

Identifying the Psychosocial Needs of Individuals with Cancer

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Le diagnostic et le traitement du cancer engendrent des besoins psychosociaux que les malades ont souvent du mal à satisfaire. Étant donné que la plupart des évaluations de besoins ne dépassent pas l'énumération des besoins afin d'examiner les barrières à franchir, les soutiens sociaux actuels ou les préférences des malades par rapport aux services, nous avons entrepris de faire l'inventaire de l'évaluation des besoins afin d'atteindre ces objectifs. La première étape a consisté à établir les catégories de besoins, en utilisant une méthodologie qualitative. Les buts de la recherche présentés dans le présent article sont les suivants : (a) comparer la façon dont le malade et les soignants identifient les besoins psychosociaux du malade; (b) établir les catégories de besoins psychosociaux; (c) vérifier les catégories résultant de l'analyse des données. On a établi vingt-sept catégories de besoins. Il existait des disparités entre les malades et les soignants en hôpital, et entre les soignants des deux centres d'oncologie au niveau de la fréquence où les catégories de besoins étaient citées. Ces disparités soulignent combien il est important de recueillir des renseignements d'après diverses perspectives.

The diagnosis and treatment of cancer creates psychosocial needs that patients often find difficult to resolve. Because most need assessments do not reach beyond enumerating needs to examine barriers to needs resolution, existing social supports or patients' service preferences, we set out to develop a needs assessment inventory to meet these objectives. The first step was to identify need categories using a qualitative methodology. The aims of the research presented in this paper are to: (a) compare patients' and professional caregivers' identification of patients' psychosocial needs, (b) establish categories of psychosocial needs, and (c) verify the categories resulting from the analysis of the data. Twenty-seven need categories were identified. There was a lack of congruency between patients and hospital caregivers and between caregivers at the two cancer centres in the frequencies with which the need categories were cited. The incongruence underscores the importance of gathering information from more than one perspective.

The diagnosis and treatment of cancer creates psychosocial needs that patients often find difficult to cope with and resolve. These needs range from the concrete to the existential. For example, Mor, Allen, Siegel, and Houts (1992) documented the daily living needs of individuals with cancer, while Ganz, Schag, Lee, and Sim (1992) documented their rehabilitation needs.

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The identification of psychosocial needs over the illness trajectory is clinically relevant for a number of reasons. Needs arising from the psychological and social difficulties patients experience are predictive of later affective illness (Haddad & Maguire, 1994), psychiatric morbidity (Parle, Jones, & Maguire, 1994), decreased adherence to therapy (Ali, Khalil, & Yousef, 1993; Dragone, 1990; Mor et al., 1992), coping strategies (Ali et al., 1993), quality of life (Ali et al., 1993; Schag, Heinrich, Aadland, & Ganz, 1990), the ability to seek benefits from the health-care system (Mechanic, 1983; Saunders & Baum, 1992; Waligora-Serafin, McMahon, Pruitt, & Davenport, 1992; Wiggers, O'Donovan, Redman, & Sanson-Fisher, 1990; Wool, Guadagnoli, Thomas, & Mor, 1989), and the outcome of medical care (Gustafson, Taylor, Thompson, & Chesney, 1993; Kiecott-Glaser & Glaser, 1987; Mor, Guadagnoli, & Rosenstein, 1991; Mor, Masterson-Allen, Houts, & Siegel, 1992; Spiegel, Bloom, Kraemer, & Gottheil, 1989).

While it is recognized that individuals with cancer, and their families, can be helped by psychosocial care, it is also recognized that the delivery of this care could be improved (Ballatori et al., 1993; Greer, 1994; Hill, Kellener, & Schumaker, 1992; Siegel, Mesagno, Karus, & Christ, 1992; Spiegel, 1994; Till, 1994; Tope, Ahles, & Silberfarb, 1993). To do so it is important to not only identify the psychosocial needs, but to also understand why needs remain unmet, evaluate current care, and determine preferences for future care. Standardized instruments often lack the specificity required to identify cancer-related problems (Holland, 1984). As well, patients frequently find it difficult to voice their concerns (Frank, 1991; Holland, 1984; Lochman, 1983; Mitchell & Glicksman, 1977; Wool et al., 1989) and busy outpatient and inpatient settings are not conducive to talking about problems (Friedman, Lehane, Weinberg, & Cooper, 1993; Saunders & Baum, 1992). Patients' perceptions of their needs often do not correspond with those of the professional caregivers (Ballatori et al., 1993; Camp & O'Sullivan, 1987; Fernsler, 1986; Lilley, 1987; Longman, Atwood, Sherman, & Benedict, 1992; Mullan & Stross, 1990; Sung, 1989; van Angthoven & Plomp, 1989), and thus services are not used to capacity (Buttram, 1990; Wool et al., 1989). A needs-assessment inventory can help patients articulate their needs.

A search of the available needs-assessment instruments did not locate an ideal tool. We therefore set out to develop an inventory that would not only enumerate patients' psychosocial needs, but also identify the existing sources of social support, barriers to the resolution of needs, and service preferences of patients. This paper will describe the

first stage of our research: the development of a set of psychosocial needs categories.

Purpose

We undertook a two-phase project: a qualitative study designed to establish categories of need, and a quantitative study designed to develop and verify the reliability and validity of an inventory of needs based on cancer patients' problems, concerns, and worries. The development of the needs categories is the focus of this paper. The objectives of Phase I were to: (a) compare psychosocial needs as identified by patients and professional caregivers, (b) establish categories of psychosocial needs, and (c) verify the categories resulting from analysis of the data.

Literature Review

Needs assessment is an obvious, straightforward, and commonsense approach to planning supportive care. Despite the diversity in methods and in the cancer populations studied, commonly cited concerns and problems include: pain, side effects, psychological needs, activities of daily living, self-care concerns, fear of recurrence and death, ability to cope, social interaction, finances and employment, resuming one's personal life, and sexual functioning (Canadian Cancer Society, 1990, 1992; Christ & Siegel, 1990; Friedman et al., 1993; Ganz, Schag, Polinsky, Heinrich, & Flack, 1987; Greer, 1994; Guadagnoli & Mor, 1991; Gustafson et al., 1993; Houts, Yasko, Kahn, Schelzel, & Marconi, 1986; Longman et al., 1992; Pistrang & Barker, 1992; Rapoport, Kreitler, Chaitchik, Algor, & Weissler, 1993; Schag & Heinrich, 1990; Vachon, Lancee, Conway, & Adair, 1990; Waligora-Serafin et al., 1992).

Although a number of needs assessments are available, we were unable to find a tool that (a) was developed for an adult cancer population, (b) elicits needs directly from the patients, (c) differentiates the method of resolving need from the need itself, (d) is comprehensive in its coverage of needs, (e) is valid and reliable and built upon patient-generated definitions, (f) has a manageable number of needs categories and differentiated levels of need, and (g) when possible, identifies barriers to needs resolution and service preferences.

A subset of the instruments developed for an adult cancer population relied on key informants, social indicators, community surveys, and professional judgements (Licitra et al., 1994; Maguire, Faulkner, &

Regnard, 1993; McDonald & Natarajan, 1989; Rust & Kloppenborg, 1990; Wellisch, Fawzy, Landsverk, Pasnau, & Wolcott, 1983). Other tools, while eliciting needs directly from patients, did not differentiate the method of resolving need from the need itself; this includes assessments of both information needs and service needs (Campbell-Forsyth, 1990; Galloway, Bubela, McKibbin, McCay, & Ross, 1993; Gustafson et al., 1993; Harrison-Woermke & Graydon, 1993; Jones, 1992; Mor, Guadagnoli, & Wool, 1987; Volker, 1991; Wolcott, Fawzy, Landsverk, & McCombs, 1986). Relatively few assessments were comprehensive in their coverage of needs; many studies examined subsets of needs such as nutritional, spiritual, self-care, and daily living needs (Bryan, Greger, Miller, Weinberger, & Loehrer, 1991; Chernoff & Ropka, 1988; Clifford & Gruca, 1987; Longman et al., 1992; Mor et al., 1992; Robinson & Posner, 1992; Siegel et al., 1992). In addition, few needs assessments had adequate validity and reliability testing or used samples of sufficient size (Wingate & Lackey, 1989).

Few quality-of-life (QOL) measures (Padilla, Ferrell, Grant, & Rhiner, 1990) and needs assessments are inductively developed from either cancer patients' or caregivers' reports of needs. Although patients are the best source of information, they have trouble expressing their concerns and asking questions. The patient and the caregiver each brings a unique perspective to the evaluation of needs. Without patient input, we work only from our own experience and assumptions, which, research shows, does not always reflect the patient's experience. Padilla and Kirshner (1991) point out, with respect to QOL domains, that it is impossible, without patient-generated definitions, to determine whether available instruments have overlooked critical aspects of care. Health caregivers, from years of experience with a variety of patients, can provide insight into the diversity of needs, and how they change over time, as well as identify needs that patients leave unexpressed. Osoba, Aaronson, and Till (1991) maintain that if a QOL questionnaire is to truly reflect the concerns of patients it must be a cooperative effort between caregivers and patients.

Method

This research used a qualitative design that relied on focus groups of patients and hospital caregivers to elicit information on psychosocial needs. This approach is particularly appropriate when the phenomenon under consideration has not been adequately identified or defined, or when a fresh perspective on a familiar problem is required (Stern,

1980). It allows patients and caregivers to relate their own experiences without having a conceptual framework imposed upon their interpretations.

Gathering the Data: The Nominal Group Technique

Among the several techniques available for collecting information from groups, the nominal group technique (NGT) appeared to be the one best suited to our needs. The NGT, developed by Delbecq and Van de Ven (1971), is a structured group meeting that begins with each individual recording his or her responses to a limited number of open-ended questions. At the end of five to 10 minutes, a structured sharing takes place, involving clarification, discussion, and voting. It has the advantage of being both (a) applicable in situations where individual judgements need to be tapped and combined in an efficient yet effective manner, and (b) sufficiently structured to focus on the generation of needs while minimizing conceptual or methodological biases.

The NGT is an expedient and efficient process for the creative generation of ideas, particularly when a large number of individuals is involved. In addition, the technique encourages maximum feasible participation, and participants are given equal opportunity to contribute to the group discussion. The NGT also involves a search process that assures independent generation of individual ideas unhampered by the reactive process that often confounds interactive groups. The influence of group opinion and dominant personalities can inhibit individual input. However, group discussion based on ideas generated independently of the group can serve to clarify and evaluate a person's ideas and allow the group to precipitate and stimulate ideas. This preserves the balance between task accomplishment and interpersonal social maintenance functions. Nominal groups have been found to be superior to interacting groups in generating information relevant to problem-solving (Delbecq, Van de Ven, & Gustafson, 1986).

Modifying the NGT somewhat, individuals were first asked to respond in writing, without interaction, to a set of open-ended questions. The questions differed slightly for the patient and the caregiver groups. Patients were asked the following two questions:

1. What do you think are the most difficult things about having cancer?
2. What are your concerns?

Hospital caregivers were asked the following questions:

1. What do you think patients find most difficult about having cancer?
2. What are patients' concerns?

The second step was a round-robin recording of the responses to the above questions. Each person was asked for several ideas that were recorded on a flip chart. Group members were allowed to ask only questions to gain additional information or to clarify an idea. After the first round, group participants were asked again, in the same manner, whether they had anything to add. The third step consisted of a serial discussion of the needs listed on the flip chart.

The sessions were conducted in a standardized way. Care was taken to introduce and describe the procedure uniformly to each group. The importance of each person's input was always emphasized. The group leader remained as neutral as possible, offering only points of clarification regarding the process and ensuring that no one participant dominated the discussion; she did not express her own ideas or knowingly offer positive or negative evaluations of the ideas presented. The entire procedure took approximately an hour and a half.

Description of the Groups

The patient groups consisted of outpatients at the Princess Margaret Hospital (PMH) who were staying at the Lodge, an alternative-care facility, situated adjacent to the hospital, for out-of-town ambulatory patients and their immediate families. The Lodge has an 80-bed capacity and the average occupation rate is 85%.

Participation was voluntary and individual written responses were anonymous. Thirty-six patients and one spouse participated — 20 women (including the spouse) and 16 men — in five groups. One individual did not indicate his or her gender. The mean age, for the women, was 57 years, ranging from 36 to 72 years; for the men, 59.5 years, ranging from 31 to 80 years. A variety of cancer sites and types was represented: for the women, bone, brain, colon, breast, stomach, melanoma, leukaemia, head and neck, and gynaecological system; for the men, bone, lung, thyroid, prostate, melanoma, pituitary, and head and neck. For the women, the time elapsed since diagnosis ranged from one month to five years, with a mean of 1.2 years; for the men, from four months to 10 years, with a mean of 2.4 years.

All PMH caregivers who had direct clinical responsibilities or direct contact with patients were invited to participate. The PMH is a cancer centre for both inpatient and ambulatory care. Approximately 5500 new patients are referred for medical and radiation treatment each year. Again, participation was voluntary and the individual written responses were anonymous. Group sessions were conducted with nurses (38.0%), imaging and radiation technicians (12.0%), dental, pharmacy, physiotherapy, respiratory, and nuclear medicine technicians (9.3%), social work and chaplaincy personnel (9.2%), support staff in the departments of medicine and radiation (7.7%), unit coordinators (7.0%), dietitians (4.2%), housekeeping and security personnel (3.5%), and volunteers (3.5%). Twenty-seven groups were formed. Eight physicians (5.6%), from medicine, radiation, and diagnostic imaging, were interviewed individually. Altogether, 142 hospital caregivers participated in this stage of the questionnaire construction.

Data were also collected by means of face-to-face interviews with 51 staff nurses at the Toronto Bayview Regional Cancer Centre (TBRCC), an outpatient referral facility that provides chemotherapy and radiation treatment for approximately 4200 new patients a year. Nurses' oncology experience ranged from two to 15 years. Nurses representing every disease site were interviewed. The question that elicited these data was: "What do you see as the primary problems your patients have to face?"

Analyzing the Data

Content analysis was chosen because it consists of a set of analytical procedures aimed at furthering the understanding of a phenomenon by measuring the frequency, order, or intensity of occurrences of words, phrases, or sentences (Krippendorff, 1980; McLaughlin & Marascuilo, 1990; Weber, 1985). The analysis was carried out using a procedure similar to the one described by Waltz, Strickland, and Lenz (1984) and involved seven steps:

1. The content universe was defined as all the individual responses to the questions and the round-robin group discussion, as recorded on the flip charts. Each word or phrase, written on a questionnaire or recorded on a flip chart, that reflected a patient's concern or problem represented a unit of analysis.

2. All the words or phrases were entered on individual index cards. Separate sets of cards were kept for the questionnaires and the group discussions as recorded on the flip chart. When responses were identical, the frequency was recorded. Responses that were similar, but not identical, were recorded separately. For example, the phrases "fear of death" and "fear of dying" were recorded on separate cards.
3. To address the issue of interrater reliability, the investigators independently categorized the words or phrases recorded from the questionnaires and the flip charts and from the interviews with the TBRCC nurses. Some responses were excluded because they were too general or vague to be classified, or because they did not represent a patients' need but were either a hospital caregivers' need or a barrier to need resolution. Separate analyses were undertaken for patients and each set of hospital caregivers.
4. Based on this initial sorting of the data and a review of the literature, the principal investigators defined the need categories,* then reviewed and resorted the results of the previous step. When consensus could not be achieved, a third party was asked to make a final decision on categorization.
5. Patients' and hospital caregivers' need categories were compared.
6. A set of need categories resulted from the previous steps.
7. Ten health-care professionals were asked to review the need categories and indicate, using a three-point scale, the importance of each need to patients. This group included two nurses, a chaplain, a dietitian, a volunteer, a social worker, a radiation oncologist, a patient education specialist, and the vice-president of patient-care services. The panel members were chosen to reflect the multidisciplinary nature of the supportive care available to patients. All the professional caregivers had extensive clinical oncology experience; none of them had been part of the groups and none of them had been interviewed previously.

This method, as with any method, has its limitations. The lack of random selection of the participants, as well as the difficulty and effort involved in recruiting reasonably large numbers of participants, limits

*Coding list and definitions available from the authors upon request

the generalizability of the findings to the larger populations. The open-ended nature of the responses makes summarization and interpretation difficult. In addition, error can be built in because of bias generated through group interaction and introduced by the group leader, who can unknowingly provide cues as to the desired responses. However, we believe that the NGT, when combined with careful analysis, minimizes error and produces a set of needs categories reflective of patients' psychosocial concerns and problems.

Results

Patient Perspective on Psychosocial Need

Individual patients' descriptions of their psychosocial needs were broken down into 21 categories of needs. The *most* frequently cited needs were: fear of recurrence, fear of the unknown, concerns around treatment efficacy and side effects, cure, fear of death, and acceptance of the illness. The *least* frequently cited were pain, information needs, anger, return to a normal lifestyle, family welfare, and separation from the home and family. Group discussion concurred with the individual responses and also recognized recurrence, fear of the unknown, and treatment as primary patient concerns. A 56-year-old man with head and neck cancer related some of these concerns:

Dealing with the fact. Concerns about it reoccurring. Although I'm told that it is gone and it is five years since the operation, there is a vulnerability of its coming back. Dealing with the post operation and treatment situation seems to be the most bothersome — a lifestyle change. [I] felt my body had let me down.

When asked what was most difficult about having cancer, an elderly man with bone cancer expressed in these few words the courage and isolation that cancer engenders: "Keeping a smile on your face!"

Although concerns over one's emotional reactions to the illness and interactions with the health-care system were described only infrequently by individual patients, they were regarded as important matters in the group discussions. Interactions with the health-care system, in fact, became a heated topic in every group. Many patients were dissatisfied with aspects of their care, particularly at the time of diagnosis. A woman with head and neck cancer recounted her problems around diagnosis: "My dentist did not come back after I complained about the symptoms. A second opinion gave the diagnosis.

It took two years to make the diagnosis." A 36-year-old mother with leukaemia voiced her concerns:

People don't understand what you are going through. You have to go through it alone — "inside." Not being able to do the things you used to do for yourself and having to ask all the time for help and not being able to get help or not getting enough help. Having the people at the community cancer society or any other agency try to solve the problems you are having [and] not leave it on your lap but to do the "leg work" for you in trying to solve any problems and not stopping until it is solved.

Not everyone, however, was negative. While the wife of a patient with prostate and bone cancer related some of her difficulties coping,

Immediate family are in a form of denial and think I am superwoman. They are having a hard time to accept [the cancer] and I, wife of a cancer patient, am trying to understand and sort it out,

she also made positive mention of the health-care system:

[We] have had a lot of stress, frustrations and run around. It is a great inspiration from the Princess Margaret Hospital to want to help. I would like to help other people who don't know what is available to them just from what my husband and I experienced.

Caregiver Perspective on Psychosocial Need

The caregiver perspective comes from two cancer centres, the PMH and the TBRCC. Caregivers at the PMH most frequently identified the following as patients' needs: finances and employment, treatment concerns, fear of the unknown, and family adjustment. They infrequently mentioned cure, return to a normal life, existential concerns, social roles, anger, nutrition, and hope.

A physician offered an eloquent description of patients' fears: "The primary problem a cancer patient faces is the initial confrontation with one's own death and later the confrontation with physical disability and the desperate attempt to put life in order." His voice was echoed by a nurse: "Although life is uncertain, uncertainty becomes more realistic and this then spells disaster for them."

Identifying the Psychosocial Needs of Individuals with Cancer

Group discussion of caregivers' individual perspectives on patient need resulted in a different ordering of patient needs. Although both individual responses and group discussion frequently recognized finances and employment, fear of the unknown, and family adjustment as patient concerns, group discussion placed greater emphasis on family welfare, information needs, change in body image, stigma, and fear of death than did the individual caregiver responses. Many caregivers were acutely aware of patients' concerns for their families, as expressed by these comments:

Providing for/caring for a loved one in spite of illness or impending death.

Explaining to the family and having them accept the implications of the disease.

The whole family is upside down. In some cultures, family do not want to talk about the cancer with the patient.

Nurses at the TBRCC most frequently cited information needs, emotional responses, and treatment concerns as patient needs. One nurse remarked, "Patients need information about what they can hope for." Another commented, "They have no information to work with. They can't even formulate the questions when they get here." Other nurses discussed the emotional consequences of cancer:

Confusion. The patient is faced with so many things and they have to make a decision. Emotions can interfere with making a decision. It is hard to concentrate, to make a decision.

The big thing is they have to learn to live with the chronic aspects of it — take medication for the rest of their lives.

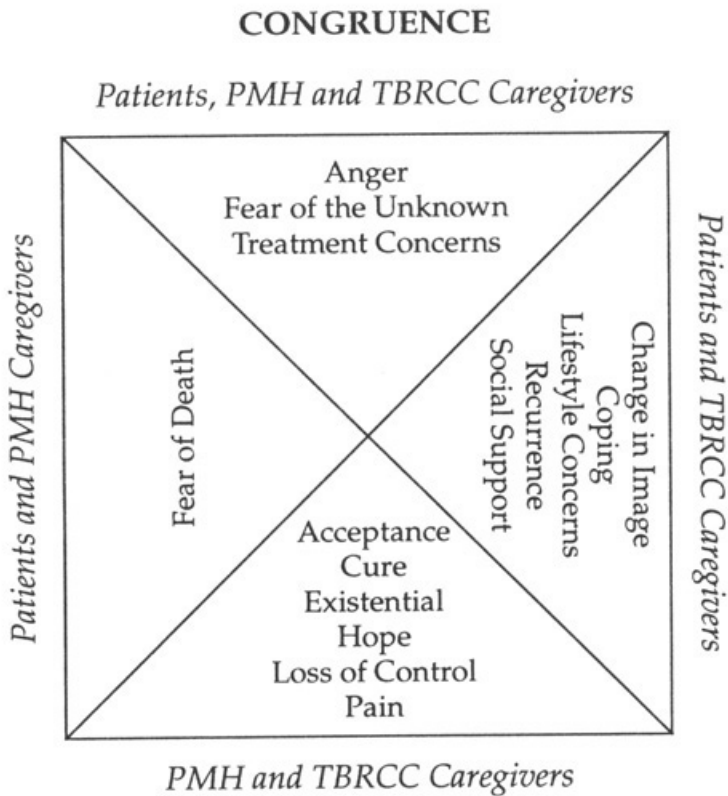
Facing the day-to-day reality [and] seeing others, children, can really hit rock bottom.

Patient-Hospital Caregiver Congruence

Comparison of the individual responses of patients, PMH caregivers, and TBRCC caregivers indicates that when patient needs are compared according to their ranking in the top, middle, or lower third of the order, there was little congruence of all three groups (Figure 1).

Figure 1:

Patient-Hospital Caregiver Congruence in Ranking of Need Categories



INCONGRUENCE

Finances and Employment
 Family Adjustment
 Family Welfare
 Interaction with the Health Care System
 Stigma
 Information Needs
 Sexuality
 Separation from Home
 Return to a Normal Life
 Social Roles
 Nutrition

Patients and caregivers from the two cancer centres ranked anger, fear of the unknown, and treatment concerns similarly. There was greater congruence between patients and TBRCC nurses, with similar rankings assigned to change in image, coping, lifestyle concerns, recurrence, and social support. Caregivers at the two facilities agreed in their rankings of acceptance, cure, existential concerns, hope, loss of control, and pain. In 12 of the 27 need categories, the rankings were dissimilar.

Comparison of the group discussions for patients and PMH caregivers provides a slightly different picture. Although congruence on fear of the unknown and treatment concerns echoes the individual responses, the group discussions also display congruence on social support, health-care system, stigma, information needs, and separation from the family. For example, a physician provided this insight into the barriers that physicians place between themselves and patients — thereby obstructing the pathway to wellness, particularly in relation to psychosocial concerns:

We are not sensitive enough to the patient. If not voiced, we may only know by happenstance. We do not take the time to talk to the patient. Some patients feel uncomfortable talking about these issues.

Caregivers from both cancer centres identified concerns that patients did not express, or emphasized those that patients brought up only infrequently, such as pain, hope, existential concerns, sexuality, and nutrition.

Content Validity

The content validity of the need categories was judged by having a panel of 10 hospital caregivers, including volunteers, rate the importance of each category to patients. As shown in Table 1, at least 80% of the panel judged each need category to be *very important* or *somewhat important*. Ten of the need categories were judged by at least 70% of the panel as *very important* and another six categories were judged by at least 50% of the panel as *very important*. The following needs were estimated by 50-80% of the panel to be *somewhat important*: social roles, change in body image, information needs, nutrition concerns, interaction with the health-care system, return to a normal lifestyle, separation from family or home, and sexuality.

Table 1

Importance Rating I by a Multidisciplinary Panel of Professional Health Caregivers (Including Volunteers) N = 10

| | Very Important % | Somewhat Important % | Not at All Important % |
|--|------------------------|----------------------------|------------------------------|
| Ability to Cope | 100.0 | 0.0 | 0.0 |
| Acceptance of Diagnosis and Prognosis* | 44.4 | 55.6 | 0.0 |
| Anger | 50.0 | 40.0 | 10.0 |
| Changes in Lifestyle | 70.0 | 30.0 | 0.0 |
| Changes in Social Roles | 40.0 | 60.0 | 0.0 |
| Cure | 50.0 | 40.0 | 10.0 |
| Emotional Concerns | 70.0 | 30.0 | 0.0 |
| Existential Concerns | 40.0 | 50.0 | 10.0 |
| Family Adjustment | 70.0 | 30.0 | 0.0 |
| Family Welfare | 70.0 | 30.0 | 0.0 |
| Fear of Death | 80.0 | 20.0 | 0.0 |
| Fear of Recurrence* | 44.4 | 44.4 | 11.1 |
| Fear of the Unknown | 80.0 | 20.0 | 0.0 |
| Financial Concerns | 50.0 | 40.0 | 10.0 |
| Hope | 70.0 | 30.0 | 0.0 |
| Image Concerns | 20.0 | 80.0 | 0.0 |
| Information* | 44.4 | 55.6 | 0.0 |
| Loss of Control | 80.0 | 20.0 | 0.0 |
| Nutritional Concerns | 20.0 | 80.0 | 0.0 |
| Pain | 90.0 | 10.0 | 0.0 |
| Problems with the Health Care System | 20.0 | 60.0 | 20.0 |
| Return to a Normal Lifestyle | 50.0 | 50.0 | 0.0 |
| Separation from Family or Home | 50.0 | 50.0 | 0.0 |
| Sexual Concerns | 40.0 | 50.0 | 10.0 |
| Social Support | 60.0 | 40.0 | 0.0 |
| Stigma | 20.0 | 80.0 | 0.0 |
| Treatment Concerns | 70.0 | 30.0 | 0.0 |

* n = 9

Discussion

Before summarizing the results of our attempt to identify and categorize needs, we offer a few words of caution: handle with care. Several limitations, imposed by the method and by the organization in which the data were collected, can compromise the conclusions. The number of staff was greater than that of patients. Inclusion of a large number of participants is time-consuming in both recruiting members and conducting the research.

The non-random sampling of the populations also imposes a limitation. We gathered information from outpatients staying at the Lodge. It is quite possible that we did not adequately identify the needs of inpatients or of patients within commuting distance of the hospital. Also, because the Lodge staff makes an extraordinary effort to meet the needs of patients and encourages patients to bring a family member with them, a number of needs, such as family adjustment, may have been either given low priority or not expressed. This underscores the importance of interaction between the organizational environment and method of analysis. Although all the words, phrases, and sentences used by the participants were included in the analysis, the non-random selection of participants is an issue that must be taken into consideration since external validity is a goal of content analysis.

Difficulties in responding to open-ended questions, particularly on the part of the patients, may also compromise the process of identifying needs. For example, sexual concerns were never identified as needs by the patients. Another methodological caution is that the item generation is only as good as the open-ended questions. Nonetheless, our systematic research approach gives us confidence in our findings as a basis for identifying and classifying the psychosocial needs of patients, and using these categories to construct a needs-assessment inventory.

The two most striking findings create something of a paradox. On the one hand, when the frequency with which a need is cited is ignored, the majority of need categories (21 out of 27) were reported by all three groups. Of the six need categories not identified by all three groups, only nutrition and social roles were reported as patient needs by one group — the PMH caregivers. On the other hand, there was the lack of congruence between patients and hospital caregivers and between caregivers at the two cancer centres in the frequencies with which need categories were cited. We do not see this as cause for concern; the incongruence underscores the need to gather information from more than one perspective.

The difference in the need categories mapped out by each group indicates that none of the categories should be eliminated at this point. The hospital caregivers' perspective identifies the needs patients either feel reluctant to talk about, such as sexuality, or leave unexpressed, such as hope or the existential meaning of the illness. Frank (1991) points out that it takes time for an ill person to understand her or his needs and that it is difficult for a patient to give a coherent reply to the seemingly simple question "What do you need?" In the beginning, patients are

often trying to grasp the meaning and enormity of the diagnosis, and, as they continue along the illness path, their needs change continually. A nurse at the TBRCC summarized this succinctly: "The total impact of cancer. It affects the entire life... like a pebble in a pond... it has an impact that is tangible and intangible."

There were a number of unanticipated benefits to having conducted this study. Some staff members, particularly those in support functions, such as secretaries, technicians, and housekeeping personnel, appeared to feel empowered by the opportunity to discuss patients' needs. We hope that the process served to facilitate a better understanding of the psychosocial dimensions of illness. Lastly, and most important, the fact that someone was not only interested in what they had to say, but sought their participation, appeared to be therapeutic for many patients. Quite often, patients remained after the group session was over to keep the discussion going.

Identifying need domains is the first step in developing "need maps" as clinical and research tools. A needs-assessment inventory can help nurses address patients' cancer-related problems and thus help to enhance their quality of life. With an inventory based on patients' needs, derived from the perspectives of both patients and hospital caregivers, it will be possible to accurately identify the changing needs of patients over the illness trajectory. It is our hope that the PMH Needs Assessment Inventory will enable nurses to reach beyond people's ostensible invulnerability and numbness to not only help patients cope with expressed needs but also help them face their private pain, fears, and vulnerabilities.

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Identifying the Psychosocial Needs of Individuals with Cancer

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