The needs of patients with advanced, incurable cancer

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BACKGROUND: Limited research has investigated the specific needs of patients with advanced incurable cancer. The aim of this study was to describe the prevalence of perceived needs among this population.

METHODS: Medical specialists from two regions in New South Wales, Australia, identified patients with advanced, incurable cancer, who were estimated to have a life expectancy of < 2 years and were not receiving formal palliative care. Of the 418 eligible patients, 246 (59%) consented to participate. Consenting patients completed the Needs Assessment for Advanced Cancer Patients questionnaire, which has demonstrable validity and reliability. Patients’ perceived needs were assessed across the seven domains of the questionnaire: psychological, daily living, medical communication and information, symptom related, social, spiritual and financial needs.

RESULTS: Patients identified the greatest areas of need in relation to psychological and medical communication/information domains. Patients’ specific needs were highest in dealing with a lack of energy and tiredness, coping with fears about the cancer spreading, and coping with frustration at not being able to do the things they used to do.

CONCLUSION: This study indicates that patients with advanced, incurable cancer have high levels of unmet needs, especially in relation to the areas of psychological and medical communication/information needs. The data have the potential to guide the development of interventions aimed at meeting the current unmet needs of patients with advanced, incurable cancer.

Keywords: advanced cancer; terminal cancer patients; perceived needs

Assessing and fulfilling the needs and concerns of cancer patients is an important role for health-care professionals. Research indicates that there are high levels of unmet needs among cancer patients; the most prominent relating to the provision of information and psychological support (Gustafson et al., 1993; Foot and Sanson-Fisher, 1995; Meredith et al., 1996; Sanson-Fisher et al., 2000; Janda et al., 2006; Barg et al., 2007). Although such research provides an indication on how to increase quality of care to cancer patients, there has been little quantitative research regarding the specific needs of patients with advanced, incurable cancer, creating uncertainty as to what areas need to be addressed when caring for this vulnerable population group.

This uncertainty is intensified by the methodological limitations found in a majority of studies with this population. Some studies failed to distinguish between ‘needs’ and ‘problems’ (MacAdam and Smith, 1987). Although patients may perceive they have a problem, they can also decide that they will endure due to circumstance and will not register a need. For example, the hair loss resulting from chemotherapy may be a problem that the patient is prepared to accept in an effort to prolong life and hence they perceive no need for help. Other research in the field has only examined one area of need (Grobe et al., 1982; Christ and Siegel, 1990) or one type of cancer (Murray et al., 2004; Aranda et al., 2005; Davies et al., 2008). Finally, other studies have relied on the retrospective reports of family members or friends (Houts et al., 1988), increasing the likelihood of bias created by perceptions and time.

Such deficiency in information emphasises the importance to overcome the methodological problems, so that the needs of these patients can be adequately assessed and appropriate support can be provided. This study aimed to examine the prevalence of unmet needs among a sample of patients with advanced, incurable cancer who were not receiving formal palliative care. Patients’ perceived needs were assessed using a multidimensional tool with demonstrated validity and reliability.

MATERIALS AND METHODS

Participants

Forty-four medical specialists from the Sydney and Hunter regions of New South Wales in Australia recruited patients for the study. Patients were defined as eligible if their medical specialist judged that they had a life expectancy of > 3 months but < 2 years, and they were not under the care of the local Palliative Care Unit. Patients under the care of this unit were excluded as patients with advanced incurable cancer who are not in palliative care have been less studied. The Needs Assessment for Advanced Cancer Patients (NA-ACP) questionnaire has been validated for this population. Patients who were too physically ill, too emotionally distressed, < 18 years of age or not literate in English were excluded.
The questionnaire

The ‘Needs Assessment for Advanced Cancer Patients’ is a pen and paper questionnaire, specifically developed to assess the needs of people who have advanced, incurable cancer. The questionnaire has acceptable levels of internal consistency and test–retest reliability, as well as construct validity (Rainbird et al., 2005). The version of the NA-ACP used in this study comprised 132 'needs' items. These items were used to calculate scores for the seven domains of possible need, psychological, medical communication/information, daily living, symptom related, social, spiritual and financial needs. Patients were asked to indicate their level of need for help for each need item on a 5-point Likert scale (1 = not applicable, 2 = satisfied, 3 = low need, 4 = moderate need and 5 = high need) during the previous 4 months in an optimal health-care system. This 4-month time frame was recommended, given feedback from consumers and clinicians who indicated that such a passage of time was necessary to capture important issues for the population under study. The format of the Likert scale allows participants to indicate the following:

1. whether they have experienced a need within the specified time frame
2. whether their experienced needs have been met
3. if their needs have not been met, how much help they require (Sansom-Fisher et al., 2000).

Additional questions

The Needs Assessment for Advanced Cancer Patients includes a number of demographic questions regarding the patient’s age, gender, marital status, family income and level of education. Patients were also asked to identify the original site of their cancer and any treatment they had received. Two optional questions included in this section asked patients what their doctor had told them in relation to life expectancy given their disease and their own perceptions about this matter.

Procedure

Eligible patients were given an information package by their medical specialist, who also briefly explained the study. The information package consisted of (i) a letter that outlined the objectives of the study and what participation would involve, (ii) a consent-to-contact form, to be completed if patients were interested in the study, (iii) a non-consent question sheet, which asked basic demographic questions and (iv) a reply paid envelope for the return of the relevant forms. Those patients who returned a consent-to-contact form were then sent a copy of the questionnaire for the return of the relevant forms. Those patients who returned a consent-to-contact form were then sent a copy of the questionnaire to view it before deciding whether they wished to take part in the study. A suitable time to visit their home was then arranged. Consent-to-contact forms were then sent a copy of the questionnaire to view it before deciding whether they wished to take part in the study. A suitable time to visit their home was then arranged. Eligible patients were now under the care of the Palliative Care Unit (n = 19). They were then asked basic demographic information. The obtained sample size was sufficient to ensure that need estimates were within ±6.5% of patients’ true need levels with 95% confidence.

RESULTS

Consent rate

The medical specialists distributed 457 information packages to patients of whom 39 were excluded because: (i) they had died between the time of returning the consent-to-contact form and being contacted about taking part in the study, (n = 21); (ii) they were now under the care of the Palliative Care Unit (n = 9); (iii) they could not be contacted (n = 7); or (iv) they were not literate in English (n = 2). Of the 418 eligible patients, 246 (59%) patients gave their consent to participate. Of the 172 non-consenters, 92 (53%) completed a background question sheet, which provided basic demographic information. The obtained sample size was sufficient to ensure that need estimates were within ±6.5% of patients’ true need levels with 95% confidence.

Demographic characteristics

Patients in the study sample ranged in age from 27 to 89 years (mean = 61 years, s.d. = 11.9), 53% of the participants were female, 72% were married, and the most common types of cancer were breast (24%), colorectal (19%) and lung (11%).

There were no significant differences between the consenters and non-consenters in terms of gender, marital status or original cancer site. However, there was a difference on the basis of age (\(\chi^2 = 16.53, \text{d.f.} = 5, P < 0.01\)). The consenting sample included a greater proportion of patients in the age brackets of 40–49 and 50–59 years and a smaller proportion in the older age brackets of 70–79 and 80 + years.

Comparison between the study sample and the 1994 NSW sample (Coates and Armstrong, 1997) showed significant differences in relation to gender (\(\chi^2 = 10.75, \text{d.f.} = 1, P < 0.01\)), age (\(\chi^2 = 121.7, \text{d.f.} = 5, P < 0.01\)) and original cancer site (\(\chi^2 = 147.3, \text{d.f.} = 7, P < 0.01\)). The study sample was overrepresented in terms of females, those aged 40–49 and 50–59 years, and the breast, colorectal, lymph node and ovarian cancer cases. Males, those aged 70–79 and 80 + years, and those with cancer of the prostate, lung and other cancers, were underrepresented in the sample compared with the NSW sample (Table 1).

Prevalence of needs

Overall needs Analysis indicated that 95% (n = 234) of the participants had experienced some level of need for help (that is, low, moderate or high) on one or more items. Further, 89% (n = 219) of patients reported having a moderate or high level of need for help on at least one item.

Needs by domain More than one-third of the patients reported a moderate/high level of need for help on items within the psychological or emotional domain (39–40%). Over thirty per cent had moderate/high needs on the medical communication/information domain (31–35%). The three most prevalent moderate/high needs ranged from 15 to 22% in the symptom domain and 10–30% in the financial domain. The prevalence of moderate/high need on the remaining domains ranged from 10 to 15% (financial 11–12%, spiritual 11–15% and social 10–13%). Of the non-domain-based items, the three most prevalent items related to patients’ physical needs with over 40% reporting moderate/high needs in relation to dealing with lack of energy or tiredness, 28% dealing with pain and 27% dealing with feeling unwell most of the time (Table 2).

Needs by item Fifty per cent of the most prevalent moderate/high need items related to the psychological or emotional domain and 45% related to medical communication/informational domain. The remaining 5% related to one of the non-domain-based items and can be related to patients’ physical needs (Table 3).
The most prevalent items were: need for assistance in dealing with a lack of energy or tiredness (41%, n = 100); coping with fears about the cancer spreading (40%, n = 99); and coping with frustration at not being able to do the things they used to do (40%, n = 98).

Perceptions of life expectancy

The doctor’s view  Two hundred and twenty-three (91%) patients responded to the question regarding what their doctor had told them about their life expectancy. Of these, 39% (n = 88) indicated that their doctor had not discussed their life expectancy. A further 24% (n = 53) reported that their doctor said they did not know how long they would live. Although 17% (n = 40) responded that their doctor thought they would live for <2 years, 7% (n = 15) indicated that their doctor thought they would live for >2 years and 2% (n = 5) reported that their doctor did not think their cancer was life threatening. Another 2% (n = 4) of patients had asked their doctor not to tell them how long they had to live. The remaining 8% (n = 18) of patients gave an alternative response, such as, that they had not asked their doctor about their life expectancy; they had been told their cancer was incurable; they had been told a certain length of time some time ago; or the doctor had given a broad time frame (for example, ‘between 18 months and 5 years’).

Patients’ own views of their life expectancy  Two hundred and twenty-six patients (92%) completed the question relating to their own perception of their life expectancy. The majority of patients had given a broad time frame (for example, ‘between 18 months and 5 years’).

DISCUSSION

This study has identified those areas in which patients with advanced, incurable cancer have a perceived need for help or assistance. However, a number of methodological issues should be considered when reviewing the findings.

Methodological considerations

The overall consent rate was 59%. Given the patient group, who tend to be fatigued, unwell and/or elderly, the obtained consent rate could be considered acceptable. Some quality of life studies on
advanced cancer patients do not report the consent rates (Hiromoto and Dungan, 1991; Dudgeon et al., 1995; Gates et al., 1995; Vachon et al., 1995; Schofield et al., 2006). Others include their measures as part of a clinical trial or as part of hospital procedure (MacAdam and Smith, 1987; Tamburini et al., 1992). Consequently, rates of consent in this project are favourable (Hagerty et al., 2004; Aranda et al., 2005).

There were no significant differences in gender, marital status and original cancer site between the consenting and non-consenting patients. However, there were differences between the groups in relation to age, with the consenters including a greater prevalence of cancer pain was reported as being 74% for a similar population group (Teunissen et al., 2007).

The needs of patients with advanced, incurable cancer

This research has shown that 95% of patients with advanced, incurable cancer have some level of perceived need for help and that they experience moderate or high needs across a variety of domains. These data suggest that the existing health-care system is not meeting the needs of these patients.

Areas of unmet need were in the psychological and the medical communication/informational domain. Up to 40% of the patients reported a moderate or high level of need in relation to these areas. Of the 20 most prevalent need items, 50% related to patients’ psychological or emotional needs and 45% to medical communication or information. This result is not surprising given the nature of this patient population’s prognosis. The results are similar to those in literature using the Supportive Care Needs Survey, examining, in general, the needs of cancer patients, those with brain tumours, those with melanoma and those with breast cancer (Bonevski et al., 1999; Sanson-Fisher et al., 2000; Janda et al., 2008; Minnstrell et al., 2008).

Twenty-eight per cent of patients reported a need for help in relation to dealing with pain. As cancer pain can occur in conjunction with a number of other symptoms, such as depression, anxiety and experiencing fluctuating mood states, pain may underlie those psychological consequences (Grond et al., 1994). This result is at odds with previous reviews, in which the prevalence of cancer pain was reported as being 74% for a similar population group (Teunissen et al., 2007).

The most prevalent item was need for assistance in dealing with a lack of energy or tiredness, with 41% of the participants reporting a moderate to high need. This is not surprising as a lack of energy may prevent these patients from leaving the home to socialise. This lack of control over their activities has been associated with feelings of frustration, increased anxiety and depression due to tiredness or lack of energy (Langer and Rodin, 1976; Chen and Chang, 2004; Wu and Yao, 2007). Helping patients cope with this symptom should be an important aspect of care.

There are several possible reasons why patients perceive that their informational and psychological support needs are not being met. First, health-care providers may not be aware that patients have needs in these areas. Research suggests that oncologists are often unaware or do not establish a range of psychosocial, physical and informational concerns of their patients (Newell et al., 1998; Hagerty et al., 2004). Recent literature indicates that psychosocial concerns are becoming of paramount importance to many health-care providers, including oncologists (Trivedi et al., 2007). Second, health-care providers may have provided the required information, but the patients do not recall having received this material. Patients may avoid such information to help maintain a sense of hope (Leydon, 2000; Beadle et al., 2004). Another explanation may include deficits in health-care providers’ training and education, system time and related financial restrictions or competing priorities. The research does provide support for this range of explanations, particularly in relation to meeting patients’ informational needs (Girgis and Sanson-Fisher, 1995). Many clinicians do not feel competent at some aspects of communication skills (Girgis and Sanson-Fisher, 1995), with many reluctant to give estimations of life expectancy (Hagerty et al., 2005). Providing communication skills training to clinicians and other health-care providers helps increase their self-rated confidence in delivering bad news (Baile et al., 1999; Fallowfield and Jenkins, 2004). Clinicians may be unaware of other sources of information and help that can be provided. Allied help professionals can offer a range of services, such as information about symptom management or counselling services (Takeyasu and Hutson, 2004).
CONCLUSIONS

The findings of this study indicate that patients who have advanced, incurable cancer experience high levels of need in relation to psychological/emotional and medical communication/information issues. The findings suggest the need to explore mechanisms by which the health-care system can positively respond to these justifiable needs. It also provides an example of a reliable and valid measure, the NA-ACP, which could be used by health-care providers to gain a deep understanding of their patients needs, in turn creating an opportunity to provide valuable and effective care. It is essential that strategies that attempt to reduce the needs of this vulnerable group are developed and rigorously trialed.

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REFERENCES

Aranda S, Schofield P, Weih I, Yates R, Milne D, Faulkner R, Voudouris N (2005) Mapping the quality of life and unmet needs of urban women with metastatic breast cancer. Eur J Cancer Care 14: 211 – 222

Baile WF, Kudelka AP, Beale EA, Globor GA, Myers EG, Greisinger AJ, Bast RC, Goldstein MG, Novack D, Lenzi RR (1999) Communication skills training in oncology: description and preliminary outcomes of workshops on breaking bad news and managing patients reactions to illness. Cancer 86: 887 – 898

Bag FK, Cronholm PF, Stratton JB, Kedden S, Knott K, Grater J, Houts P, Palmer SC (2007) Unmet psychosocial needs of Pennsylvanian with cancer 1985 – 2005. Cancer 110: 631 – 639

Beadle GF, Yates PM, Najman JM, Clavarino A, Thomson D, Williams G, Kenny L, Roberts S, Mason B, Schlect D (2004) Beliefs and practices of patients with advanced cancer: implications for communication. Br J Cancer 91: 254 – 257

Bonevski B, Cockburn J (1997) Breaking Bad News to Patients About Recurrence of Breast Cancer: A Review of the Literature. NHMRC National Breast Cancer Centre: NSW, Australia

Bonevski B, Sanson-Fisher R, Hersey P, Paul CL (1999) Assessing the perceived needs of patients attending a melanoma clinic. J Psychosoc Oncol 17: 101 – 118

Chen M, Chang H (2004) Physical symptom profiles of depressed and nondepressed patients with cancer. Palliat Med 18: 712 – 718

Christ G, Siegel K (1990) Monitoring quality-of-life needs of cancer patients. Cancer 65: 760 – 765

Coates M, Armstrong B (1997) Cancer in New South Wales. Incidence and Mortality 1994. NSW Cancer Council: Sydney

Davies NJ, Kinman G, Thomas RJ, Bailey T (2008) Information satisfaction in breast and prostate cancer patients: implications for quality of life. Psychooncology 17: 1048 – 1052. Available at: www.interscience.wiley.com Accessed on 19 February 2008

Dudgeon DJ, Raubertas RF, Doerner K, O’Connor T, Tobin M, Rosenthal SN (1995) When does palliative care begin? A needs assessment of cancer patients with recurrent disease. J Palliat Care 11: 5 – 9

Fallowfield L, Jenkins V (2004) Communicating sad, bad, and difficult news in medicine. Lancet 363: 312 – 319

Foot G, Sanson-Fisher RW (1995) Measuring the unmet needs of people living with cancer. Cancer Forum 19: 131 – 135

Gates MF, Lackey NR, White MR (1995) Needs of hospice and clinic patients with cancer. Cancer Pract 3: 226 – 232

Girgis A, Sanson-Fisher RW (1995) Breaking bad news: consensus guidelines for medical practitioners. J Clin Oncol 13: 2449 – 2456

Grobe ME, Ahmann DL, Ilstrup DM (1982) Needs assessment for advanced cancer patients and their families. Oncol Nurs Forum 9: 26 – 30

Grond S, Zech D, Diefenbach C, Bischoff A (1994) Prevalence and pattern of symptoms in patients with cancer pain: a prospective evaluation of 1635 cancer patients referred to a pain clinic. J Pain Symptom Manage 9: 372 – 382

Gustafson DH, Taylor JO, Thompson S, Chesney P (1993) Assessing the needs of breast cancer patients and their families. Qual Manag Health Care 2: 6 – 17

Hagerty RG, Butow PN, Ellis PA, Lobb EA, Pendlebury S, Leigh N, Goldstein D, Lo SK, Tattersall MH (2004) Cancer patient preferences for communication of prognosis in the metastatic setting. J Clin Oncol 22: 1721 – 1730

Hagerty RG, Butow PN, Ellis PM, Dinitry S, Tattersall MHN (2005) Communicating prognosis in cancer care: a systematic review of the literature. Ann Oncol 16: 1005 – 1053

Hiramoto BM, Dungan J (1991) Contract learning for self-care activities: a protocol study among chemotherapy outpatients. Cancer Nurs 14: 148 – 154

Houts PS, Yasko JM, Harvey HA, Kahn SB, Hatz AJ, Hermann JF, Schelzel GW, Bartholomew MJ (1988) Unmet needs of persons with cancer in Pennsylvania during the period of terminal care. Cancer 62: 627 – 634

Janda M, Eakin EG, Bailey L, Walker D, Troy K (2006) Supportive care needs of people with brain tumours and their carers. Support Care Cancer 14: 1094 – 1103
Janda M, Steginga S, Dunn J, Langbecker D, Walker D, Eakin E (2008) Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Educ Couns* 71: 251–258

Langer EJ, Rodin J (1976) The effects of choice and enhanced personal responsibility for the aged: a field experiment in an institutional setting. *J Pers Soc Psychol* 34: 191–198

Leydon GM (2000) Cancer patients’ information needs and information seeking behaviour: in depth interview study. *BMJ* 320: 909–1005

MacAdam DB, Smith M (1987) An initial assessment of suffering in terminal illness. *Palliat Med* 1: 37–47

Meredith C, Symonds P, Webster L, Lamont D, Gillis CR, Fallowfield L (1996) Information needs of cancer patients in west Scotland: cross sectional survey of patients’ views. *BMJ* 313: 724–726

Minstrell M, Winzenberg T, Rankin N, Hughes C, Walker J (2008) Supportive care of rural women with breast cancer in Tasmania, Australia: changing needs over time. *Psychooncology* 17: 58–65

Murray SA, Kendall M, Boyd K, Worth A, Benton TF (2004) Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliat Med* 18: 39–45

Newell S, Sanson-Fisher RW, Girgis A, Bonaventura A (1998) How well do medical oncologists’ perceptions reflect their patients’ reported physical and psychosocial problems? *Cancer* 83: 1640–1651

Rainbird KJ, Perkins JJ, Sanson-Fisher RW (2005) The Needs Assessment for Advanced Cancer Patients (NA-ACP): a measure of the perceived needs of patients with advanced, incurable cancer.

A study of validity, reliability and acceptability. *Psychooncology* 14: 297–306

Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P, The Supportive Care Review Group (2000) The unmet supportive care needs of patients with cancer. *Cancer* 88: 226–237

Schofield P, Carey M, Aranda S (2006) Psychosocial issues for people with advanced cancer: overcoming the research challenges. *Cancer Forum* 30: 18–21

Takayesu J, Hutson H (2004) Communicating life-threatening diagnoses to patients in the emergency department. *Ann Emerg Med* 43: 749–755

Tamburini M, Rosso S, Gamba A, Mencaglia E, De Conno F, Ventafridda V (1992) A therapy impact questionnaire for quality-of-life assessment in advanced cancer research. *Ann Oncol* 3: 565–570

Teunissen S, Wesker W, Kruitwagen C, de Haes H, Voest E, Graeff A (2007) Symptom prevalence in patients with incurable cancer: a systematic review. *J Pain Symptom Manage* 34: 94–104

Trivedi S, Petera J, Fillip S, Hrstka Z (2007) Methods of intervention in reducing the psychosocial impact while dealing with cancer as a disease: a clinician’s point of view. *J Cancer Res Ther* 3: 135–139

Vachon MLS, Kristjanson L, Higginson I (1995) Psychosocial issues in palliative care: the patient, the family, and the process and outcome of care. *J Pain Symptom Manage* 10: 142–150

Wu C, Yao G (2007) Relations among self-certainty, sense of control and quality of life. *Int J Psychol* 42: 342–352