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What goes up does not always come down: patterns of distress, physical and psychosocial morbidity in people with cancer over a one year period

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Abstract

***Background*: As the concept of distress as the 6th vital sign gains strength in cancer care, research on the experience of patients is critical. This study longitudinally examined patients' physical and psychosocial concerns over the year following diagnosis.**

***Methods*: Between July 2007 and February 2008, patients attending a large tertiary cancer centre were recruited to participate in a study examining their levels of distress, pain, fatigue, depression and anxiety over a year.**

***Results*: A total of 877 patients provided baseline data with 620, 589 and 505 retained at 3, 6 and 12 months, respectively. Overall, levels of distress, depression and anxiety decreased significantly over the study period. No significant changes were found in levels of pain or fatigue. Demographics (being unmarried) and medical interventions (particularly having radiation therapy) predicted persistent distress, anxiety and depression, whereas receiving psychosocial support predicted decreased levels of distress, anxiety and depression. Some patients reported continued clinical levels of distress (29%), pain (19%) and fatigue (40%) 12 months post diagnosis.**

***Discussion*: For some people, distress, depression, and anxiety may be transient and decrease over time, but for others they may be sustained. Pain and fatigue may remain present in many cancer patients. There is a need to modify current clinical practice to facilitate the appropriate assessment and management of distress.**

Keywords: distress; pain; fatigue; longitudinal study; usual care

Introduction

Distress in cancer patients is a highly prevalent and significant problem with incidence rates at all phases of the illness estimated at 35–55% [1–3]. Cancer prevalence is expected to double in the next 20 years worldwide [4], and an increasing number of patients will be faced with elevated distress. Distress has been defined as extending 'along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears, to problems that can become disabling such as depression, anxiety, panic, social isolation and spiritual crisis' [5]. The Canadian Strategy for Cancer Control, along with other national and international organizations, supports and advocates for identifying distress as the sixth vital sign in cancer care, thus calling for its routine monitoring [6,7].

Some longitudinal studies, defined operationally as including two or more cross-sectional assessments, examining the trajectory of distress have reported that distress levels may decrease over time [8], whereas others report that distress levels may be maintained [9,10] or even increase over time [11,12]. Breast cancer patients who experienced chronic distress during the first year of diagnosis reported greater long-term distress (6 years later) [13]. Anxiety and depression decreased over time in newly diagnosed geriatric patients [9,14] and advanced lung cancer patients [9]; however, patients reporting higher anxiety and depression initially also experienced sustained anxiety and depression [12,15,16].

Given that distress is associated with reduced survival, quality of life and satisfaction with care [17], identifying patients who may be at high risk for persistent distress over time may assist health professionals in developing more efficient and efficacious interventions tailored to these individuals [18]. Younger breast, colorectal, lung and prostate cancer patients reported higher anxiety and depression at their 3-month follow-up [15]. Similarly, younger patients were more likely to experience persistent anxiety during and following radiation therapy [19]. Findings on the impact of gender on distress, anxiety and depression trajectories are still inconclusive. Post-treatment anxiety was higher for male head and neck cancer patients in one study [16], whereas depression was higher for female melanoma patients [14]. Female patients also reported higher distress in a study with breast, lung, prostate and colon cancer patients [18], whereas female and highly educated patients reported greater decreases in depression over time in another [14].

In terms of medical factors, people undergoing oncological treatment may report higher psychological distress [20]. In head and neck cancer patients, anxiety may be maintained [21] or decreased following radiation therapy [16], whereas depression is reported to increase [16,21]. Conflicting results have been reported for type of cancer [18]. In breast cancer patients, no demographic or medical factors predicted changes in distress [10]. It is suggested that variations in predictors of these outcomes may be related to methodological factors, including patient sample, timing of follow-up and measures used [14].

Although these studies do contribute to the literature on experiences of distress, depression and anxiety over the disease trajectory in the cancer population, many are limited by their inclusion criteria (i.e. patients with particular diagnoses [9,10,12,16,18,22] or receiving particular treatments [19,22]), shorter length of follow-up [9,10,18,22] or fewer assessment time points [12,15,16]. Studies in heterogeneous populations often suffer from smaller sample sizes [15,19]. The current study builds upon this previous work by examining distress levels at baseline, 3, 6 and 12 months later in a large representative sample of cancer patients attending a tertiary cancer centre. Levels of depression, anxiety, pain and fatigue were also assessed during this time, as these are the symptoms most commonly reported in the cancer population, which consistently predict clinical levels of distress [2,23,24].

Methods

Objectives

The objectives of this study were:

1. to examine levels of distress, depression, anxiety, pain and fatigue from time of diagnosis over the course of a full year in a large cohort of cancer patients with a variety of diagnoses;
2. to explore the associations between changes in outcomes over time and demographic and medical characteristics.

Participants

All ambulatory oncology patients over 18 years of age who were new to the Tom Baker Cancer Centre (TBCC) were eligible for the study. If the person was unable to read or speak English or was physically unable to complete the screening, that limitation was noted and the person was deemed ineligible.

Measures

Demographics and cancer history

Participants completed a questionnaire assessing background characteristics and cancer history variables, including age, gender, marital status, living arrangements, education, ethnic/cultural background, income, source of income and stage of treatment process. Type of cancer was gathered through chart audits.

Distress thermometer

The distress thermometer (DT) is a 0–10 visual analogue scale vertically oriented in the form of a usual thermometer. The item asked patients to rate 'how much distress you have been experiencing in the past week, including today'. A cut-off score of ≥ 4 has been shown to perform best in terms of sensitivity and specificity for identifying cancer patients with high psychological distress [23,25,26].

Fatigue thermometer (FT)

Fatigue was identified in a previous study as the most common problem for cancer patients in our setting [2], and cancer-related fatigue is known to be very common [2]. Fatigue was evaluated on a 0–10 point numeric rating scale similar to the distress thermometer; patients were asked to rate 'how much fatigue you have been experiencing in the past week, including today'. For consistency with the National Comprehensive Cancer Network guidelines for fatigue [27], a cut-off of ≥ 4 was used to identify cases of possible fatigue.

Pain thermometer (PT)

Pain has been identified as the '5th vital sign' in cancer care [28] and, in earlier screening, was the second most common problem in our population [2]. The Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials suggests a numerical rating scale from 0 to 10 similar to that Cleeland and Ryan used to quantify how much pain patients have been experiencing [28,29]. The item asked patients to rate 'how much pain you have been experiencing in the past week, including today'. A cut-off of ≥ 4 was used to identify cases of pain [30].

The Psychological Screen for Cancer (PSSCAN part C) [31]

This instrument was developed for screening in clinical practice and as a research tool. Part C consists of 10 items rated on a five-point Likert scale, ranging from 'not at all' to 'very much so' to measure anxiety and depression. The measure has been validated in two separate groups of cancer patients; Cronbach's alpha ranged from 0.79 to 0.89, and test–retest stabilities ranged from 0.49 to 0.87 [31,32]. A cut-off score of ≥ 11 on each subscale indicates high anxiety and distress [31,32].

Use of psychosocial resources

Patients' use of the Psychosocial Resources Department at TBCC was assessed at each time point using a self-report single item that asked patients to answer yes or no to 'used psychosocial resources such as counseling, support groups, meditation, smoking cessation, financial assistance and nutritional counseling'.

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Procedures

Between July 2007 and February 2008, research assistants approached eligible participants in the outpatient waiting room for consent to participate. Consenting patients completed a paper and pen questionnaire booklet while waiting, which took no longer than 15 min. For all eligible patients who did not consent to the study, research assistants recorded reasons for non-completion. Participants were followed 3, 6 and 12 months later either via email or telephone to complete the screening measures. Treatment as usual was available to patients during the course of this study; however, patients were only referred to services to address their concerns if they specifically asked the research assistant for a referral. Patients reporting thoughts of suicide were contacted by a staff member within 24 h for a suicide assessment and were offered referrals as appropriate. All procedures were approved by the Conjoint Health Research Ethics Board of the University of Calgary, Faculty of Medicine/Tom Baker Cancer Centre.

Data analysis

The dependant variables were individual slopes on each of the outcome measures, including the DT, PT, FT and PSSCAN depression and anxiety subscales. For the assessment of objective 1, a slope of outcome on time (measured in months) using standard linear regression was estimated for each participant [33]. These regression models provide 'solutions to commonly observed problems of missing data, serial correlation, time-varying covariates, and irregular measurement occasions, and they accommodate systematic person-specific deviations from the average time trend' [33]. A slope was created for each participant who provided data at baseline and at least one follow-up. One-sample *t*-tests were conducted on these slopes to determine whether the degree of change in outcomes differed from zero.

For the assessment of objective 2, a multiple linear regression on distress slope was conducted to identify any potential demographic or medical risk factors for prolonged distress. Similar to our previous study [1], demographic variables included age, gender (male/female), marital status (married/not married), income (below/above $50 000) and education (below/above high school). Medical variables included type of cancer (gastrointestinal/other), use of psychosocial resources (never/at least once) and receipt of each of surgery, chemotherapy and radiation therapy (never/at least once). Distress intercept score (as a baseline measure of distress) was also included, along with the interactions between distress intercept score (as a baseline measure of distress) and all other variables in the model. We repeated this regression model with anxiety and depression slopes.

The percentage of patients at risk for clinically elevated levels of outcomes at each time point was calculated. Clinically elevated levels of distress, pain and fatigue were determined using a cut-off score of ≥4 and anxiety and depression using a cut-off score of ≥11. Data were analysed using Statistical Package for the Social Sciences (SPSS) Version 19 (IBM Corp., New York, USA).

Results

Participants

A total of 1717 patients were approached to participate in the study, and 1196 (70.1%) completed baseline data. Only participants whose first visit to the TBCC was within 1 month of their baseline screening are described in this analysis. The 'first visit' designation was given to patients who were newly diagnosed and visiting the centre for the first time, as well as patients who were visiting the centre for the first time due to a diagnosed recurrence. Eight hundred and seventy-seven of the 1196 (73.3%) met this criterion (Figure 1).

Of these 877 patients, 709 (80.8%) provided data for at least one follow-up, so the linear slope of change in each outcome could be estimated. Table 1 describes the demographic characteristics and medical interventions of the participants who provided data for the slopes analysis (n = 709) and those participants who provided baseline data only (n = 168). People who provided slopes data had higher baseline pain mean score and were also more likely to have used psychosocial resources. They were also more likely to have received chemotherapy, surgery

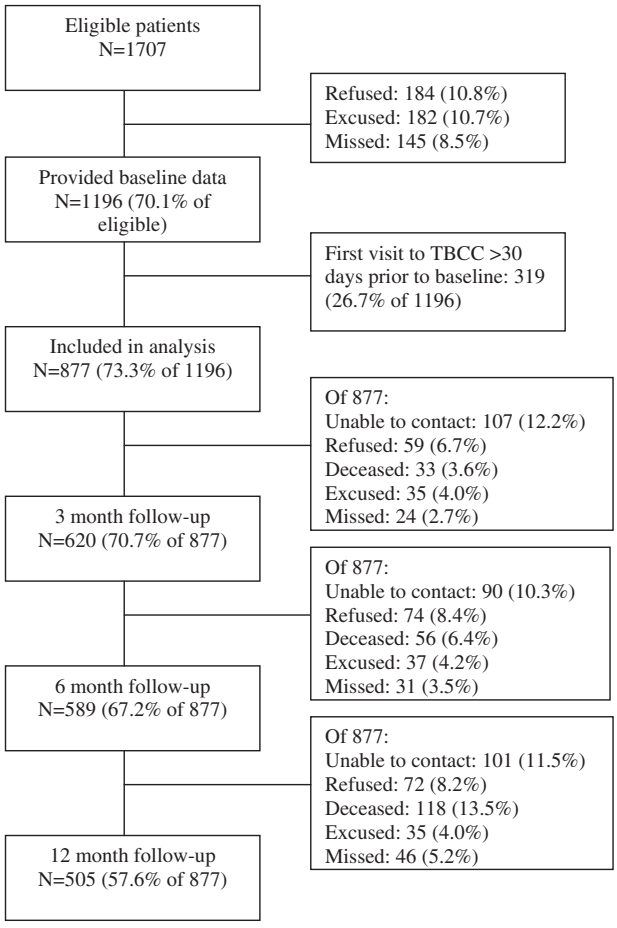

Figure 1. Study Flow Chart

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Table 1. Demographic and medical interventions for patients included and excluded from the slopes analysis (n = 877)

Demographic and medical interventions	Slopes (n = 709)		Baseline only (n = 168)			
	N	%	*N*	%	*p*-value	Cohen's *d*
Mean age (years)	62.3		63.0		0.04	
SD	14.1		15.7			
Gender						
Male	406	57.4	106	63.1	0.18	
Female	301	42.6	62	36.9		
Marital status						
Single	58	8.4	14	8.5	0.99	
Married	464	66.9	101	61.2	0.27	
Separated	19	2.7	7	4.2	0.85	
Divorced	48	6.9	14	8.5	0.84	
Widow/widower	54	7.8	19	11.5	0.62	
Common law	39	5.6	7	4.2	0.88	
Committed	12	1.7	3	1.8	0.96	
Living arrangements						
Not alone	558	82.4	144	86.7	0.18	
Alone	119	17.6	22	13.3		
Education						
Elementary school (1–6)	13	1.9	11	6.7	0.56	
Middle school (7–9)	57	8.3	23	14.1	0.43	
High school (10–12)	239	34.6	53	32.5	0.77	
Community college	130	18.8	34	20.9	0.78	
Some university	65	9.4	17	10.4	0.90	
Completed university	117	16.9	13	8.0	0.41	
Postgraduate	70	10.1	12	7.4	0.80	
Family income						
Less than $30 000	108	15.8	45	28.7	0.07	
Less than $50 000	163	23.8	33	21.0	0.73	
Less than $80 000	108	15.8	23	14.6	0.89	
Less than $100 000	77	11.3	8	5.1	0.59	
More than $100 000	115	16.8	19	12.1	0.61	
Prefer not to say	113	16.5	29	18.5	0.80	
Source income						
Employment	295	42.9	55	34.4	0.24	
Pension/retirement (CPP)	246	35.8	71	44.4	0.84	
Family members (spouse/parent)	63	9.1	18	11.3	0.78	
Social assistance	26	3.9	3	1.9	0.86	
Prefer not to say	33	4.8	7	4.4	0.96	
Other	24	3.5	6	3.8	0.97	
Diagnosis						
Gastrointestinal	180	25.4	54	32.1	0.33	
Prostate	142	20.0	33	19.6	0.96	
Skin	81	11.4	17	10.1	0.88	
Gynaecologic	71	10.0	8	4.8	0.63	
Head and neck	60	8.5	5	3.0	0.67	
Haematological	48	6.7	15	9.0	0.76	
Breast	42	5.9	3	1.8	0.77	
Testicular	17	2.4	10	6.0	0.63	
Brain	12	1.7	10	6.0	0.59	
Thyroid	16	2.3	4	2.4	0.99	
Lung	15	2.1	4	2.4	0.97	
Other	25	3.5	5	3.0	0.96	
Receipt of treatment at least once						
Surgery	229	32.3	39	23.2	0.02	
Chemotherapy	227	32.0	7	4.2	<0.001	
Radiation therapy	150	21.2	1	0.6	<0.001	
Use of psychosocial resources at least once						
No	534	77.7	164	93.7	<0.001	
Yes	143	22.3	11	6.3		
Distress (DT) baseline						
Mean	4.00		4.09		0.73	−0.03
SD	2.88		3.00			
Pain (PT) baseline						
Mean	1.86		1.59		0.03	0.09
SD	2.65		3.20			

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Table 1. *Continued*

Demographic and medical interventions	Slopes (n = 709)		Baseline only (n = 168)			
	N	%	*N*	%	*p*-value	Cohen's *d*
Fatigue (FT) baseline						
Mean	3.27		3.77		0.05	−0.16
SD	2.89		3.17			
Anxiety (PSSCAN) baseline						
Mean	8.87		8.64		0.53	0.06
SD	4.15		4.08			
Depression (PSSCAN) baseline						
Mean	6.46		6.37		0.73	0.03
SD	3.03		3.23			

SD, standard deviation; CPP, Canada Pension Plan; DT, distress thermometer; PT, plan thermometer; FT, fatigue thermometer; PSSCAN, Psychosocial Screen for Cancer.

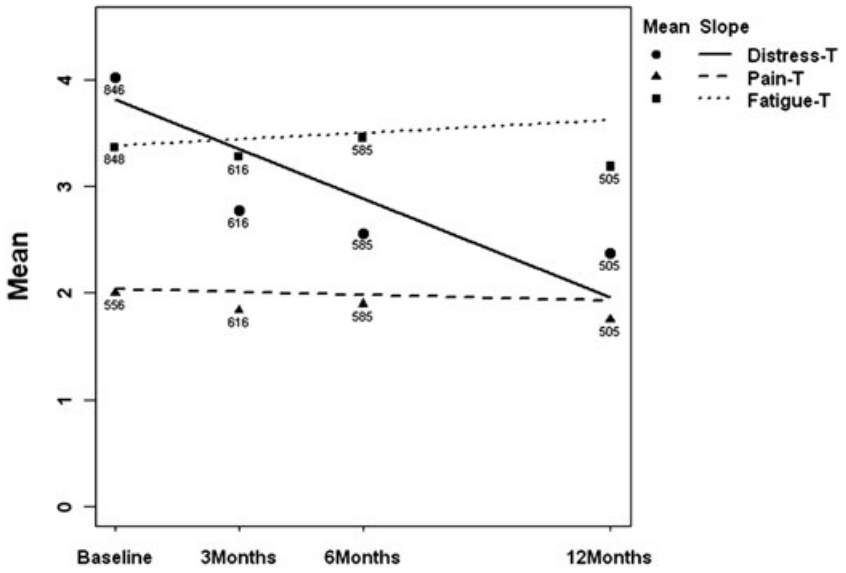

Figure 2. Slope and mean scores over 12 months for the distress thermometer (Distress-T) (n = 691), pain thermometer (Pain-T) (n = 452) and fatigue thermometer (Fatigue-T) (n = 682). The individual data points presented are the mean scores for participants on the DT, PT and FT at baseline, 3, 6 and 12 months. The sample size is reduced at each follow-up as noted in Figure 1, so a different sample of patients is represented by these mean scores at each follow-up time point

and radiation therapy at least once during the study. There were no other differences between the groups.

The proportion of patients who completed their follow-up screening measures via telephone was 68% at 3 months, 67% at 6 months and 64% at 12 months. Independent t-tests revealed lower anxiety and depression scores for patients completing the 3-month and 6-month follow-up via telephone compared to via the internet ($p < 0.05$). Patients completing the 6-month and 12-month follow-up via telephone reported higher pain and fatigue scores ($p < 0.05$). However, effect sizes were small (all values of Cohen's $d < 0.33$).

Objective 1: changes in distress, depression, anxiety, pain and fatigue over time

On average, the level of distress experienced by participants decreased significantly over time ($M = -0.15$, SD = 0.45; $t(690) = -9.02$, $p < 0.001$), as did the level of anxiety ($M = -0.21$, SD = 0.53; $t(694) = -10.51$, $p < 0.001$) and depression ($M = -0.06$, SD = 0.34; $t(695) = -4.371$, $p < 0.001$). However, there was no significant change in the level of pain ($M = -0.01$, SD = 0.41; $t(451) = -0.45$, $p = 0.65$) or level of fatigue ($M = 0.02$, SD = 0.42; $t(685) = 1.24$, $p = 0.21$) experienced by participants (Figures 2 and 3).

Objective 2: demographic and medical risk factors for prolonged psychosocial burden

People reporting higher baseline distress ($\beta = -0.56$, $t = -15.02$, $p < 0.001$) and people who had not received surgery ($\beta = 0.08$, $t = 2.08$, $p < 0.05$) had a greater reduction in distress over time. There was a trend for people who had used psychosocial resources at least once to report greater reductions in distress ($\beta = 0.07$, $t = 1.95$, $p = 0.052$).

People with higher anxiety at baseline ($\beta = -0.42$, $t = -6.45$, $p < 0.001$) had greater reductions in anxiety. There were significant interactions between baseline

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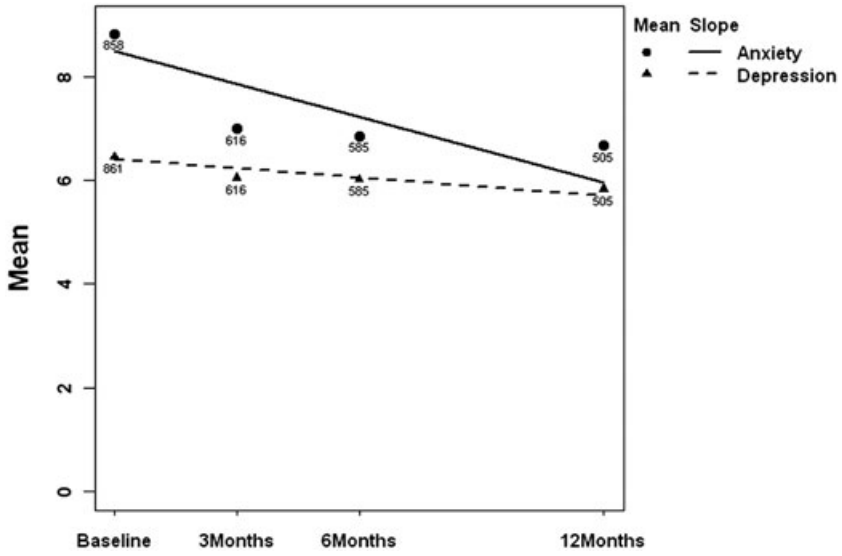

Figure 3. Slope and mean scores over 12 months for the Psychosocial Screen for Cancer (PSSCAN) Anxiety (n = 695) and Depression subscales (n = 696). The individual data points presented are the mean scores for participants on the PSSCAN anxiety and depression subscales at baseline, 3, 6 and 12 months. The sample size is reduced at each follow-up as noted in Figure 1, so a different sample of patients is represented by these mean scores at each follow-up time point

anxiety and marital status, radiation therapy and diagnosis variables. People with higher anxiety at baseline had a greater reduction in anxiety if they were married ($\beta = -0.11$, $t = -2.59$, $p < 0.05$), had not received radiation therapy ($\beta = 0.11$, $t = 2.27$, $p < 0.05$) or had a diagnosis other than gastrointestinal cancer ($\beta = -0.11$, $t = -2.26$, $p < 0.05$). People with higher depression at baseline ($\beta = -0.48$, $t = -11.83$, $p < 0.001$), people who had not received radiation therapy ($\beta = 0.08$, $t = 2.16$, $p < 0.05$) and those who reported that they had used psychosocial resources ($\beta = 0.10$, $t = 2.55$, $p < 0.01$) reported a greater reduction in depression.

Proportion of patients experiencing clinically elevated levels of distress, pain, fatigue, anxiety and depression at each time point

The proportion of patients experiencing clinically elevated levels of distress, pain, fatigue, anxiety and depression at each follow-up time point is presented (Figure 4). At baseline, just over half of participants (51.1%) reported a cut-off score of $\geq$4 on the DT. A minority of patients reported clinical levels of pain (23%), whereas 43.6% reported clinical levels of fatigue using the same cut-off score of $\geq$4 on the PT and FT. Clinical levels of anxiety and depression were classified using a cut-off score $\geq$11; at baseline 25.9% of participants reported anxiety whereas 10.7% reported depression.

Discussion

As the concept of distress as the 6th vital sign gains strength in the cancer domain, longitudinal research on the experience of patients is critical. This study documents the illness experiences of patients as they move through the cancer trajectory. Our first objective was to examine the changes in distress, depression, anxiety, pain and fatigue over time using a slopes analysis. The levels of distress, depression and anxiety of patients decreased significantly over time. Previous studies examining changes in distress have reported inconsistent results; distress decreased in one study [8] but was maintained [9,10] and even increased over time in other studies [11,12]. Anxiety and depression have also been found to decrease over time in newly diagnosed patients [9,14], but remain high in patients initially reporting higher anxiety and depression [12,15,16].

Consistent with previously reported rates of distress [1,2,23,24,34], half of the patients were experiencing clinically elevated levels of distress at baseline, and 29% of people were still experiencing clinically elevated levels of distress 12 months later. Fewer people were experiencing clinically elevated levels of anxiety and depression at 12 months. Clinically, this is an important finding as it highlights that for some, distress, anxiety and depression will decrease over time whereas for others these concerns may persist.

No significant decreases in pain or fatigue were observed over the study period, with approximately 20% and 40% of patients indicating significant levels post diagnosis, respectively. Both pain and fatigue have been endorsed as important components of distress [35], and in 1999, pain was endorsed as the fifth vital sign [28]. Despite the increased attention on strategies to efficiently manage these concerns [36,37], pain and fatigue remain salient for patients. Connecting patients to the appropriate resources should help to decrease the proportion of patients experiencing these concerns, but further work in this area is required.

This study also began to explore demographic and medical risk factors for prolonged symptom burden. Reflecting our previous findings [1], higher baseline distress significantly predicted greater reductions in distress. The same also held true for anxiety and

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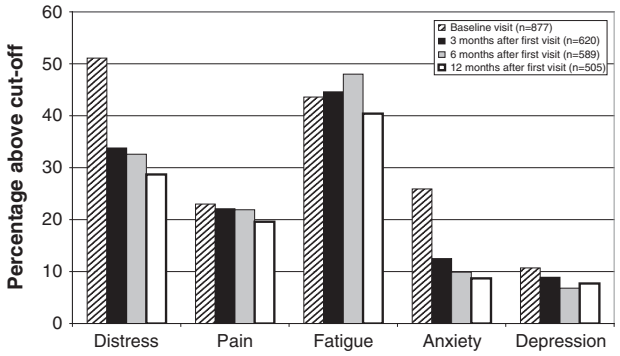

Figure 4. Prevalence of people reporting clinical distress, pain, fatigue, anxiety and depression over time. *N* = 570 for pain thermometer variable at baseline

depression. People who were highly anxious initially and had a gastrointestinal diagnosis reported more persistent anxiety, reflecting previous findings in this population where anxiety at diagnosis predicted a similar status 6 months later [38]. Highly anxious or depressed people who were married reported a greater reduction in anxiety and depression than single, divorced or widowed people, possibly reflecting the stress-buffering effects of social support, as seen in other research. Indeed, being married has previously been associated with lower anxiety and depression in cancer patients [39,40] and lower distress in lung cancer patients [24].

Receipt of surgery predicted smaller reductions in distress and receipt of radiation therapy predicted smaller reductions in anxiety and depression, compared with those who did not have these treatments. This makes sense given that people receiving radiation therapy report low quality of life [41] and high rates of sleep disturbance and fatigue [42–45]. Radiation therapy also incurs increased risk for long-term treatment effects due to the number of visits required and the associated side effects [46], with one study reporting that 40% of patients remained anxious at the completion of treatment [47]. Preparing people about what to expect prior to treatment with radiation therapy in particular may assist in addressing psychological morbidity [48], especially in individuals with high initial anxiety. This work may help us identify which patients are at risk to experience persistent distress and help target this group for screening, assessment and intervention.

The benefits of using psychosocial resources for reducing depression are consistent with the findings of our earlier study [1], while using resources in this study also tended to reduce general distress as well as depression. Despite the high prevalence of psychosocial morbidity, only 20% of participants reported using psychosocial resources during the 1-year period. Given the ability of psychosocial resources to improve well-being [49], methods for connecting patients to these resources if distress and depression persist are required.

Given the prevalence of distress and symptom burden confirmed longitudinally in this study, it is not surprising that attention is now shifting from documenting the prevalence of distress to how we should best identify and manage these concerns. Screening for distress, the 6th vital sign, has gained considerable attention as a strategy for proactively identifying key concerns to facilitate further assessment and referral [50]. Screening for distress advocates for the completion of a screening tool by every patient, which is then used to facilitate a conversation with the health care team and prompt further assessment and appropriate referrals. This study provides a baseline for this work and will help inform decisions about how screening programs are designed.

Previous work in the area of screening for distress has explored automatically referring patients to resources based on screening scores, but our results suggest that this may be unnecessary and potentially burdensome. Our findings that distress, depression and anxiety decreased significantly for some participants are consistent with Fitch's model of service provision, which suggests that all patients require screening, basic emotional support and relevant information; however, not all patients will have their concerns met by this level of intervention. Between 35% and 45% will experience more complex or severe concerns that will require additional specialized intervention [51]. Although this breakdown is theoretically based, it lends support to the recommendation that screening should be used as a red flag indicator to guide further assessment and inform the clinician about whether additional services are required.

For example, the stepped model of care followed by the Psychosocial Resources Department at the TBCC [52,53] is designed to funnel patients from less resource-intensive interventions to more intensive interventions as necessary. The first level of services provided are usually shorter interventions (classes or 1-day seminars), often delivered in groups, and requiring less human resources (and hence less cost) than individualized care. They are designed to address the usual concerns of patients and help to identify cases with more complicated needs that would then be triaged into more personalized, longer, intensive services including counselling and psychiatry.

The high rate of distress 12 months post diagnosis highlights the need to explore the components of distress and how these change over time. Distress, by definition, is multi-factorial in nature and screening the range of psychosocial, practical and physical concerns that may impact distress is recommended [50]. Future work could explore the specific concerns endorsed by patients, as well as the points in the cancer trajectory where they are most prevalent, in order to inform planning for targeted clinical services [54].

Despite the substantial sample size and the length of follow-up, this study has some limitations. Not everybody completed a follow-up measure so not all participants are included in the slopes analysis. The majority of the data obtained in the study was via self-report including demographics, outcomes and use of services. In addition to being

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less expensive and time consuming, self-report data on co-morbidities, diagnosis, recurrence and treatment have been reported to be as accurate as medical chart data [55–57]. In this study, people completed follow-up screening via telephone or email. Some studies report no differences between data obtained via telephone and postal questionnaires [58,59], whereas another found people report higher quality-of-life scores via telephone than via mail [60]. There were some differences in mean outcome scores reported by patients using the different data collection methods at follow-up; however, the effect sizes were small and there could be other differences between those who use email versus phone completion methods (e.g. education, age) that may also account for this variation.

The three thermometers used to assess distress, pain and fatigue have been used in a number of previous studies with cancer patients [5,23,25,27,30,61]; and the use of single-item screening tools has been reported to be as valid for detecting outcomes as multi-dimensional tools [30,62,63]. The additional benefits of single item tools are that they are more efficient and less burdensome to patients and to health professionals implementing the tools [30,62,63]. Research has shown that acceptability to clinicians is one of the most important factors in the uptake of screening tools [64].

Although some patients may adjust to their situation and resolve distress, anxiety and depression over time, this is not the case for all patients. Conditions such as pain and fatigue may persist over the course of the illness and be an iatrogenic consequence of the treatment. These findings highlight the need to modify current clinical practice to facilitate appropriate screening, assessment and intervention throughout the cancer journey to address distress [65]. By monitoring the cancer population in a systematic and ongoing manner, providers may identify people in a more timely way for whom distress, physical and psychosocial morbidity are a significant burden.

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References

1. Carlson LE, Groff SL, Maciejewski O, Bultz BD. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clin Oncol* 2010;**28**:4884–4891.
2. Carlson LE, Angen M, Cullum J *et al.* High levels of untreated distress and fatigue in cancer patients. *Br J Cancer* 2004;**90**:2297–2304.
3. Zabora J, BrintzenhofeSzoc K, Curbow B, Hooker C, Piantadosi S. The prevalence of psychological distress by cancer site. *Psycho-Oncology* 2001;**10**:19–28.
4. Boyle P, Levin B. World Cancer Report 2008.
5. National Comprehensive Cancer Network I. Practice guidelines in oncology—v.1.2002: distress management. 2002;version 1.
6. Holland JC, Bultz BD, National Comprehensive Cancer Network (NCCN). The NCCN guideline for distress management: a case for making distress the sixth vital sign. *J Natl Compr Canc Netw* 2007;**5**:3–7.
7. Rebalance Focus Action Group. A position paper: screening key indicators in cancer patients: pain as a 5th vital sign and emotional distress as a 6th vital sign. *Can Strat Can Cont Bulletin* 2005 **7**:4.
8. Epping-Jordan JE, Compas BE, Osowiecki DM *et al.* Psychological adjustment in breast cancer: processes of emotional distress. *Health Psychol* 1999;**18**:315–326.
9. Akechi T, Okuyama T, Akizuki N *et al.* Course of psychological distress and its predictors in advanced non-small cell lung cancer patients. *Psycho-Oncology* 2006;**15**:463–473.
10. Andreu Y, Galdon MJ, Dura E, Martinez P, Perez S, Murgui S. A longitudinal study of psychosocial distress in breast cancer: prevalence and risk factors. *Psychol Health* 2011, DOI: 10.1080/08870446.2010.542814.
11. Wang XS, Fairclough DL, Liao Z *et al.* Longitudinal study of the relationship between chemo-radiation therapy for non-small-cell lung cancer and patient symptoms. *J Clin Oncol* 2006;**24**:4485–4491.
12. Couper JW, Love AW, Duchesne GM *et al.* Predictors of psychosocial distress 12 months after diagnosis with early and advanced prostate cancer. *Med J Aust* 2010;**193**:S58-S61.
13. Lam WW, Shing YT, Bonanno GA, Mancini AD, Fielding R. Distress trajectories at the first year diagnosis of breast cancer in relation to 6 years survivorship. *Psycho-Oncology* 2010;in press. doi: 10.1002/pon.1876
14. Stommel M, Kurtz ME, Kurtz JC, Given CW, Given BA. A longitudinal analysis of the course of depressive symptomatology in geriatric patients with cancer of the breast, colon, lung, or prostate. *Health Psychol* 2004;**23**:564–573.
15. Hulbert-Williams N, Neal R, Morrison V, Hood K, Wilkinson C. Anxiety, depression and quality of life after cancer diagnosis: what psychosocial variables best predict how patients adjust? *Psycho-Oncology* 2011;in press. doi: 10.1002/pon.1980
16. Neilson KA, Pollard AC, Boonzaier AM *et al.* Psychological distress (depression and anxiety) in people with head and neck cancers. *Med J Aust* 2010;**193**:S48-S51.
17. Bidstrup PE, Johansen C, Mitchell AJ. Screening for cancer-related distress: summary of evidence from tools to programmes. *Acta Oncol* 2011;**50**:194–204.
18. Trask PC, Griffith KA. The identification of empirically derived cancer patient subgroups using psychosocial variables. *J Psychosom Res* 2004;**57**:287–295.
19. Dunn LB, Aouizerat BE, Cooper BA *et al.* Trajectories of anxiety in oncology patients and family caregivers during and after radiation therapy. *Eur J Oncol Nurs* 2011, DOI: 10.1016/j.ejon.2011.01.003.
20. Gao W, Bennett MI, Stark D, Murray S, Higginson IJ. Psychological distress in cancer from survivorship to end of life care: prevalence, associated factors and clinical implications. *Eur J Cancer Care* 2010;**46**:2036–2044.
21. Kelly C, Paleri V, Downs C, Shah R. Deterioration in quality of life and depressive symptoms during radiation therapy for head and neck cancer. *Otolaryngol Head Neck Surg* 2007;**136**:108–111.
22. Manne S, Rini C, Rubin S *et al.* Long-term trajectories of psychological adaptation among women diagnosed with gynaecological cancers. *Psychosom Med* 2008;**70**:677–687.
23. Jacobsen PB, Donovan KA, Trask PC *et al.* Screening for psychological distress in ambulatory cancer patients. *Cancer* 2005;**103**:1494–1502.
24. Graves KD, Arnold SM, Love CL, Kirsh KL, Moore PG, Passik SD. Distress screening in a multidisciplinary lung cancer clinic:

prevalence and predictors of clinically significant distress. *Lung Cancer* 2007;**55**:215–224.
25. Mitchell AJ. Pooled results from 38 analyses of the accuracy of distress thermometer and other ultra-short methods of detecting cancer-related mood disorders. *J Clin Oncol* 2007;**25**:4670–4681.
26. Ransom S, Jacobsen PB, BoothJones M. Validation of the distress thermometer with bone marrow transplant patients. *Psycho-Oncology* 2006;**15**:604–612.
27. National Comprehensive Cancer Network CRF Panel. Practice guidelines in oncology—v.2.2005: cancer-related fatigue. http://wwwnccnorg/professionals/physician_gls/PDF/fatigue pdf 2005. Accessed August 2011
28. Dworkin RH, Turk DC, Farrar JT *et al.* Core outcome measures for chronic pain clinical trials: IMMPACT recommendations. *Pain* 2005;**113**:9–19.
29. Cleeland CS, Ryan KM. Pain assessment: global use of the Brief Pain Inventory. *Ann Acad Med Singapore* 1994;**23**:129–138.
30. Butt Z, Wagner LI, Beaumont JL *et al.* Use of a single-item screening tool to detect clinically significant fatigue, pain, distress, and anorexia in ambulatory cancer practice. *J Pain Symptom Manage* 2008;**35**:20–30.
31. Linden W, Vodermaier AA, McKenzie R, Barroetavena MC, Yi D, Doll R. The Psychosocial Screen for Cancer (PSSCAN): further validation and normative data. *Health Qual Life Outcomes* 2009;**7**:1–8.
32. Linden W, Yi D, Barroetavena MC, MacKenzie R, Doll R. Development and validation of a psychosocial screening instrument for cancer. *Health Qual Life Outcomes* 2005;**3**:54.
33. Gibbons RD, Hedeker D, Elkin I *et al*. Some conceptual and statistical issues in analysis of longitudinal psychiatric data. Application to the NIMH treatment of Depression Collaborative Research Program dataset. *Arch Gen Psychiatry* 1993;**50**:739–750.
34. Hawkes A, Hughes K, Hutchison S, Chambers S. Feasibility of brief psychological distress screening by a community-based telephone helpline for cancer patients and carers. *BMC Cancer* 2010;**10**:14.
35. NCCN Clinical Practice Guidelines in Oncology. NCCN practice guidelines for the management of psychosocial distress. 2008;**45**.
36. Escalante CP, Kallen MA, Valdres RU, Morrow PK, Manzullo EF. Outcomes of a cancer-related fatigue clinic in a comprehensive cancer center. *J Pain Symptom Manage* 2010;**39**:691–701.
37. Borneman T, Koczywas M, Sun V *et al.* Effectiveness of a clinical intervention to eliminate barriers to pain and fatigue management in oncology. *J Palliat Med* 2011;**14**:197–205.
38. Nordin K, Glimelius B. Predicting delayed anxiety and depression in patients with gastrointestinal cancer. *Br J Cancer* 1999;**79**:525–529.
39. Lloyd-Williams M, Friedman T. Depression in palliative care patients—a prospective study. *Eur J Cancer Care (Engl)* 2001;**10**:270–274.
40. Parker PA, Baile WF, de Moor C, Cohen L. Psychosocial and demographic predictors of quality of life in a large sample of cancer patients. *Psycho-Oncology* 2003;**12**:183–193.
41. Gritz ER, Carmack CL, de Moor C *et al.* First year after head and neck cancer: quality of life. *J Clin Oncol* 1999;**17**:352–360.
42. Miaskowski C, Paul SM, Cooper BA *et al.* Predictors of the trajectories of self-reported sleep disturbance in men with prostate cancer during and following radiation therapy. *Sleep* 2011;**34**:171–179.
43. Miaskowski C, Paul SM, Cooper BA *et al.* Trajectories of fatigue in men with prostate cancer before, during, and after radiation therapy. *J Pain Symptom Manage* 2008;**35**:632–643.
44. Bower JE, Ganz PA, Desmond KA, Rowland JH, Meyerowitz BE, Belin TR. Fatigue in breast cancer survivors: occurrence, correlates, and impact on quality of life. *J Clin Oncol* 2000;**18**:743–753.
45. Ashbury FD, Findlay H, Reynolds B, McKerracher K. A Canadian survey of cancer patients' experiences: are their needs being met? *J Pain Symptom Manage* 1998;**16**:298–306.
46. Kim Y, Roscoe JA, Morrow GR. The effects of information and negative affect on severity of side effects from radiation therapy for prostate cancer. *Support Care Cancer* 2002;**10**:416–421.
47. Munro AJ, Potter S. A quantitative approach to the distress caused by symptoms in patients treated with radical radiotherapy. *Br J Cancer* 1996;**74**:640–647.
48. Schofield P, Gough K, Ugalde A, Carey M, Aranda S, Sanson-Fisher R. Cancer Treatment Survey (CaTS): development and validation of a new instrument to measure patients' preparation for chemotherapy and radiotherapy. *Psycho-Oncology* 2010, DOI: 10.1002/pon.1896.
49. Newell SA, Sanson-Fisher RW, Savolainen NJ. Systematic review of psychological therapies for cancer patients: overview and recommendations for future research. *J Natl Cancer Inst* 2002;**94**:558–584.
50. Bultz, BD Groff SL, Fitch, M, Screening for Distress Toolkit Working Group, Canadian Partnership Against Cancer (CPAC). Guide to implementing screening for distress, the 6th vital sign. Part A: background, recommendations, and implementation. 2009.
51. Fitch MI. Providing supportive care. In *Supportive Care Framework: A Foundation for Person-Centred Care*, Fitch MI, Porter HB, Page GG (eds). Pappin Communications: Pembroke, Ontario, 2008;23–24.
52. Cunningham AJ. Adjunctive psychosocial therapy for cancer: what we know and what we need to know. *Chronic Dis Can* 1995;**16**:S13-S18.
53. Cunningham AJ, Edmonds CV. Group psychological therapy for cancer patients: a point of view, and discussion of the hierarchy of options. *Int J Psychiatry Med* 1996;**26**:51–82.
54. McDowell ME, Occhipinti S, Ferguson M, Dunn J, Chambers SK. Predictors of change in unmet supportive care needs in cancer. *Psycho-Oncology* 2010;**19**:508–516.
55. Phillips KA, Milne RL, Buys S *et al.* Agreement between self-reported breast cancer treatment and medical records in a population-based Breast Cancer Family Registry. *J Clin Oncol* 2005;**23**:4679–4686.
56. Mukerji SS, Duffy SA, Fowler KE, Khan M, Ronis DL, Terrell JE. Comorbidities in head and neck cancer: agreement between self-report and chart review. *Otolaryngol Head Neck Surg* 2007;**136**:536–542.
57. Schootman M, Jeffe DB, West MM, Aft R. Self-report by elderly breast cancer patients was an acceptable alternative to surveillance, epidemiology, and end results (SEER) abstract data. *J Clin Epidemiol* 2005;**58**:1316–1319.
58. Almonte M, Silva Idos S, Asare A *et al.* Sexual behavior and HPV infection in British women, by postal questionnaires and telephone interviews. *J Med Virol* 2011;**83**:1238–1246.
59. Gundy CM, Aaronson NK. Effects of mode of administration (MOA) on the measurement properties of the EORTC QLQ-C30: a randomized study. *Health Qual Life Outcomes* 2010;**8**:35.
60. Buskirk TD, Stein KD. Telephone vs. mail survey gives different SF-36 quality-of-life scores among cancer survivors. *J Clin Epidemiol* 2008;**61**:1049–1055.
61. National Comprehensive Cancer Network. NCCN clinical practice guidelines in oncology: adult cancer pain. 2011.
62. Mitchell AJ. Short screening tools for cancer-related distress: a review and diagnostic validity meta-analysis. *J Natl Compr Canc Netw* 2010;**8**:487–494.
63. Jean-Pierre P, Figueroa-Moseley CD, Kohli S, Fiscella K, Palesh OG, Morrow GR. Assessment of cancer-related fatigue: implications for clinical diagnosis and treatment. *Oncologist* 2007;**12**Suppl 1:11–21.
64. Mitchell AJ, Vahabzadeh A, Magruder K. Screening for distress and depression in cancer settings: 10 lessons from 40 years of primary-care research. *Psycho-Oncology* 2011;**20**:572–584.
65. Bultz BD, Groff SL. Screening for distress, the 6th vital sign in oncology: from theory to practice. *Oncology Exchange* 2009;**8**:8.