric history (reference: no history)				2.7	(0.2 to 5.3)	**.04**
Physical symptoms				0.7	(0.5 to 0.9)	**<.0001**
Anxious-preoccupation				0.9	(−0.7 to 2.5)	.27
Helpless-hopeless				1.8	(−0.5 to 4.1)	.12
Benefit finding				0.0	(−0.0 to 0.1)	.31
Social support				−0.3	(−0.5 to −0.1)	**.003**
Unmet needs				0.2	(0.1 to 0.4)	**.003**

Model 1 presents the effects of time alone; model 2 includes predictors of psychological distress. Estimated regression parameters include the Intercept (mean BSI-18 Total score at T1), Time 2 (mean difference between BSI-18 Total scores at T1 and T2) and Time 3 (mean difference between BSI-18 Total scores at T1 and T3).
^{a}Significant predictors in bold for emphasis, ^{b}*p*-value for time effect.

following treatment, changes over time were not statistically significant ($p = .24$) and mean scores at all assessments were well below suggested cut-offs for caseness (6.6, 5.5 and 6.1 respectively). Psychological distress was significantly associated with a prior history of psychiatric illness ($p = .04$). It was also positively associated with the total number of physical symptoms ($p < .0001$), negatively associated with levels of social support ($p = .003$) and positively associated with the total number of unmet needs ($p = .003$) reported at T1.

Psychological distress trajectories

Eighty-one of the 91 participants who completed T3 were included in the trajectories analysis (nine were excluded due to cancer recurrence, one did not complete the BSI-18 at T3). Most participants were assigned to the 'resilient' group ($n = 65$, 80%). The remainder were assigned to the 'chronic' ($n = 7$, 9%), 'recovered' ($n = 5$, 6%) and 'delayed' ($n = 4$, 5%) groups. For each Bonanno trajectory group, mean distress scores are shown in Figure 2, demographic and medical characteristics are summarized in Table 3 and psychosocial characteristics are compared in Table 4. Notably, a comparatively larger proportion of the 'recovered' group was aged 65 or under and a comparatively larger proportion of the 'chronic' group had a history of psychiatric illness (Table 3). On psychosocial variables, large-sized differences were observed between the 'resilient' group and the other Bonanno groups: on average, the 'chronic' group reported more unmet needs, helplessness-hopelessness, anxious preoccupation, benefit finding and physical symptoms, and less social support; the 'delayed' group reported more unmet needs, helplessness-hopelessness and anxious preoccupation; and the 'recovered' group reported more anxious preoccupation, benefit finding and physical symptoms.

Discussion

This study examined trajectories of psychological distress in cancer survivors in the immediate post-treatment phase using an established theoretical model and explored whether these trajectories could be differentiated by baseline patient factors. The study overcame several limitations of prior research, which to date have largely studied women with breast cancer exclusively, or included mixed groups of patients and survivors at different phases of the cancer journey. Using a rigorous methodology to examine the model in survivors across a range of high survival cancers who are all at the same point (e.g., immediately after completing treatment) enabled the influence of medical and treatment factors on psychological distress to be studied.

Self-reported levels of psychological distress were low on average and remarkably stable in most survivors sampled. Stability in the initial post-treatment period has been reported by others [21,22]. As such, our findings reinforce the belief that most survivors adjust well after treatment. Nonetheless, for some, time alone may not lead to recovery, at least in the first six months after treatment. End of treatment is, therefore, an opportune time to screen for psychological distress and canvass other difficulties associated with elevated levels of distress including persistent physical symptoms, unmet needs and lack of social support.

The data presented in this study also supports others' findings [4,7] that exclusively looking at mean scores to describe the course of distress for survivors may mask subgroups of survivors who experience different courses of psychological distress, and particularly those who experience severe or worsening distress. Four distinct trajectories of psychological distress described by the Bonanno model were identified in this sample. The prevalence of each of these groups was noted as an important outcome of this project. Power to detect between-groups differences as statistically significant was limited by the number of people in each group; however, some large-sized differences were observed between the trajectories. Over 80% of survivors experienced continuing low levels of distress after treatment. Others have similarly found high proportions of resilient participants [5,11]. This is encouraging and suggests that although cancer and its treatment can be stressful, and there can be ongoing effects and unmet needs, most individuals are able to manage well, with sustained low levels of distress.

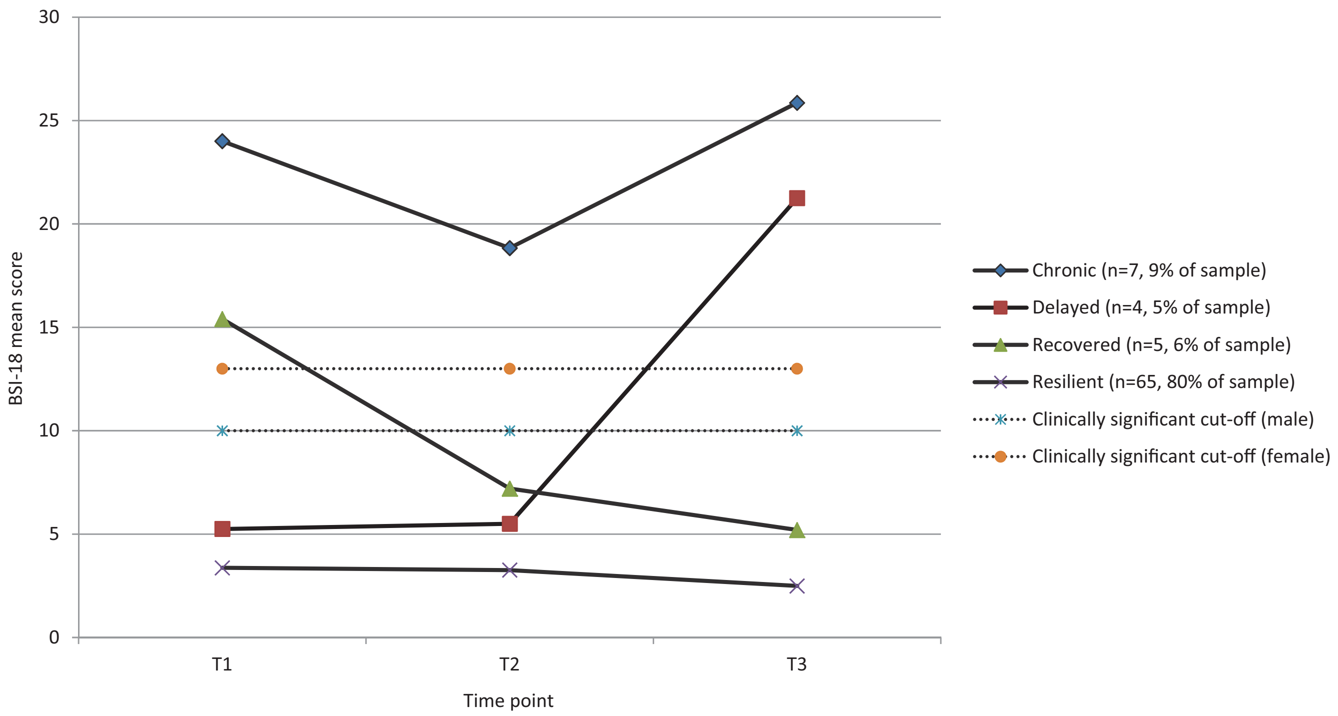

Figure 2. Mean psychological distress scores for each trajectory, classified by BSI-18 critical cut-off score.

Table 3. Demographic and medical characteristics by Bonanno trajectory group.[a]

Variable	Category[b]	Chronic ($n = 7$) %	Delayed ($n = 4$) %	Recovered ($n = 5$) %	Resilient ($n = 65$) %
Gender	Male	57	75	40	54
Age	65 years or under	43	25	80	48
Marital status	Married/defacto	71	75	80	71
Employment	Working (full/part time)	14	50	20	25
Residential location	Metropolitan	86	75	80	83
First language	English	71	100	80	91
Psychiatric history	Documented history of anxiety or depression	43	0	0	6
Tumour type	Breast	29	25	40	31
	Prostate	43	50	20	29
	Colorectal	0	0	20	14
	Haematological	29	25	20	17
Cancer stage	Early (1–2)	71	50	60	77

[a] Data are percentages within Bonanno trajectory group for listed categories.
[b] Unlisted category for each variable: gender, female; age, over 65 years; marital status, never married, divorced or widowed; employment, sick leave, retired or not working; residential location, rural; first language, not English; psychiatric history, no documented history of anxiety or depression; and cancer stage, advanced disease (Stage III or IV).

Table 4. Psychosocial characteristics by Bonanno trajectory group.[a]

	Resilient		Recovered		Delayed		Chronic	
Outcome	Mean	SD	Mean difference (95% CI)	ES[b]	Mean difference (95% CI)	ES[b]	Mean difference (95% CI)	ES[b]
T1 Unmet needs (total)	3.9	5.1	−2.1 (−9.4 to 5.1)	0.4	5.1 (−2.1 to 12.4)	**1.0**	8.3 (2.7 to 13.9)	**1.5**
T1 Helplessness-Hopelessness	1.2	0.3	0.2 (−0.2 to 0.6)	0.6	0.3 (−0.1 to 0.8)	**1.0**	0.8 (0.5 to 1.1)	**2.3**
T1 Anxious Preoccupation	1.7	0.6	0.8 (0.1 to 1.4)	**1.3**	0.8 (0.1 to 1.6)	**1.5**	0.7 (0.1 to 1.2)	**1.2**
T1 Benefit finding (total)	30.3	22.0	26.2 (−1.0 to 53.4)	**1.2**	14.7 (−12.5 to 41.9)	0.7	21.6 (0.6 to 42.6)	**1.0**
T1 Social support	19.9	4.0	1.7 (−3.0 to 6.3)	0.4	2.3 (−2.8 to 7.5)	0.6	−7.4 (−11.3 to −3.4)	**1.8**
T1 Physical symptoms (total)	7.2	4.0	4.8 (0.4 to 9.3)	**1.3**	1.3 (−3.6 to 6.3)	0.3	8.6 (4.7 to 12.4)	**2.1**

[a] Data are means and standard deviations for the 'resilient' group, and mean differences with 95% confidence intervals for the 'recovered', 'delayed' and 'chronic' groups (i.e. each group was compared with the 'resilient' group). Effect sizes (ES) to estimate the size of the difference are provided for group comparisons: 0.2 = small-sized difference, 0.5 = medium-sized difference; 0.8 = large-sized difference.
[b] Large-sized differences in bold for emphasis.

Nevertheless, timely, accurate identification and management of the minority who experience difficulties remains an important priority. In this case, nine percent of participants were chronically distressed in the six months after treatment, reporting an array of physical and psychosocial difficulties. This group was clearly differentiated from the larger, 'resilient' group, with large reported differences for all of the psychosocial outcomes. Survivors with elevated distress at end of treatment should be more comprehensively assessed for unmet needs, physical symptoms, lower social support, higher levels of benefit finding and use of maladaptive coping strategies. Management of these risk factors may reduce the risk of ongoing chronic distress. Although the group was small, having a documented history of psychiatric illness strongly differentiated those who were chronically distressed, from those who were resilient (43% compared to 6%). It is critical that resources and interventions are appropriately targeted towards this small but important group of chronically distressed individuals.

There are two important points to note: first, psychiatric history is often underreported. It is likely that the number of survivors with previous or current anxiety or depression is even higher, given current statistics which estimate that 20% of Australians in the community meet the criteria for mental disorders during any 12 month period [23]. Second, 23 survivors were not invited to participate because the treatment team judged that they were not cognitively or psychologically fit to participate. This judgment was required from the ethical review committee and was not based on formal assessment, rather a sense that these patients would not 'cope' with the additional burden of the research project. It is unclear, though perhaps likely, that at least some of these individuals may have been experiencing clinically significant distress. Institutional and clinical gatekeeping in psychological research requires further consideration.

Surprisingly few survivors experienced recovered patterns of distress. Of 12 participants who had high distress at baseline, five (42%) recovered to below clinical levels during the study, four of these within three months of finishing treatment. The remainder went on to experience chronic distress. The 'recovered' group had considerably lower distress scores at T1 than survivors assigned to the 'chronic' group (15 compared to 24, see Figure 2), suggesting that it might be possible to differentiate individuals likely to experience chronic distress by screening for the highest scores at end of treatment, and perhaps again three months later. Surprisingly, both the 'recovered' and 'chronic' groups reported higher benefit finding scores at T1, compared to the resilient group. Both were able to see positive outcomes from their cancer experience, a characteristic often expected in the lower distress groups [16], though some have argued that those who are resilient have little need for growth [24]. However, the chronic group was also differentiated by higher unmet needs, higher helplessness-hopelessness and lower social support. Others have found these to be strong, consistent predictors of chronic psychological morbidity [5]. Focused research should examine these relationships more comprehensively, as these factors may be key to determining who will recover and who will not, and then targeting intervention appropriately.

The 'delayed' group was the most difficult group to characterize. Only four out of 81 survivors experienced this trajectory. Others have observed similarly low proportions for a delayed group, ranging from between four and fifteen percent of their samples [4,5,11]. The greatest increase in distress was reported between T2 and T3 for this group. That is, it was only after three months that this group experienced worsening distress. It is possible that this correlates with a milestone in survivors' recovery journey, for example, their follow-up oncologist appointment, where they might expect to be 'recovered' but do not yet feel well.

This group also represents a significant challenge as they are not easily distinguished from the resilient group through distress screening at the end of treatment, with only slightly higher T1 scores. However, they had more unmet needs and used more maladaptive coping styles (helplessness-hopelessness and anxious preoccupation) compared to the resilient group. Screening for these at the end of treatment and in follow-up visits could identify those at risk of delayed distress. Strategies for coping with ongoing difficulties, such as self-recognising rising distress and where to seek help, and resetting expectations around returning to normal should be discussed with this group.

Overall, demographic and treatment characteristics were less useful at distinguishing distress trajectories than expected. The BSI-18 has gender-specific clinical cut-off scores which may explain why this factor was not significant. Instead, it seems that assessing physical symptoms and the modifiable psychosocial characteristics measured in this study may be more critical in identifying and managing distressed survivors. Anxious preoccupation, characterized by constant preoccupation with cancer and feelings of devastation, anxiety, fear and apprehension [18], appears to be a particularly good indicator of survivors at risk of experiencing all three non-resilient trajectories, suggesting that those showing signs such as cancer-related worry and fear of recurrence may be more susceptible to psychological distress.

Limitations

Findings are limited to the survivor populations included in the study. Sampling bias is noted for the inclusion of only English speaking participants with certain cancer types. The exclusion of survivors who were cognitively or psychologically impaired may mean that the number of highly distressed survivors is underestimated. In addition, the small proportions of survivors reporting significant levels of psychological distress meant that elements of the analysis were exploratory only. Findings must be considered in the context of small sample size, and correspondingly large confidence intervals, for some results. Nevertheless, they may inform hypotheses for future testing. Finally, only T1 variables were examined to describe differences between distress trajectories here. This is because treatment completion is when most survivors attend discharge appointments with their treatment team, so it is essential to understand which factors could be screened for at this time which may be indicative of later distress. However, there may also be factors associated with later distress which only become apparent after treatment completion (e.g., at T2), which were not examined here. Similarly, the relationship between the longitudinal trajectories of these factors with the distress trajectories is also an area of interest [25] and should be investigated further to understand how different psychosocial factors vary together over time.

Conclusion

Most survivors experience low distress and may not require intense follow-up care. Screening for distress after treatment, along with a more comprehensive assessment of unmet needs, physical symptoms and coping styles in those with elevated levels, is critical to identifying those at risk of experiencing non-resilient trajectories. Preparing survivors for what to expect and when to seek help may help to reduce their likelihood of delayed or chronic distress. Future research should address whether trajectories differ if baseline distress is measured at diagnosis, rather than the end of treatment, and longer-term outcomes should be observed for changes beyond the first 6 months after treatment.

Disclosure statement

The authors report no conflicts of interest.

Funding

Kerryann Lotfi-Jam was supported by an NHMRC Public Health Postgraduate Scholarship [Grant: 567146] to undertake this work.

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