

Psychosocial oncology care, beyond the tertiary cancer centre

Pamela Otfinowski, BA, BScN

Susan M. Christian, MSc, CGC

Wendy D. Mackenzie, MHSA, BScN, RN

Michael Handman, PhD

Barry D. Bultz, PhD, CPsych

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[[résumé](#)]

A significant proportion of cancer patients require psychosocial care. Services to meet these needs are not easily accessible to many patients who live great distances from a tertiary cancer centre. A survey study was performed to determine the availability of psychosocial oncology care beyond the tertiary cancer centres in Alberta, Canada. Results showed that 95% of health care providers who responded to our survey felt that it was important for cancer patients to have access to psychosocial care. However, only 18% were satisfied with the support services available in their community. Recommendations were developed based on the results of the study, the principles of the Canadian health care system, and standards put forth by the Canadian Association of Psychosocial Oncology. These recommendations include identifying qualified psychosocial oncology providers, allocating more time for professionals to counsel cancer patients, linking psychosocial oncology professionals across the province and increasing awareness of psychosocial oncology services.

Un pourcentage important de patients atteints du cancer ont besoin de soins psychosociaux. Les services qui peuvent répondre à ces besoins ne sont pas faciles d'accès pour beaucoup de patients vivant loin d'un centre d'oncologie tertiaire. On a réalisé un sondage pour déterminer la disponibilité de soins psychosociaux en oncologie ailleurs que dans les centres d'oncologie tertiaires en Alberta, au Canada. Le sondage a montré que 95 % des répondants prestataires de soins étaient d'avis qu'il est important pour les patients atteints d'un cancer d'avoir accès à des soins psychosociaux. Seulement 18 % étaient toutefois satisfaits des services de soutien

disponibles dans leur communauté. On a formulé des recommandations fondées sur les résultats de l'étude, les principes du système de soins de santé du Canada et les normes mises de l'avant par l'Association canadienne d'oncologie psychosociale. Ces recommandations visent notamment à trouver des prestataires qualifiés de soins en oncologie psychosociale, à accorder plus de temps aux professionnels pour qu'ils conseillent leurs patients atteints du cancer, à établir un réseau de professionnels de l'oncologie psychosociale de la province et à faire mieux connaître les services d'oncologie psychosociale.

Introduction

It is well established that cancer not only affects the physical functioning of a patient but can be detrimental to an individual's psychological and social functioning.¹⁻⁴ The literature indicates that approximately 30% to 40% of all cancer patients will need specialized psychosocial oncology support at some point during their illness.¹⁻⁴ Although these needs are evident for patients living in both large cities and rural and remote areas, the services to address psychosocial oncology distress are not equally accessible.⁵⁻⁸

McGrath and colleagues^{9,10} have studied the needs of cancer patients living in rural communities. Results from a study assessing psychosocial support following treatment for hematological malignancies found that distance was one of the main barriers in accessing services. Other obstacles included lack of local services and lack of awareness of local services.¹⁰ This study also found that, upon returning to their community following treatment, 41% of patients felt the health and allied health professionals in their community did not have sufficient knowledge about their illness.

Alberta is geographically divided into 17 health regions with responsibility for health services for their residents. Many of these regions are sparsely populated: approximately 38% of Alberta's population resides outside the 2 main urban areas with tertiary cancer centres — Edmonton and Calgary.¹¹ Because patients often have to drive several hours to obtain services at a large centre, the provincial health authority for cancer programs, the Alberta Cancer Board, recently opened additional cancer centres around the province. This allows cancer patients to receive some services closer to home.

At the time of this survey, the support services available to cancer patients living outside of Edmonton and Calgary were informal and inconsistent, both between and within regions. Furthermore, family physicians (FPs), social workers,

psychologists and psychiatrists were providing care without training specific to the experience and needs of cancer patients.

To improve the provision of psychosocial oncology, in 1999 the Canadian Association of Psychosocial Oncology (CAPO) developed the "National Psychosocial Oncology Standards for Canada."¹² Psychosocial oncology is defined as "a professional sub-specialty in oncology" and includes "the formal study, understanding and treatment of the social, psychological, emotional, spiritual, quality of life and functional aspects of cancer as applied across the cancer trajectory from prevention through bereavement."¹² The CAPO Standards state that patients should have access to psychosocial services regardless of geographical location.

The Alberta Cancer Board hopes to improve access and awareness of psychosocial services in rural and remote areas of Alberta. In an effort to achieve this goal, an assessment of the status of available psychosocial services was needed.

The purpose of this study was four-fold:

1. to sample a group of rural health care professionals and determine what proportion of cancer patients they refer for psychosocial care;
2. to identify support services being offered to these patients;
3. to assess community health care professionals' satisfaction with available psychosocial oncology services; and
4. based on the results, to provide recommendations to improve access to services.

Materials and methods

As part of the Alberta Cancer Board's efforts to provide greater access to psychosocial services in rural Alberta, a cross-sectional survey was performed in December 1999. Questionnaires and self-addressed, postage-paid envelopes were mailed to health care professionals providing psychosocial care outside of the Edmonton and Calgary regions. The CAPO definition of psychosocial oncology¹² was included in an accompanying letter to further clarify the scope of services being assessed. The study population included all rural and remote health care social workers registered with the Alberta Association of Registered Social Workers (now known as the Alberta College of Social Workers), psychologists registered with the Psychologists' Association of Alberta, and psychiatrists registered with the College of Physicians and Surgeons of Alberta (CPSA). In

addition, 25% of Albertan FPs practising outside of Edmonton and Calgary and registered with the CPSA, were randomly sampled. A group represented by 25% of FPs was chosen for practical purposes and to equalize the study subgroups.

Participants were asked to complete 12 multiple-choice questions ([Appendix 1](#)) addressing their current practice and their satisfaction with psychosocial oncology care in their region. Space was also provided for comments. Chi-squared analysis was used where appropriate, although most of the data were descriptive in nature.

Results

Five hundred and forty-eight questionnaires were mailed out; 173 were returned. Of these, 15 were excluded from the study either because the health care professional had moved or the questionnaire was returned blank. Incomplete questionnaires were included. A total of 158 questionnaires were included in the study, giving a response rate of 30% (158/533). There was no significant difference in the response rate based on profession. In addition, each health care region in Alberta was represented.

Overall, 95% (144/151) of respondents reported that they felt it was important or very important for their cancer patients to have access to psychosocial support in their community. Eighty-four percent of professionals (129/153) felt that $\geq 50\%$ of their patients could benefit from accessing such services (10% [15/153] were unsure of the proportion that could benefit). There was no significant difference in responses based on profession.

FPs were also asked what proportion of their cancer patients they refer for psychosocial support. Twenty-five percent (17/68) stated that they do not refer any of their patients, 41% (28/68) refer less than 30% of their patients, and 31% (21/68) refer 30% or more.

Eighty-six percent (60/70) of FPs thought they were the primary source of support and counselling for their cancer patients and their families in the community. Peer support groups were reported as the second most common primary source of support and counselling (11%). Twenty-seven percent of respondents stated that they had referred patients to peer support services. Other support services referred to included social work, psychology, psychiatry, home care/palliative care, grief counsellor, support groups, nursing staff, Internet support and holistic health services.

When participants were asked if they were satisfied with the current psychosocial support services available in their community, 18% (27/149) reported they were satisfied, 54% (81/149) were not satisfied and 28% (41/149) were unsure. There was no difference in satisfaction with services based on profession.

When asked if they were interested in being educated to provide psychosocial oncology care, 67% (44/66) of FPs, 87% (26/30) of social workers, 88% (36/41) of psychologists and 82% (9/11) of psychiatrists reported that they were interested.

A significant difference was found between health care profession and whether or not individuals felt that they had adequate time to address the psychosocial needs of their cancer patients. Only 23% (16/69) of FPs and 29% (9/31) of social workers felt that they have adequate time to address these needs versus 43% (17/40) of psychologists and 58% (7/12) of psychiatrists ($p < 0.001$).

A significant difference was found between health care professionals who were interested or very interested in learning more about psychosocial oncology: 78% (52/67) of FPs stated that they were interested in learning more versus 100% (30/30) of social workers, 98% (40/41) of psychologists, and 100% (12/12) of psychiatrists ($p < 0.004$).

Many respondents provided comments addressing issues not directly asked in the questionnaire. The comments were classified into 4 categories: 1) rural isolation or lack of services ($n = 19$), 2) the need to increase awareness of services ($n = 11$), 3) lack of time or compensation ($n = 6$) and 4) other ($n = 20$). The category entitled "other" contained comments ranging from lack of experience with cancer patients to suggestions on improving services.

Discussion

Results of this survey reveal that, in December 1999, 95% of health care professionals practising outside of the regions of Edmonton and Calgary, felt that it was important for cancer patients to have access to psychosocial care. As previously stated, the literature suggests that 30% to 40% of all cancer patients will require professional psychosocial support.¹⁻⁴ However, results show that only 31% of Albertan FPs who responded were referring the appropriate proportion ($\geq 30\%$) of cancer patients for support. Respondents' comments suggest that the lower than expected rate of referrals is likely due to lack of services or lack of awareness of services in their community. Research has shown that physicians often have

difficulty recognizing when patients are experiencing psychosocial distress.¹³ Overall, in our study only 18% of health care professionals were satisfied with the support available in their community.

Our survey found that the FPs who completed the questionnaire felt they were the most accessed source of support for cancer patients. Interestingly, however, only 23% of FPs felt that they had adequate time to address their cancer patients' psychosocial needs.

The survey conducted is limited because the question set is small and the survey assesses community psychosocial oncology services through health care professionals. It would be valuable to assess awareness of, and satisfaction with, community psychosocial resources directly from individuals affected by cancer. This could be done through a questionnaire or focus groups involving cancer patients living in rural and remote areas of Alberta.

Recommendations

Recommendations to improve psychosocial oncology care throughout the province of Alberta are based on the results of this study, the principles of the Canadian health care system and the CAPO Standards.¹²

1.

Health care professionals should be identified in each region and educated to provide psychosocial oncology care to patients living in their community. Regionally employed social workers and psychologists are likely the most practical individuals to provide professional support to cancer patients in their community because of their abundance in rural and remote areas and the fact that there is no charge to patients for their services. The CAPO Standards state that psychosocial oncology professionals will have a graduate degree in social work, psychology, psychiatry or at least 3 years' supervised experience in psychosocial oncology post-baccalaureate.¹² It should be noted that many communities of Alberta do not have professionals with education or experience to achieve this standard.

Overall, 87% and 88% of social workers and psychologists stated that they were interested in being educated to provide psychosocial oncology care, respectively.

2.

Because only 29% of social workers and 43% of psychologists felt that they have

adequate time to address the psychosocial needs of cancer patients, the time allocated to counselling cancer patients should be re-assessed by the health regions.

3.

A network should be developed among psychosocial oncology health care professionals living in communities across the province to provide professional support and further improve patient care.

4.

An effort should be made to increase awareness of services available within each community. It would be helpful for health care professionals and peer support groups to collaborate and educate FPs, as the primary care providers, about their services.

McGrath and colleagues⁹ found that 9/11 (82%) breast cancer patients who were aware of the availability of a social worker in rural and remote Queensland, Australia, pursued psychosocial care. Their study suggests that a large obstacle for cancer patients receiving counselling is awareness of the availability of psychosocial oncology care providers.

McGrath and colleagues⁹ suggest that although many rural regions do have a range of existing services, many patients fall through the cracks and are not appropriately supported. The presence of social workers and psychologists in rural areas of Alberta suggests that this may also be true in Alberta. The development of a formal provincial psychosocial oncology program could work toward increasing awareness of services among health care professionals across Alberta.

The Alberta Cancer Board has recently funded a Psychosocial Oncology Initiative with the intention of developing a structured provincial program. The program will use the recommendations discussed in this paper to develop psychosocial oncology services in the province. The main goals will be to educate health care professionals providing psychosocial care to cancer patients beyond the tertiary centres, to directly link psychosocial oncology professionals at the tertiary cancer centres with professionals in the outlying regions, and to increase community awareness of all psychosocial services. The program will also include an evaluation component.

Affairs and Community Oncology, Alberta Cancer Board, Calgary, Alta.; Wendy D. Mackenzie, MHSA, BScN, RN, Medical Affairs and Community Oncology, Alberta Cancer Board, Edmonton, Alta.; Michael Handman, PhD, Department of Psychology, Cross Cancer Institute, Edmonton, Alta.; Barry D. Bultz, PhD, CPsych, Department of Psychosocial Resources, Tom Baker Cancer Centre, Calgary, Alta.

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Correspondence to: Susan Christian, Department of Medical Genetics, Alberta Children's Hospital, 1820 Richmond Rd., Calgary AB T2T 5C7

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