ORIGINAL ARTICLE

Assessment of palliative care cancer patients' most important concerns

Walter F. Baile · J. Lynn Palmer · Eduardo Bruera · Patricia A. Parker

Abstract

Aims Patients in the palliative care setting have a number of concerns not necessarily connected to their medical problems, such as spiritual and relationship issues. When these problems are not properly assessed and addressed, they may become a significant source of distress for patients and families. The aims of the present study were to assess the concerns of patients attending a palliative care clinic, to examine physicians' ratings of patient concerns, to access the concordance between patients' and physicians' ratings, and to assess the association between patients' concerns and their level of distress.

Methods We evaluated 137 patients attending a symptom control and palliative care clinic. Patients completed the Concerns Checklist, Hospital Anxiety and Depression Scale, and Cancer Behavior Inventory at the beginning of their visit. The Concerns Checklist was completed by the patient's clinic physician immediately after the visit and was used to estimate how accurate the physician was in identifying patients' concerns. We examined the correlation between the total number of patient concerns and their levels of anxiety, mood disturbance, and self-efficacy.

Results Patients were most concerned about loss of function, the future, and caring for themselves. Concordance between physician and patient rating of concerns was poor (all kappas, 0.26 or lower). Higher levels of patient concerns were associated with greater anxiety ($r=0.52$) and depressive symptoms ($r=0.40$) and lower self-efficacy ($r=-0.37$).

Conclusions There was generally poor concordance between patients reporting of their concerns and physicians reporting of the patients' concerns. In addition, patients' with more concerns also had higher levels of anxiety and depressive symptoms. Thus, it is important to find strategies to more accurately identify patients' concerns, so that they can be adequately addressed.

Keywords Palliative care · Concerns · Assessment

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The impact of advanced cancer on patients' quality of life, information needs, and psychological distress has been well documented [22, 27, 34, 37, 50, 51]. For example, Kutner et al. [25], in a study of 78 terminally ill patients, identified seven key issues for patients that were broad in scope and included both the physical dimension of illness such as pain and psychosocial concerns such as role change and financial burden. In another study of 120 patients with advanced cancer [16], patients reported a wide range of cancer-related concerns including concerns about spiritual, familial, physical, and emotional issues. While oncologists have shown an interest in having more information about their patients' well-being in non-medical areas of their lives, they are naturally focused principally on the complex

medical problems inherent in oncology visits [45]. Meanwhile, patients are often reluctant to bring up psychosocial issues or concerns that trouble them [13, 14]. For this reason, illness and lifestyle-related concerns often go unaddressed during the routine oncology visit [18, 35]. A number of patients in the study of Greisinger et al. [16], for example, indicated that although their disease was assessed and re-assessed during their illness, the non-medical issues causing distress were rarely a focus of their care. In this regard, Hancock et al. [17], in a recent review on the topic of providing end of life and prognostic information to patients with advanced disease including cancer patients, concluded that physicians tended to underestimate the information needs of patients and that physicians often did not provide needed information unless patients asked for it. Finally, a study of 61 cancer patients and 19 cancer center health professionals found that issues patients want help with may not be the same issues that health professionals feel are most important to patients [41].

These findings are important because when patients lack information, or have issues which go unresolved, it can lead to distress including clinical anxiety and depression [12, 35, 49]. For example, Parle et al. [35] showed that newly diagnosed cancer patients with higher concern scores were more likely to develop a clinical anxiety or depressive disorder within 3 months subsequent to diagnosis. Heaven and Maguire [19] reported a significant association between advanced cancer patient concerns (including non-medical concerns such as loss of independence and family issues) and their scores on the Hospital Anxiety and Depression Scale. Other studies have shown that patients' unmet needs and specific worries can also affect patient satisfaction with the clinical encounter, impact patient compliance, and impede the ability to cope with the demands of cancer treatment [6, 42]. Thus, addressing patients' concerns is an important component of providing support to the patient and family and potentially reducing distress.

Foley [15], one of the pioneers of palliative care movement clearly articulated the comprehensive goals of palliative care: "Palliative care provides the infrastructure of care where current knowledge of symptom management, psychological and spiritual care and family support can be applied to improve the quality of living for patients and families." This call has been echoed in the National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care [3], The Institute of Medicine report on Improving Care at the End of Life [1] and is also incorporated into recommendations of the American Society of Clinical Oncology Task Force on End of Life Care [2].

Recent efforts have focused on having patients' complete symptom and quality of life questionnaires and giving this information to clinicians with the goal of promoting discussion of major areas of impairment [23, 46]. The results of these studies have found that receiving feedback about patients' symptoms and quality of life increased physician–patient communication around specific quality of life areas in general, but providing feedback to clinicians did not increase patients' satisfaction with the clinical encounter [12, 47]. This may be explained by the fact that quality of life measures focus on either general domains of functioning or specific symptoms such as pain and anxiety but do not relate these to specific patient concerns such as lack of support from family or friends or the amount of information patients have about aspects of the illness compared to what they desire [11, 24, 48].

The distress associated with the concerns of cancer patients has been a topic of a task force of the National Cancer Center Network, which recommends screening for patient distress [4, 14]. Global assessments of distress have been developed that can accurately identify patients who are most distressed so that they can be referred to appropriate psychosocial interventions [9, 10, 51]. Pinpointing specific patient concerns, which can then be appropriately addressed in the clinical encounter, is a first step in addressing patient distress. In order to enhance the argument for screening, it would be useful to know how well physicians detect cues about patients' concerns and are able to accurately identify them. While there are some data on this indicating that physicians may be inaccurate in their assessment of patients' most important concerns [13, 14], additional information is needed especially in the palliative care setting. The aims of the present study were to assess the concerns of patients attending a palliative care clinic, to examine physicians' ratings of patient concerns and the concordance between patients' and physicians' ratings, and to assess the association between patients' concerns and their level of distress.

Methods

Patients

The study population consisted of patients attending the outpatient symptom control and palliative care (SPC) clinic. Participants were eligible for this study if they were at least 18 years of age, were diagnosed with cancer, and were able to speak and read English fluently. Participants were excluded if they displayed any signs of cognitive impairment in relation to person, place, or time.

Procedures

A trained research assistant recruited patients awaiting a consultation in the SPC just prior to their clinic visit in the

waiting area. The study was described and, if interested, verbal and written consent was obtained. The study was approved by the Institutional Review Board of The University of Texas M. D. Anderson Cancer Center.

At the beginning of the visit, prior to being seen by the physician, patients completed the Concerns Checklist (CCL), the Hospital Anxiety and Depression Scale (HADS), and the Cancer Behavior Inventory—Brief Form (CBI-B). After the visit, the attending physician completed a physician version of the CCL, identifying which issues he/she thought were important concerns for the patient, based on the interaction with the patient during the visit.

Assessment measures

Demographic and medical variables Each participant completed a demographic and information questionnaire. Demographic information included age, ethnicity, marital status, gender, educational background, and occupation. Medical variables included the following: when cancer was diagnosed, type of cancer, forms of treatment, and information on other major medical illnesses. Information on patients' medical histories, such as the stage of cancer, was extracted from patients' charts.

Concerns checklist [33]

The CCL is a 15-item instrument designed specifically for use with palliative care cancer patients in outpatient clinics. Several studies have demonstrated the psychometric properties of this measure [28]. The revised version of the CCL has also demonstrated satisfactory construct validity and reliability in a study of 180 cancer patients shortly after initial treatment for cancer [28]. The checklist allows patients to rate the degree of worry on a 0 (not at all) to 3 (very much) scale, as to how much each concern or item on the scale is troubling to the patient over the past week. There are 11 items listed and 4 lines for patients to add additional concerns. Thus, each concern or item generates a score from 0 to 3, and for this study, we calculated a total score by summing the first 11 items. In a recent paper by Lidstone et al. [28] that assessed the concerns of 480 cancer patients, the mean number of symptoms/concerns reported was 10.2 with a standard deviation of 5.8. Higher total scores were associated with more advanced disease, a diagnosis of lung or brain cancer, and female gender. Four of the six items, which were endorsed by more than 50% of the population, were psychosocial in nature. Categories receiving higher concerns scores were "worries or concerns about the future" (32%), "worries or concerns about important people in your life" (21%), "caring for yourself" (18%), and "the way that doctors/nurses communicate with you" (11%).

Hospital anxiety and depression scale

The HADS [52] is a 14-item questionnaire, which screens for anxiety and depression in a hospital medical outpatient setting. This scale has been widely used and is well validated for use with cancer patients [5, 21, 32, 39, 40]. There are separate subscales for anxiety and depression, each composed of seven items. Each item is scored on a 0 to 3 scale, from "not at all" to "most of the time". For each construct, a score below 8 is in the normal range, 8–10 is borderline, and above 10 indicates a probable disorder of the relevant mood. In a recent study of 1,474 cancer patients, the mean score on the anxiety subscale was 6.06 (standard deviation (SD)=4.03)) with a range between 0 and 21, and on the depression subscale, it was 4.61 (SD= 3.93) with a range between 0 and 20 [40]. The Cronbach's alpha for the two subscales is 0.89. The HADS has been widely used in medical settings, and its items have been selected to reflect emotional disturbance rather than physical symptoms associated with disease.

Cancer behavior inventory version 2.0 (brief version)

The CBI-B [30, 31, 36] was used to measure patients' self-efficacy for coping with their cancer. The CBI-B consists of 14 items. The short form was derived from the original CBI, which has 33 items. Cronbach's alpha for the entire CBI was 0.94 and the test–retest reliability coefficient was 0.74. The short form has been shown to be internally consistent (r=0.85) [31]. It has been shown to be associated with measures of quality of life and coping. The individual items are summed to yield a total score.

Statistical considerations

Initially, descriptive analyses of study variables were conducted. We then assessed the level of agreement between the patient and physician ratings of the patients' concerns by calculating a kappa statistic for each of the 11 items on the concern checklist. A kappa value of greater than 0.60 is generally considered acceptable [26]. Finally, we examined the correlation between the total number of concerns patients had and their levels of anxiety, depression, and self-efficacy using Spearman correlation coefficients because the data did not appear normally distributed. SAS software (SAS Institute Inc., Version 9.1, Cary, NC, USA) was used for all calculations.

Results

One hundred thirty-seven patients participated in the study. The demographic and medical characteristics of the sample

are summarized in Table 1. Fifty-five percent were male, and the average age was 58.8 years (SD=13.1; range=21.1 to 88.7 years). The majority of patients were Caucasian (68%). Sixty-five percent of patients were married, and 40% had a college degree or higher. Patients had a variety of cancer diagnoses with the most common being pulmonary (26%), gastrointestinal (26%), or genitourinary (20%). All patients had metastatic disease.

Descriptive information on the measures of concerns, anxiety and depression, and self-efficacy is presented in Table 2. Patients indicated that they were most concerned about: (1) not being able to do their usual activities, (2) the future, and (3) about caring for themselves. Areas in which they reported being least concerned about included (1) not getting enough support from others and (2) spiritual/religious issues.

Table 1 Demographic and medical characteristics

Characteristics	Mean (SD) or percentage
Age in years, mean (SD)	60.9 (5.9)
Gender (%)	
Male	55
Female	45
Ethnicity (%)	
White	68
African American	20
Hispanic/Latino	10
Asian	2
Marital status (%)	
Married/living with partner	65
Divorced/separated	17
Widowed	10
Never married	9
Education (%)	
High school or less	33
Some college	27
College graduate	15
Some graduate/professional school	9
Graduate/professional degree	16
Cancer type (%)	
Pulmonary	26
Gastrointestinal	19
Genitourinary	15
Gynecologic	10
Breast	10
Melanoma/skin	8
Lymphoma	4
Head and neck	3
Other	5

The mean HADS anxiety score for the sample was 6.9 (SD=4.2) with 42% scoring 8 or higher, indicating the possible presence of potentially significant anxiety symptomatology. The mean HADS depression score for the sample was 7.0 (SD=4.1) with 44% scoring 8 or above, indicating the presence of potentially significant depressive symptomatology.

The physicians rated patients as having most concerns about (1) the future, (2) not being able to do usual activities, and (3) treatment, and they believed patients had fewest concerns about (1) intimate/sexual relationships and (2) spiritual/religious issues. As can be seen in Fig. 1, physicians generally reported that the patients had more concerns in each of the areas than patients reported.

Concordance between patients and physicians ratings of patients' concerns

We examined the concordance between patients and their physicians' rating of the patients' concerns by calculating a kappa coefficient for the patients' and the physicians' ratings on each of the 11 items. As can be seen in Table 2, the concordance between patients' and physicians' ratings was generally low, indicating no significant agreement between doctor and patient ratings. The highest concordance was items related to concerns patients had about the future (kappa=0.26) and caring for themselves (kappa=0.21).

Association between patients' concerns, depression, anxiety, and self-efficacy

Patients who reported having more concerns also reported more symptoms of anxiety ($r=0.52$) and depression ($r=0.40$). In addition, patients who reported having more concerns on the CCL reported lower self-efficacy ($r=-0.37$).

Discussion

This paper sought to examine patients' concerns and to explore the relationship between palliative care patient concerns as measured by a standardized concerns checklist and a number of variables including anxiety, depressive symptoms, and self-efficacy. We also examined the concordance with their doctor's ratings using the same concerns checklist. We found that physicians tended to significantly overestimate almost every concern the patient reported except that of "caring for yourself" and worries about "the future" for which we found a significant concordance between patient and physician reports. Although these two items were statistically significant,

Table 2 Descriptive information on the measures of concerns, anxiety and depression, and self-efficacy

Concern	Patient (SD)	Doctor (SD)	kappa	p value
Needing more information about illness/treatment	1.04 (1.06)	1.66 (0.95)	0.11	0.150
Doctor's communication with you	1.00 (1.15)	1.59 (0.94)	0.09	0.268
Anything about treatment	1.37 (1.06)	1.89 (0.86)	0.07	0.405
Not being able to do usual activities	1.83 (1.02)	2.07 (0.85)	0.16	0.086
Caring for yourself	1.41 (1.13)	1.78 (0.87)	0.21	0.022
Not getting enough support from others	0.54 (0.93)	1.17 (0.84)	0.09	0.268
Relationships with significant others	0.76 (1.09)	1.33 (0.91)	0.01	0.875
About appearance	0.83 (0.94)	1.38 (0.78)	0.09	0.253
Intimate/sexual relationship	0.94 (1.09)	0.97 (0.82)	0.11	0.478
Spiritual/religious issues	0.57 (0.94)	1.06 (0.73)	−0.06	0.469
The future	1.55 (1.11)	2.11 (0.83)	0.26	0.001

p values ≤0.05 indicate significant agreement between doctor and patient

concordance was still quite low. Previous research by our group has found that palliative care specialists had a trend to underestimate the severity of symptoms reported by patients using the Edmonton Symptom Assessment System [33]. The reason for this consistent overestimation of the importance of different concerns needs to be determined in future prospective studies. These studies should ideally include a qualitative component in an effort to better determine the reasons for scoring concerns at a certain level of intensity by both patient and physicians. The findings of overrating are generally reassuring since these are more likely to result in efforts to refer patients for interdisciplinary care as compared to under rating of symptoms and/or concerns.

The association between frequency and severity of expression of concerns and patients' scores on anxiety, depression, and self-efficacy suggests that patients who consistently expressed multiple concerns should be assessed for anxiety and depression and treated accordingly.
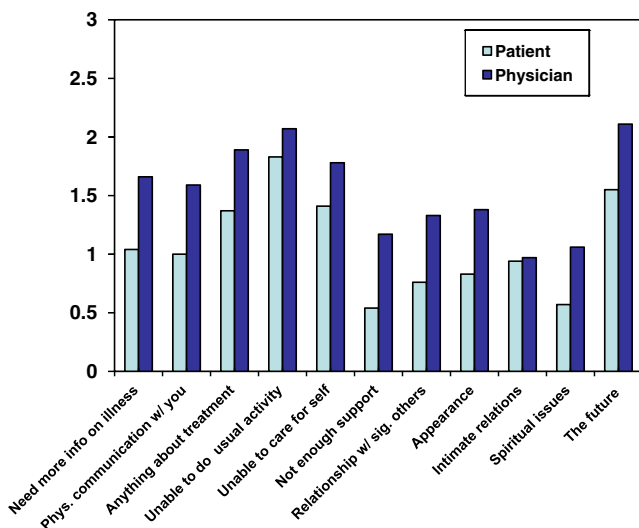

Fig. 1 Mean ratings of concerns by the patients and their physicians

Maguire [29] noted that the failure of health professionals to detect anxiety and depression is paralleled by their inability to detect patient concerns. This is borne out in the study by Parle et al. [35], in which only 40% of newly diagnosed cancer patient concerns will have been disclosed in the following year. In our study, concordance was lowest between concerns about relationships with significant others and spiritual/religious issues. This finding was not reassuring since these two concerns ranked high on patient ratings of importance to them. This is important because in palliative care a common model used is for the physician to act as a gatekeeper for patient distress in that they are typically the ones to bring in other members of the cancer team such as chaplaincy, social work, or psychology when needed. Thus, the ability of physicians to accurately identify most pressing patient concerns may be an important prerequisite to effective resource utilization. Variation in what matters most indicated to them that "customized" or individualized approaches to providing end of life care be adapted [20].

The method we used to determine concordance was to give the physician a checklist similar to the patient's and ask him/her to estimate the amount of concern about each item on the checklist. Because physicians completed the checklist after each visit, the data required him/her to remember the discussions with the patient which, in a busy clinic may not be easily recorded. On the other hand, it is possible that neither the patient nor the physician initiated a conversation about a particular concern leading to a "blind estimate" on the part of the doctor. For the most part, physicians "overshot" their assessment of what preoccupied patients on a number of common stressors that patients have. One could argue that this was an educated guess in which the physician eared on the side of giving concern more importance than it actually had. To determine this would have required additional exploration, for example, recording the consultation meetings in order to evaluate whether the concerns were discussed.

The utility of a concerns checklist is that it may allow specific concerns to be more accurately pinpointed and potentially addressed. Steinhauser and colleagues [43] found that patient ratings of what is important to them may not only be very different from their doctors but also from family members and other caregivers. Patients who reported more concerns also self-reported more anxiety and depression. This can be explained by the fact that patients who face more difficult challenges are likely to feel more overwhelmed and depressed. On the other hand, patients with anxiety and depression may be less likely to cope with the challenges they face with advanced cancer, making identification of these patients important since resources can be directed their way or direct treatment of their depression and/or anxiety could be initiated.

Our findings and those from other studies suggest that patient assessment conducted by a palliative care specialist may fail to detect issues that are important to advanced cancer patients. The patient's reluctance to disclose, the fear on the part of the clinician of opening a "Pandora's Box" of problems, lack of training, and the hectic nature of the clinic environment may all conspire toward producing this outcome. Having patients complete psychosocial and spiritual assessments in addition to the traditional physician/nurse model is a possible way to identify and help manage the multiple and complex issues associated with progressive incurable illness. Some pilot studies have been conducted with these clinics where patients undergo an assessment by multiple disciplines in one visit [8, 44]. Some studies have also showed that the utility of checklists as a screening tool for patients with cancer is feasible. In one study [38], investigators showed that most patient concerns could be provided with enhanced information, although many of these patients had early stage cancer and may have been facing different concerns from patients with more advanced disease. Butow and colleagues showed that when physicians are actively involved in addressing patient concerns presented to them on a prompt sheet, this actually reduced the length of the patient visit compared with those who did not previously list concerns and increased the frequency with which patients discuss the important area of the outcomes of their cancer [7].

Some limitations of the current study should be noted. First, this study was conducted at a specialized cancer center and therefore the patient sample may differ from patients who are treated in community hospitals or other settings. All of these patients had metastatic disease and the extent and type of concerns of patients with early stage disease the ability for physicians to accurately identify early stage patients' concerns may differ and warrants future study. Additionally, the sample was largely Caucasian (68%), and therefore, the results may not generalize other ethnic groups. Patients in this sample may also have more financial resources and thus perhaps better

support that allows them to travel long distances to receive care. In addition, because this study was cross-sectional, it is not possible to evaluate the causal relationship between patients' concern and their distress. It may be, for example, that patients who are more distressed report more concerns or alternatively that having more concerns leads to greater distress. A prospective design would more definitively determine the nature of these relationships. Future research is also needed to identify to what extent concerns are discussed during oncology visits and whether discussion of concerns leads to more concerns being addressed or resolved.

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