

When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for haematological malignancies

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Abstract

Objective: To determine patients' information, emotional and support needs at the completion of treatment for a haematological malignancy. **Methods:** A self-report questionnaire was mailed to 113 adult patients. **Results:** Sixty-six questionnaires were returned. The most frequently endorsed patient needs related to care co-ordination and help to manage the fear of recurrence. The most frequently endorsed unmet needs included managing the fear of recurrence, the need for a case-manager and the need for communication between treating doctors. Predictors of unmet needs included younger patients ($p=0.01$), marital status ($p=0.03$) and employment ($p=0.03$). Almost two thirds of patients (59%) reported they would have found it helpful to talk with a health care professional about their experience of diagnosis and treatment at the completion of treatment and endorsed significantly more need in the arenas of Quality of Life ($p=0.03$) and Emotional and Relationships ($p=0.04$). **Conclusion:** This study provides valuable data on haematological cancer patients' needs in the first 12 months of finishing treatment. It appears that many needs emerge or remain unresolved at this time. **Practice implications:** An opportunity for patients to talk with a health professional about making the transition from active treatment to extended survivorship may be helpful.

Key words: unmet needs, haematological malignancy, survivorship, completion of treatment interview

1. Introduction

Collectively, the haematological cancers are the fifth most common tumour group of adult Australians with an estimated 3,878 new cases of lymphoma and 1,049 cases of myeloma annually [1]. These are the two most common haematological cancers.

Biologically, haematological cancers are cancers of the bone marrow (the leukemias) and the immune system (the lymphomas and myeloma) and effective treatment targeted at these organs necessarily has marked effects upon normal bone marrow and immune function. Consequently treatment is more complex and debilitating than other cancer treatments, with increased risk of severe infection, and more need for bone marrow support with red cell and platelet transfusions. The most complex treatments are autologous and particularly allogeneic bone marrow transplantation. The latter usually involves an in-patient stay of several weeks, with life-long subsequent follow up for most patients. Less intense out-patient-based therapies, such as CHOP chemotherapy for non-Hodgkin lymphoma or induction regimens for myeloma, are also monitored every two to four weeks for periods of three to six months. Thus, during periods of treatment, haematological cancer patients may become heavily dependent upon hospital facilities and staff. Interaction with nursing staff on hospital wards may provide psychological support and many institutional haematology departments provide access to a social worker and liaison-psychiatrist. Some provide access to counselling and clinical psychologist support. The focus traditionally has been upon providing these supports during treatment.

The prevalence of psychological disorders in cancer populations during treatment is well documented [2]. In the largest study of adults diagnosed with cancer to date (n = 4,496), an overall rate of distress of 35% was found for the sample [3]. Anxiety was found to account for 30% of distressed cases, and depression for 19% of all cases reporting high levels of distress [3]. Other reactions reported in the literature include phobic reactions [4], and post-traumatic stress [5].

An Australian study showed that 135/303 (45%) cancer patients had a psychiatric disorder of whom 127/303 (42%) were diagnosed with depression or anxiety, or both [4]. The prevalence of anxiety and depressive disorders in the general population of Australia is estimated to be approximately 9% [6]. While estimates vary depending on study populations and instruments used, the research literature provide strong evidence that a diagnosis of cancer places people at a far greater risk of psychological disorder compared to the general population.

In haematological/lymphatic cancers, moderate to severe anxiety has been commonly reported [7]. Levels of psychological distress are likely to be higher when disease burden or complications are more severe. For example, in patients who have had a bone marrow transplant, the level of anxiety was found to be significantly higher in those patients who went on to develop grade II-IV graft-versus-host disease (GVHD) compared to those who developed grade 0 – 1 GVHD. While the duration of PTSD following bone marrow transplant is unclear, one large study of patients with various cancer types found that, at

mean 4 year follow-up post transplant, patients with PTSD continued to show significantly poorer physical, social and role functioning [8].

Research suggests that the needs of these distressed cancer patients are currently not adequately met by the health system. In an Australian study [9] 40% of cancer patients (n = 888) reported experiencing unmet needs across a range of domains. Factors associated with higher level of unmet needs in the psychological domain included not being in remission, younger (31-60 years), and female [9]. The development of measures in the late 1990's to directly assess unmet needs improved upon previous methodology by directly measuring the gap between a person's experience of a service and the actual service required [8,10]. This information permits the identification of high-risk groups likely to benefit from targeted preventative interventions.

An examination of the literature on survivorship suggested that emotional distress and need for support do not cease for the survivor when treatment is completed and for many cancer patients, a greater psychological challenge lies in the resumption of life, work and relationships after treatment [11]. Two key documents published in 2006, the IOM report *From Cancer Patient to Cancer Survivor: Lost in Transition (2007)* [12] and a special issue of the *Journal of Clinical Oncology* addressing cancer survivorship (November 2006), delineate a number of issues specific to the survivorship phase. These notably include fear of recurrence, persistent side effects such as fatigue, loss of fertility and altered body image, cognitive impairment [13, 14], loss of fertility and sexual function

[15, 16] and difficulty adjusting to normal life after the intense and life-changing experience of cancer [12, 17, 18]. Other themes described by cancer survivors include the struggle between independence and dependence, balance, a sense of wholeness, life purpose, reclaiming life, dealing with multiple losses, having control, the altered meaning of health, and surviving cancer from a family perspective [19].

Another area of concern is re-engaging with or seeking employment once treatment is completed. One large national survey showed that nearly one-fifth of the cancer survivors who worked before or after their cancer diagnosis experienced employment problems because of their cancer [20]. Unemployment and financial strain impose an additional psychological burden on cancer survivors [21].

It is clear that studies on survivorship issues are increasing. This research highlights the need to be aware of the physical, emotional and social impact of cancer in the longer-term but gives little insight into the shorter-term needs of patients on completing treatment. As most studies reviewed did not include haematological malignancies in their sample, this study sought to address the gap in the literature by assessing the unmet informational and emotional needs of patients within the first year of completing treatment for haematological malignancies.

2 Methods

2.1. Participants and recruitment

Patients were eligible for inclusion in the study if they had completed chemotherapy or radiotherapy for haematological malignancies with the intention of cure or substantial remission; were aged 18-80; were not suffering from a mental illness, and could read/speak English proficiently. Participants needed to be at a minimum 6 weeks from finishing treatment (to allow for re-staging and the follow-up consultation) and at a maximum 12 months from treatment (to capture bone marrow transplant patients who are on regular and longer follow-up).

Participants were recruited through the Haematology Department at Sir Charles Gairdner Hospital and Royal Perth Hospital. All eligible participants were sent a letter inviting them to participate in the study by the Head of the Haematology Department and the treating clinician at each Institution. This procedure ensured confidentiality of clinic records. An opt-out card was included for those who did not wish to participate or be contacted regarding this project. Patients for whom an opt-out card was not received were phoned by the researcher to explain the study, to answer questions, and to obtain verbal consent. An information sheet, a consent form for written consent and the questionnaire battery was then mailed with a reply paid envelope. Non-returnees were mailed a reminder and replacement questionnaire after 2 weeks, and telephoned after a further two weeks. Ethical approval was obtained from the Sir Charles Gairdner Hospital Human

Research Ethics Committee, Royal Perth Hospital and the Edith Cowan University Human Research Ethics Committee.

2.2 Measures

Demographic characteristics: The survey collected data on demographic characteristics, for example age, education, occupation, employment status, marital status, diagnosis, date completed treatment, type of treatment. Patients were also asked their understanding of the current status of their cancer with options of a) cured, b) in remission, c) don't know, and e) other. They were also asked if they considered themselves a cancer "survivor" with potential responses of "no", "yes", "not yet", or "don't know". Finally patients were asked if they would have found it helpful to speak to a health professional at the completion of their treatment about their experience of diagnosis, treatment and making the transition from active treatment.

Information and emotional support needs: The Cancer Survivors Unmet Needs measure (CaSUN) contains 35 supportive care need items, six positive outcome items and an open-ended item [21]. Psychometric evaluation supports the acceptability, internal consistency, construct and face validity and content validity of the measure. Factor analysis identified five distinct need domains with high internal consistency: (1) *Existential Survivorship* (e.g. "cope with changes to my beliefs", "make decisions about my life in context of uncertainty", "explore spiritual beliefs"); (2) *Comprehensive Cancer Care* (e.g. "doctors talk to each other", "manage health care with team", "local health

care services”); (3) *Information* (e.g. “up to date information”, “understandable information”); (4) *QOL* (e.g. “changes to quality of life”, “manage side effects”); and (5) *Relationships* (e.g. “impact on my relationship”, “problems with sex life”) [21].

Respondents indicated whether they have no need (0), met need (1), weak unmet need (2), moderate unmet need (3), or strong unmet need (4) within the last month. The number of met (scores of 1) and unmet needs (scores 2-4) are summed and total needs calculated from the sum of met and unmet needs.

2.3 *Data analysis*

Descriptive statistics, including means, medians, percentages, ranges and standard deviations were calculated as appropriate to describe the sample, and its characteristics. Comparisons between subgroups on demographic and disease variables (e.g. age, gender, educational level, occupational status, diagnosis, treatment modalities received, time since completion of treatment) were carried out using Chi Squared tests and Fisher’s Exact tests for categorical variables, t tests and analysis of variance for normally distributed continuous variables and Mann-Whitney and Kruskal-Wallis tests for ordinal or non-normally distributed continuous variables. Correlations between measures were assessed using Pearson’s product-moment correlation coefficient and Spearman’s Rank Correlation coefficient, as appropriate. Due to the relatively small sample size, multivariate analyses were not carried out. Qualitative data from responses to open

ended questions were coded, grouped into categories and summarised using descriptive content analysis.

3. Results

3.1 Demographic characteristics

One hundred and thirty-three patients who had been diagnosed with a haematological malignancy and who had completed treatment between September 2005 and July 2006 were recruited from two large hospitals in Perth. Sixty-six self-report questionnaires were returned (50% response rate).

The mean age was 54 (sd14.07, range 24 - 82 years). The majority were married (71%). Less than one-fifth (18%) were in full-time employment with around one-third retired (29%). Just under half were either in professional employment or retired from professional employment (40%) and 44% were in non-professional employment. One third of the sample (33%) was educated at year 10 or below. (see Table 1)

The mean number of months from completion of treatment was 8 months (sd 3.53, range 2-13). The main disease type represented in the sample was lymphoma (59%). Fewer patients had Hodgkin lymphoma (12%), around one-third (32%) of participants indicated they had non-Hodgkin lymphoma, and 15% of participants indicated “lymphoma” without specifying the type. Twenty-six percent (26%) of participants reported they had multiple myeloma. Eleven percent (11%) of respondents had leukaemia.

The majority of the participants (59%) described their cancer status as “in remission” with 4% indicating “cured”. Seventeen percent (17%) did not know their disease status. The majority of participants (54%) considered themselves a “survivor”; 36% indicated “not yet” and 3% didn’t know. Four percent (4%) preferred different words to “survivor” (e.g., “living with it”, “winner”, “fighter”, and “recovering”) and the remainder did not respond (3%).

3.2 Views on health professional input at the time of treatment completion

Almost two-thirds of respondents (59%) indicated that looking back over their experience of finishing treatment it would have been helpful at that time to talk with a health care professional about their experience of diagnosis and treatment and making the transition from active treatment.

3.3 The needs of haematology cancer patients within the first year following treatment

The mean number of needs identified by respondents on The Cancer Survivors Unmet Needs measure (CaSUN) in Sub Scale A (Information Needs and Medical Care Issues) was 1.9, sd 2.57, range 0-9); in Sub-Scale B (Quality Life) mean 1.69, sd 2.12, range 0 – 8); in Sub-Scale C (Emotional & Relationship Issues) mean 7.37, sd 4.95, range 3-12) and in Sub-Scale D (Life Perspective) mean 1.04, sd 2.51, range 0 – 6).

The ten most frequently endorsed patient needs are reported in Table 2. These related to care co-ordination and help to manage the fear of recurrence. The majority of participants reported the need to feel like they are managing their health together with the medical team (85%) to know that their doctors talk to each other to co-ordinate their care (82%) and to get the very best medical care (77%). Seventy-three percent (73%) of participants reported the need for help to manage their concerns about the cancer coming back.

3.4 Predictors of needs of haematology cancer patients within the first year following treatment

Patients who reported that it would have been helpful to speak to a health professional at the completion of treatment endorsed significantly more need in the arenas of Quality of Life ($z=-2.104$, $p = 0.03$) and Emotional and Relationships ($z = - 2.073$, $p = 0.04$).

Younger patients endorsed significantly more needs in the arena of Emotional and Relationship Issues ($z= -2.69$, $p = 0.007$).

3.5 Unmet needs of haematology cancer patients within the first year following treatment

The ten most frequently endorsed *unmet* patient needs are reported in Table 3. These related to help in managing concerns about the cancer coming back (42%); an on-going

case manager to whom they can go to find out about services when they are needed (33%) and communication between doctors to co-ordinate care (31%). The median number of unmet needs was 6 (sd 8.05, range 0 – 25).

3.5 Predictors of unmet needs of haematology cancer patients within the first year following treatment

Younger patients had a greater unmet need for help with concerns about recurrence than older patients ($\chi^2=7.20$ p = 0.007). There was a trend for patients who were close to finishing treatment to have a greater unmet need for a case- manager ($\chi^2=3.23$, p = 0.06). Patients who were not married ($\chi^2=4.51$, p = 0.023) and patients who were working ($\chi^2=4.32$, p=0.03) had a significantly greater unmet need for their doctors to talk to one another in co-ordinating their care.

4. Discussion and Conclusion

4.1 Discussion

The area of psycho-oncology has traditionally focussed on the diagnosis and management of cancer, or its prevention. With earlier detection of cancer and improved treatments, research is now shifting its focus to the increasing proportion of patients who survive cancer. This is the first study to our knowledge that has assessed the unmet needs of

patients with haematological malignancies in the first twelve months after completing treatment, the period described as “extended survival” [22].

Approximately half of the patients who participated in this current study considered themselves “survivors”. The other half preferred to describe themselves as “in remission” from their disease. This is not surprising given that the average time since completion of treatment was only eight months.

Previous studies reported that the needs most frequently endorsed by cancer survivors concerned “existential survivorship” (e.g. spiritual beliefs, the meaning of life) [23, 24] and comprehensive cancer care” (e.g. team care, communication, local health care services [24]. In the current study, 73% of participants expressed the need for help to manage their concerns about the cancer coming back with 43% considering this need unmet. This is in contrast to previous Australian studies with gynaecological cancer patients [24] where the most frequently endorsed need concerned help managing the fear of recurrence (24%) and in breast cancer [23] where 33% of women endorsed managing the fear of disease recurrence as an unmet need. However, participants in these studies ranged from 1 to 10 years post diagnosis.

A previous study of 888 cancer patients found factors associated with high levels of unmet needs in the psychological domain included not being in remission, being younger (31 to 60) years) and being female [9]. In this study also, younger patients expressed higher unmet needs for help with concerns about recurrence than older patients.

Similar to Hodgkinson and colleagues' findings [23, 24], the most frequently reported needs for haematological patients at the time of completion of treatment related to care co-ordination. Patients who were not partnered and who were working had significantly greater unmet need for their doctors to talk to one another in co-ordinating their care. This finding suggests that time may be a factor and perhaps patients' partners play a role in co-ordinating appointments and gathering information when the patient is working. Patients without a partner may be more reliant on health professionals to co-ordinate aspects of their care.

Patients who were close to finishing treatment had a greater unmet need for a case manager which may be attributed to the higher percentage of patients in the study with lymphoma (59%) and who require monitoring every two to four weeks for periods of three to six months. A collaborative approach to care management was endorsed with patients wanting to be involved together with their medical team in managing their health.

In the current study, younger patients endorsed significantly more needs around emotional and relationship issues following the completion of treatment. This is in contrast to a study on supportive care needs where gynaecological cancer survivors reported normal relationship adjustment, although functioning was at the lower end [24]. Whilst the number of respondents in the current study who underwent bone marrow transplantation is unknown, a previous study reported that sexual symptoms are

commonly reported by patients who have undergone bone marrow transplantation and may persist up to 12 months [25].

Fewer patients identified needs in the domains of information, medical care and quality of life. These findings corroborate qualitative findings gathered from telephone interviews with 20 patients in Stage 1 of the study [26] where the majority of patients reported being satisfied with the amount of information they received, their medical care and with their quality of life. Although we are reporting data from a small sample of patients, it appears that having an opportunity to talk with a health professional on the completion of treatment would be helpful, with those patients endorsing significantly more needs in the Quality of Life arena and Emotional and Relationship arenas.

4.2 *Conclusion*

The routine assessment of unmet needs can generate local quality assurance information for service providers, and result in the development of recommendations regarding the optimal allocation and delivery of limited health care resources [27]. Further research is needed as the small sample size in this study is representative of two haematological cancer treatment centres in Perth, Western Australia and service provision may vary between clinics in other locations. In addition, a larger sample size is required to accommodate different haematological cancers as treatments, such as bone marrow transplantation may produce different patient outcomes and hence different unmet needs.

4.3 *Practice implications*

The IOM Report “From Cancer Patient to Cancer survivor: Lost in Transition” has specified four essential components of survivorship care that are important targets for survivorship planning: prevention of recurrent or new cancers, surveillance for new or recurrent cancers, medical and psychosocial late effects; intervention for the physical and psychosocial consequences of cancer and its treatment; and co-ordination between specialists and primary care providers [12]. In addition several authors have identified the need for further research into interventions that improve the quality of life and quality of care of cancer survivors [28,29]

Our finding that patients who would have found it helpful to talk to a health professional at the completion of treatment had significantly more unmet needs in the areas of quality of life, emotions and relationships suggests that there is a sub group of patients who may benefit from an intervention in the form of a completion of treatment interview where the physical and psychosocial consequences of cancer and its treatment could be explored.

If further research supports the findings that an opportunity to meet with a health professional at the completion of treatment is useful to patients, a protocol to inform the structure of such a completion interview could be developed. This intervention, which would provide patients with the opportunity to talk with a health professional about their cancer journey through diagnosis, treatment and making the transition from active treatment to extended survivorship would need to be tested in a randomised controlled

trial to measure its impact on patients' information, emotional and support needs, cancer related anxiety, coping and psychological well-being after finishing treatment.

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Conflict of interest

All authors declare no financial, personal or other relationship with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work.

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