High levels of untreated distress and fatigue in cancer patients

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The purpose of the study was to assess a large representative sample of cancer patients on distress levels, common psychosocial problems, and awareness and use of psychosocial support services. A total of 3095 patients were assessed over a 4-week period with the Brief Symptom Inventory-18 (BSI-18), a common problems checklist, and on awareness and use of psychosocial resources. Full data was available on 2776 patients. On average, patients were 60 years old, Caucasian (78.3%), and middle class. Approximately, half were attending for follow-up care. Types of cancer varied, with the largest groups being breast (23.5%), prostate (16.9%), colorectal (7.5%), and lung (5.8%) cancer patients. Overall, 37.8% of all patients met criteria for general distress in the clinical range. A higher proportion of men met case criteria for somatisation, and more women for depression. There were no gender differences in anxiety or overall distress severity. Minority patients were more likely to be distressed, as were those with lower income, cancers other than prostate, and those currently on active treatment. Lung, pancreatic, head and neck, Hodgkin’s disease, and brain cancer patients were the most distressed. Almost half of all patients who met distress criteria had not sought professional psychosocial support nor did they intend to in the future. In conclusion, distress is very common in cancer patients across diagnoses and across the disease trajectory. Many patients who report high levels of distress are not taking advantage of available supportive resources. Barriers to such use, and factors predicting distress and use of psychosocial care, require further exploration.

Keywords: Neoplasms; distress; psychosocial screening; fatigue; counselling

Psychosocial distress in cancer patients has been identified as a significant and ongoing problem. The National Comprehensive Cancer Network (NCCN) Distress Management Panel has defined distress as

...a multi-determined unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends 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, ad spiritual crisis. (National Comprehensive Cancer Network, 2002)

Previous studies have documented that approximately one-third of all oncology patients will experience significant levels of distress associated with diagnosis and treatment of cancer, which warrants psychosocial treatment (Derogatis et al., 1983; Stefanek et al., 1987; Zabora et al., 1997; Sellick and Crooks, 1999; Zabora et al., 2001a; Carlson and Bultz, 2003b). Also well documented, using rigorous methodology, is the ability of various psychosocial treatments to alleviate distress levels and improve quality of life in cancer patients, reviewed in several papers and meta-analyses (e.g. Cunningham, 1995; Meyer and Mark, 1995; Bottomley, 1997; Fobair, 1997; Iacovino and Reesor, 1997; Fawzy et al., 1998; Fawzy, 1999; Blake-Mortimer et al., 1999; Cunningham, 2000; Schneiderman et al., 2001; Carlson and Bultz, 2003a).

Interventions usually assume one of four common forms: psychoeducation, cognitive-behavioural training (group or individual), group supportive therapy, and individual supportive therapy. As well, they are usually targeted to one of three points on the illness trajectory: diagnosis/pretreatment, immediately post-treatment or during extended treatment (such as radiotherapy or chemotherapy), and disseminated disease or death (Schneiderman et al., 2001). Certain modalities of treatment have been shown to be more efficacious at one or more of these time periods. For example, psychoeducation may be most effective during the diagnosis/pretreatment time period, when patient information needs are high. However, for later stage adjustment with more advanced disease, group support may be more effective (Blake-Mortimer et al., 1999), while cognitive-behaviour techniques such as relaxation, stress management and cognitive coping may be most useful during extended treatments (Fawzy, 1995; Bottomley, 1997).

Several agencies, both American and International, have developed guidelines for psychosocial care, which include screening guidelines (see Carlson and Bultz (2003b) for an overview of distress screening issues). The Canadian Association of Psychosocial Oncology has published a book of Standards which details principles of practice, professional issues, and organization and
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structure of psychosocial oncology programmes (Canadian Association of Psychosocial Oncology, 1999). Principle 7 states that ‘psychosocial service needs of patients and families are assessed systematically using appropriate tools’ (p. 5). The National Comprehensive Cancer Network (NCCN) and the American Society of Clinical Oncology (ASCO) also have guidelines regarding the identification and management of distress (available at: http://www.nccn.org/physician_gls/index.html). The NCCN guidelines were developed by a Distress Management Panel that included many researchers and clinicians directly involved in major American screening programmes. The standards of care developed by this group state that: ‘All patients should be screened for distress at their initial visit, at appropriate intervals, and as clinically indicated.’ (NCCN, 2002). They go on to delineate clinical practice guidelines for the treatment of distress.

Where there has often been a disconnect, however, is in the ability of psychosocial oncologists to use information about distress levels obtained through routine screening of patients, and to direct those patients identified as in need of services to the appropriate sources of care. This idea of screening followed by appropriate triage is not new in psychosocial oncology, but rarely happens in routine clinical practice. Researchers at Johns Hopkins University have developed a comprehensive psychosocial oncology screening programme that assesses all patients at the point of entry into the cancer care system. Based on this assessment of emotional distress and practical problems, the patients who need support are contacted personally within 48 h, and those who do not indicate significant current need are provided with information regarding the options for social and psychological care for future consultation (Zabora et al., 2001b).

Unfortunately, even routine psychosocial screening of patients is not the norm in terms of care of cancer patients. More commonly, patents are either self-referred, or referred by a member of the medical treatment team who becomes alerted to the patient's distress in the course of clinical care. This can potentially result in missing a large proportion of patients who may be in need of care, but who are either too distressed or without the instrumental resources to find their way through the often confusing medical system to reach psychosocial care. In addition, patients themselves may be so preoccupied with the physical components of their cancer that they may be unaware of the seriousness of the level of their own psychosocial distress, and potentially unaware that help is available to treat these symptoms. It may be the case, then, as a result of this unsystematic referral system, that the most disadvantaged patients may be the least likely to get necessary care.

In order to investigate this possibility, and also to comprehensively assess the most common psychosocial problems reported by a population of patients, we sought to assess every patient who visited the Tom Baker Cancer Centre for any reason (diagnosis, new patient consultation, treatment, follow-up) during the course of the concentrated screening effort to be eligible to participate in the screening programme. No restrictions were placed on age, ethnicity, gender, type of cancer, stage of illness, or disability. Patients who were unable to communicate in English were noted as such and an incomplete questionnaire was submitted with this proviso. It was ensured that each patient was assessed only once.

The Tom Baker Cancer Centre is a large regional tertiary cancer centre that serves a population of approximately 2 million people, with approximately 3500 new patients yearly, and 32 000 annual patient visits. The Department of Psychosocial Resources at the TBCC is one of the largest in Canada, employing six full-time and two part-time psychologists, two full-time and two part-time clinical social workers, as well as a number of research staff.

Instruments

Demographic and Cancer History Questionnaire The first few questions collected standard demographic and disease-related information.

Psychosocial Questionnaire The next section asked a series of questions regarding awareness and use of the Department of Psychosocial Resources at the TBCC. Questions were developed by the psychosocial staff and pretested on a group of patients for clarity and ease of understanding. Included questions are listed in Figure 1.

Problem checklist The following section included the patient problem checklist with 22 items, adapted from that used by the Johns Hopkins research group to fit the local setting. Patients were instructed to check off all problems they currently have or expect to have.

Brief Symptom Inventory – 18 (BSI–18) Published in 2001 (Derogatis, 2001), this short 18-item instrument is the latest in an integrated series of test instruments designed to measure psychological distress. Shortened from the original Symptom Checklist (SCL-90-R; Derogatis, 1983), the 53-item Brief Symptom Inventory (BSI) (Derogatis, 1993), and now the 18-item version have been normed for use with cancer patients. The BSI and the SCL-90 have been used extensively with medical populations, including cancer patients, and have demonstrated high levels of sensitivity and specificity in screening for psychological distress (Zabora et al., 1990; Carlson and Bultz, 2003b). The BSI-18 was developed specifically as a highly sensitive and efficient screen for psychiatric disorders and psychological distress. The BSI-18 is highly reliable ad valid and is significantly correlated with the BSI. The instrument yields three subscale scores: Somatization, Depression and Anxiety, with internal consistencies ranging from 0.74 to 0.89, and correlations with the BSI ranging from 0.91 to 0.96. A composite score, the General Severity Index (GSI), also shows similar high levels of reliability. Average completion time is 1–3 min. The BSI-18 is the version that the Johns Hopkins group has been recently using in their screening programme, and on which they have published norms from a large sample of patients (Zabora et al., 2001b).

In addition to continuous scoring on each subscale, cutoff scores are recommended for ‘caseness’ of each subscale and the GSI scores for cancer patients, based on the guidelines in the manual. Individuals who score at or over the cutoff values are considered to be experiencing levels of distress that require psychosocial intervention. Criteria for ‘caseness’ vary between men and women for anxiety and somatization, but not for depression.

Procedures

The assessments were collected over a 1-month period as a ‘snapshot’, or cross-sectional analysis of all patients visiting the TBCC during this time period, both new and follow-up, across all

METHODS

Subjects and setting

All patients over the age of 18 years who visited the Tom Baker Cancer Centre for any reason (diagnosis, new patient consultation, treatment, follow-up) during the course of the concentrated screening effort were eligible to participate in the screening
Psychosocial Questionnaire Questions

Prior to this survey, were you aware that a department exists at the Tom Baker whose purpose is to focus on your emotional and social needs?

☐ YES  ☐ NO

Have you ever used the services of the Psychosocial Resources Department in the past?

☐ YES  ☐ NO

Are you currently using the services of the Psychosocial Resources Department?

☐ YES  ☐ NO

Do you plan to use the services of the Psychosocial Resources Department in the future?

☐ YES  ☐ NO

If you have used the services of the Psychosocial Resources Department, who in your family used the services (check all that apply)?

☐ Myself  ☐ Spouse/partner  ☐ Children  ☐ Other: ____________________________

If you have used the services of the Psychosocial Resources Department, what specific services did you or your family use (check all that apply)?

☐ Individual counselling  ☐ Couples counselling  ☐ Group counselling
☐ Resource/financial counselling  ☐ Other (describe) ____________________________

If you have NOT used the services of the Psychosocial Resources Department, what are some of the reasons you have not done so (check all that apply)?

☐ Didn’t know about it  ☐ I feel that there is a stigma attached to it
☐ Don’t think I need help  ☐ Don’t like the name of the department
☐ Not sure if it could help  ☐ Don’t want to come back to the hospital
☐ Trouble with transportation  ☐ Parking
☐ Too far to travel  ☐ Other (please describe): ____________________________

Whether or not you have used the services of the Psychosocial Resources Department, where are you getting support during your cancer experience (check all that apply)?

☐ Family members  ☐ Friends  ☐ No support
☐ Religious community members  ☐ Outside counsellor
☐ Religious leader  ☐ Neighbours
☐ Other Cancer Centre staff  ☐ Department of Psychosocial Resources

Figure 1  Psychosocial Questionnaire Questions.
RESULTS

Subjects

Questionnaires were collected from 3095 patients over the course of the four weeks of screening. Of these, 319 (approx. 10%) declined to complete the questionnaires. The reasons for this include the following: not interested (43.5% of decliners), cannot read English (13.2%), feeling too sick (11%), too rushed (10.7%), too tired (6.6%), and other (15.4%). This left a sample of 2776 patients (90%) who completed the questionnaires. The statistics kept by the TBCC for visits in the month of January indicated that there were 750 new patient visits, and 3015 follow-up visits, for a total of 3765 patient visits. This would indicate that we captured 82.2% of all patients, with full data on 73.7%. However, these numbers may be conservative estimates, as the statistics report visits, not individual patients. Therefore, if a patient visited more than once during the month, each visit would be recorded as a separate statistic.

Demographic characteristics of the sample are presented in Table 1. The sample was 52.2% of female subjects, an average age of 60 years, with mean levels of 13 years education, and 3 years postdiagnosis. They were primarily from European, British, or Canadian origins (78.3%), and income was fairly equally distributed, with 41.8% earning less than $40 000 per year, 29.2% between $40 and $80 thousand, and 18% earning over $80 000.

In terms of cancer type, the largest group was breast cancer (23.5%), followed by prostate (16.9%), colorectal (7.5%), and lung (5.8%). Most other types of cancer were also represented, as summarised in Table 2. The primary reason for the visit was identified as follow-up in 51.9% of the cases, with tests (10.9%), chemotherapy (9.6%), and radiotherapy (9.0%) being the next most common. 7.7% of patients were at the Centre for their first visit, and the remainder were either picking up medication (1.6%), or did not check off a reason for the visit, and the remainder were either picking up medication (1.6%), or did not check off a reason for the visit (0.7%).

Table 1. Demographics

| Mean (years) | s.d. |
|-------------|-----|
| Age         | 60.00 | 14.69 |
| Education   | 13.18 | 3.42 |
| Duration of illness | 3.26 | 4.59 |

| Number | Valid percentage |
|--------|------------------|
| Gender |                  |
| Female | 1451             | 52.2 |
| Ethnicity |                |
| European | 896             | 28.3 |
| Canadian | 703             | 22.4 |
| British | 571              | 18.2 |
| E and SE Asian | 121 | 4.0 |
| Aboriginal | 31              | 1.1 |
| South Asian | 27              | 1.0 |
| Ethnicity missing | 349 | 12.6 |
| Ethnicity other | 74              | 2.7 |

| Income | Mean (years) | s.d. |
|--------|--------------|-----|
| <10000 | 145          | 5.2 |
| 10000–20000 | 354 | 12.8 |
| 20000–40000 | 659 | 23.8 |
| 40000–60000 | 493 | 17.8 |
| 60000–80000 | 316 | 11.4 |
| 80000–100000 | 203 | 7.3 |
| <100000 | 296          | 10.7 |
| Missing | 306          | 11.0 |

Distress

The mean scores for the three subscales and the GSI on the BSI-18 are presented in Table 3. The mean scores as well as the percentage of each group meeting the criteria for ‘caseness’ are displayed. Overall, close to 38% of the entire sample met the caseness criteria for Global Severity, with some variations in the prevalence of each subscale such that overall somatisation was the most common (39.7%), followed by depression (36.3%), and anxiety (30.3%). Men were more likely than women to be cases of somatisation ($\chi^2 = 5.85, P < 0.05$), whereas women were more likely to be cases of depression ($\chi^2 = 13.64, P < 0.001$). No gender differences in anxiety or the overall severity were found.

Further investigation of distress levels by ethnicity, income, type of cancer, and reason for visit are presented in Table 4. For these analyses, continuous GSI scores were compared between the categorical groups using ANOVA. Patients representing minority ethnicities were more distressed than those of Canadian/British/European descent ($F = 27.98, P < 0.001$), as were those from lower income households ($F = 24.63, P < 0.001$). Patients with prostate cancer were less distressed than patients with breast cancer ($P < 0.001$) and patients with other diagnoses ($P < 0.001$; overall $F = 35.32$), and those on active treatment were more distressed than those on follow-up treatment ($F = 3.72, P < 0.05$).
The most frequent problem endorsed was fatigue (48.5%), followed by the BSI-18 from the Johns Hopkins Oncology Centre as published by Zabora et al. (2001a) TBCC, highly significant in a positive Pearson product–moment correlation coefficient between Johns Hopkins and Tom Baker values. Distress comparisons by disease site showed that prostate cancers had the lowest levels of distress, followed by a cluster containing pancreatic, Hodgkin’s lymphoma, brain, head and neck, leukaemia, and lymphoma. The cluster of diagnoses with the lowest levels of distress included gynaecological, breast, melanoma, colon and prostate cancers.

Common problems
The top problems endorsed by patients are depicted in Figure 2. The most frequent problem endorsed was fatigue (48.5%), followed by emotions/stress (24.8%), depression (24.0%), and anxiety (24.0%). The modal number of problems endorsed by patients was 3, and the correlation between number of problems endorsed and BSI-18 GSI score was $r = 0.57$, $P < 0.001$.

Awareness and use of psychosocial resources
When asked if they were aware of the existence of a specific department whose purpose was to address the emotional and social needs of patients, 68.1% indicated awareness of such a department. When looked at by reason for visit, more patients on active treatment (72.1%), and follow-up (73.9%), than those on their first visit (49.8%) were aware of the Psychosocial Resources Department. When asked if they were aware of the existence of a specific department whose purpose was to address the emotional and social needs of patients, 68.1% indicated awareness of such a department. When looked at by reason for visit, more patients on active treatment (72.1%), and follow-up (73.9%), than those on their first visit (49.8%) were aware of the Psychosocial Resources Department. When asked if they were aware of the existence of a specific department whose purpose was to address the emotional and social needs of patients, 68.1% indicated awareness of such a department. When looked at by reason for visit, more patients on active treatment (72.1%), and follow-up (73.9%), than those on their first visit (49.8%) were aware of the Psychosocial Resources Department.
Distress was also related to demographic characteristics including younger age, female gender, minority ethnicity, lower income, longer duration of illness, and being on active treatment or newly diagnosed. These latter two items may appear to be in opposition to one another: that is, having a new cancer diagnosis and/or being on active treatment would imply a shorter duration of illness, yet longer duration of illness was also independently predictive of higher distress. This may be consistent with a U-shaped distress curve over the course of the disease continuum, with higher levels of distress around the time of diagnosis, which abate somewhat following active treatment, but may rise as time goes by (Hanson et al., 2000). The duration of illness variable may serve as a marker for disease recurrence or progression, as it is less likely that patients who of the idea of distress has begun, that is visiting the centre in large numbers. Unfortunately, accurate data on disease stage with which to verify this possibility is not available. This would be consistent with another study that found lower quality of life scores in palliative patients, compared to those in other stages of the disease continuum (Zabora et al., 1997).

However, although quality of life was worse in these palliative patients, this study did not find significant differences in overall distress across the disease trajectory.

Previous reports indicate that younger patients may suffer higher levels of distress (Wenzel et al., 1999; Carlson and Bultz, 2002), theorised to be due to a larger disruption of social and familial roles at earlier developmental stages, such as raising small children and establishing careers. It may also be perceived as less 'fair' for a younger person to be struck by cancer, thereby causing additional distress. As well, patients at earlier life stages may have more limited life experience and problem-solving skills related to such a traumatic event. Similarly, historically socially disadvantaged groups such as women, minorities, and lower income earners also report higher distress levels as in this sample, perhaps illustrating that dealing with cancer involves more challenges for these groups. However, it is also possible that these disadvantaged groups would report higher distress levels in the general public as well, suggesting that a cancer diagnosis may add to an already heightened level of distress.

The high level of fatigue in this sample was also noteworthy, with almost half of all patients reporting fatigue as a problem. This is also consistent with other studies, and fatigue is beginning to be reviewed as a major and long-term consequence of cancer and its treatment (Hann et al., 1997; Hann et al., 1999; Knobel et al., 2000; Okuyama et al., 2001). Of note is that almost half of all patients who were identified as suffering significant distress had not used psychosocial resources in the past or present, and did not intend to use the services in the future, which may not translate into actual use. It may also mean that the screening programme gave them information about psychosocial services they otherwise would not have had until later in their treatment.

Finally, the relationship of distress caseness to psychosocial use was investigated. Of interest is that almost half of all patients identified as suffering significant distress levels on the BSI-18 have not used psychosocial resources in the past or present, and do not intend to use the services in the future. This percentage is highest for cases of somatisation (50.5% of cases not using psychosocial), followed by depression (42.5%) and anxiety (41.7%).

Interestingly, the rate of endorsement of using psychosocial resources was higher in those attending for their first visit (45.1% of those who indicated past, present, or future use), compared to an even distribution of about 37 – 40% of those both receiving and not receiving support from family, friends, and community members being identified as cases. This would seem to indicate that a greater proportion of those experiencing the most distress seek out professional, rather than community support. Nonetheless, even within this group, some 50% of the distress cases do not seek professional support.

DISCUSSION

This study confirmed that a significant proportion of a large representative sample of diagnostically heterogeneous cancer patients self-reported clinical levels of distress, including anxiety and depression, across the disease continuum. Patients in this sample also reported high levels of fatigue and pain. A critical finding is that over one-third of all patients, whether currently in treatment or on long-term follow-up, continued to report significant levels of distress. This magnitude of distress is very similar to other reports, and also similar in terms of distress levels within different cancer diagnoses (Zabora et al., 2001a). The most distressed groups of patients included lung, pancreatic, Hodgkin’s lymphoma, brain, head and neck, leukemia, and lymphoma patients.

There are certain methodological advantages that make this study unique. First, we managed to capture over 80% of eligible patients who passed through the centre over the designated time period (and perhaps more), which bolsters the generalisability of these results. The sample included a heterogeneous group of patients both in terms of type of cancer, and in terms of time since diagnosis and treatment phase, thus allowing direct comparisons between diagnoses and treatment phases. One of the major limitations of this study is its cross-sectional nature. It is not possible to draw any causal conclusions from the data, or to get a sense of how the same patients would fare prospectively as they...
moved from newly diagnosed onwards. Also, although relevant to a Canadian population, the generalisability of this data to other countries is not known. However, the similarities between this data and other reports from the USA and Europe help to bolster confidence in its universality.

The data also suggest that more needs to be done to change the face of clinical oncology practice when it comes to treating issues around emotional distress. It has been suggested that distress should be considered the ‘6th Vital Sign’, after blood pressure, temperature, respiration, pulse, and pain. This push could lead to more routine consideration of distress, in the same manner the pain community has raised awareness by referring to it as the ‘5th vital sign’. The NCCN has worked to develop distress screening and treatment guidelines, as outlined in the introduction, but the challenge now is to facilitate the implementation of screening and triage into routine clinical care. Some models have been successfully utilised in research settings including the use of computerised questionnaires, often web-based or using hand-held PDAs. The data supporting the feasibility of computer-based technology is convincing, in terms of its reliability, acceptability to patients, and utility in improving clinical care around psychosocial issues (Taenzer et al., 1997; Velikova et al., 1999; Taenzer et al., 2000; McLachlan et al., 2001; Carlson et al., 2001; Bezjak et al., 2001). This may be one avenue well worth pursuing in the effort to ensure that all patients are screened and appropriately referred for treatment of the distress that so commonly accompanies cancer diagnosis and treatment.

Treatment models themselves may also have to change in face of the patient profile that may result from the implementation of routine screening. With more broad-based screening efforts and less self-referral, the demographic may shift from primarily articulate, socially competent female patients towards those who are less verbal with fewer social skills, addiction histories, or compliance problems, who may not have sought out psychosocial support otherwise. The caseload may also shift from primarily women towards a more even balance of men and women, and more head and neck cancer patients. This patient population may not respond as well to the traditional ‘talk therapy’ often used to treat cancer-related distress, and be more amenable to behavioural and problem-solving interventions. Thus, the model of changing care may well look like the stages model suggested by Cunningham, who has identified a hierarchy of different types of group therapy, based on increasingly active participation by the recipient. The five types are described as: providing information, emotional support, behavioural training in coping skills, psychotherapy, and finally spiritual/existential therapy (Cunningham, 1995). Thus, a patient could begin by attending a large-group format psychoeducational workshop, and seek further intensive therapy if necessary, at their discretion.

This study serves to highlight a problem that has by now been well documented, and begs further directions and innovations in distress treatment. The best solution may be a marriage between appropriate screening using versatile technology, and programmatic assessment and triage at critical times during the cancer experience. If this can be integrated with a range of empirically based psychosocial treatment options, the most efficient and efficacious model of patient care is likely to result.

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