

Needs of cancer patients treated in rural and urban cancer departments

Angelina Mercuri^{AC} and Susannah Kallady^B

^ARadiation Therapy Staff Austin Radiation Oncology Centre, Austin Health, Heidelberg, Victoria 3081, Australia.

^BRadiation Therapy Staff Ballarat-Austin Radiation Oncology Centre, Austin Health, Ballarat, Victoria 3350, Australia.

^CCorrespondence email: Angelina.Mercuri@austin.org.au

Abstract Literature indicates that cancer patients experience high levels of unmet needs, particularly in relation to health information, psychological requirements and physical and daily living needs. It suggests that the needs of patients living in rural areas are likely to be higher than those of urban patients due to geographical factors and health service accessibility issues. This paper will explore the needs of cancer patients with particular focus on the impact of location (rural vs. urban), present the basis of these needs and identify strategies that address the needs expressed, by reviewing current literature.

Keywords: cancer, needs, rural, strategies, urban

Introduction

Throughout the world, cancer is a major cause of morbidity and mortality, with 9 million individuals diagnosed and 5 million dying from the disease annually.¹ In Australia, approximately 55,000 new cases are detected each year, with the disease being the second most common cause of death, accounting for roughly one-quarter of all deaths.²

Most cancer patients now endure a combination of effective, though at times traumatic, treatments such as surgery, chemotherapy, radiation therapy and hormone therapy.² Although these treatments can, potentially, cure and/or prolong the lives of those with cancer, they are often associated with a plethora of physical and psychosocial problems.² The psychosocial morbidity experienced by cancer patients has been estimated using customer satisfaction surveys and, more recently, needs assessments.^{2,3}

The literature indicates that cancer patients encounter high levels of unmet needs, particularly in relation to health information and communication, psychological requirements, support needs and physical and daily living needs.^{3,4} The literature also suggests that such needs differ according to the population studied, with the unmet needs of patients living in rural areas likely to be higher than those of urban/metropolitan patients.^{1,3}

Rural areas are defined as 'sparsely settled places away from the influence of large cities and towns'.⁵ Australians living in rural and remote locations make up approximately 29% of the total population; the difficulties associated with access to community services, hospital-based services and specialist local care in such areas are well documented.^{6,7} Lack of local cancer services, few local cancer support networks and additional costs in regards to travel requirements and accommodation needs are of chief concern.⁷

This paper will investigate the needs of cancer patients, with particular focus on the impact of location (rural versus urban), present the basis of these needs, and identify strategies that address the needs expressed. It is anticipated that the results

presented will increase awareness of and provide information on what rural and urban cancer centres can do to offer their patients superior cancer care.

Physical and psychological problems experienced by cancer patients

Cancer and its treatment not only affect patients physically, through side effects like anorexia, pain, fatigue, skin reactions, nausea and alopecia,⁸ but also causes great emotional strain. Psychological emotions experienced include: uncertainty, worry, guilt and stress caused by the cancer diagnosis, as well as body image changes following treatment.⁹

Quality-of-life research has shown that cancer diagnosis and subsequent treatment can have an adverse effect on all areas of a patient's life, including work and social activities, sleep patterns and sexual activity.² Family life can also be significantly disrupted, with cancer care often altering family lifestyle and arrangements.⁷ Families may become separated while a member is being treated. For example, a patient requiring long-term treatment, such as radiation therapy, may have to live away from home when the treatment service location is distant to their place of residence.⁷

Studies investigating psychological aspects of cancer have suggested that cancer patients face clinically significant levels of anxiety and depression.² Approximately 20–40% of cancer patients reportedly display severe emotional distress.¹⁰

If unnoticed and untreated, patient distress can have a harmful impact on medical outcomes due to lack of willingness to undertake treatment programs. This may result in reduced patient satisfaction and augmented health care costs as patients make more appointments with doctors and hospitals.¹¹

It is, therefore, imperative that cancer professionals are conscious of the occurrence of such problems in their patients, and that they endeavor to prevent and/or deal with such problems when they arise.²

Needs assessments

'Needs' can be defined as the requisite of some action or resource that is necessary, desirable or beneficial to achieve optimal wellbeing.²

The needs of patients have long been obtained by hospitals and health care organisations through the use of customer satisfaction surveys.¹² A downfall of such surveys, however, is that they involve assumption of issues believed to be of importance to customers, with detailed information necessary to guide the improvement of health services often not addressed.¹²

In contrast to satisfaction surveys, needs assessments unequivocally assess and recognise specific patient issues, as well as the perceived scale of these issues.² They allow individuals and subgroups of patients with higher need levels to be identified and targeted with suitable early interventions and also make it probable for aspects of health services that need improvement to be recognised and prioritised.²

As an example, the *Supportive Care Needs Survey* is a needs assessment developed in Australia that measures the global needs of oncology patients.⁷ The survey is made up of 59 items assessing five factor-based areas of need, including psychological requirements, health information needs, physical and daily living needs, patient care and support and sexuality issues.⁷ Each question is preceded with the stem inquiry 'In the last month, what was your level of need for help with...?' with a five-point response system ranging from 'no need' to 'high need'.¹ Sixteen extra questions are associated with perceived needs for access to services and resources.⁷ The purpose of this survey, which demonstrates evidence of face, content and construct validity,¹³ is to provide a comprehensive and direct assessment on the multidimensional impact of cancer on the lives of cancer patients.¹

General needs of cancer patients

Research using needs assessments have indicated that cancer patients experience high levels of unmet needs across a range of domains.

In 2000, a large-scale study describing the occurrence and predictors of unmet needs among cancer patients in New South Wales (NSW), Australia, was conducted by Sanson-Fisher *et al.*¹ using the valid *Supportive Care Needs Survey* described above. Across all treatment groups and centres of care, the highest level of need for the 888 respondents was found to be in the psychological domain, which accounted for half of the top 10 areas of need.¹ Three of the top 10 were from the health system and information needs category and two from physical and daily living.¹

Such results are uniform with other research, which show high levels of unmet needs in the psychological^{7,12,14} physical/daily living¹⁵⁻¹⁷ and communication/information domains.¹⁴

The survey by Sanson-Fisher *et al.*¹ also demonstrated that subgroups of patients encountered different types of needs. For example, those of younger age (less than 60 years) and of more advanced cancer progression were all reported to have higher unmet needs than their counterparts.¹

Rural health

Rural community residents tend to have numerous health disadvantages compared with their urban equivalents, which reflects in the differences in health status between the two.¹⁸

For example, rural areas have steadily higher levels of health risk factors, mortality and disease incidence and hospitalisation.¹⁸ Many aspects are believed to contribute to this rural health disadvantage, including:

- geographic isolation and restricted access to health care resources
- reduced preventative and early detection programs
- shortage of health care services and specialists
- socioeconomic discrepancies due to:
 - aging population
 - poor education
 - economic disadvantage
 - increase in those uninsured or underinsured.¹⁸⁻²²

Rural location has been found to influence doctor referral behavior given that distance, travel time and access by car or public transport often play a part in a patient's decision to attend appointments.²³ Additional time and financial resources are usually required for patient travel.²⁴ Generally, rural patients are less well off in terms of income compared to metropolitan patients, yet must meet higher costs due to travel expenses and accommodation.²⁴

In Australia, those living in rural and remote areas have a poorer survival rate after a cancer diagnosis.⁶ Advanced cancer at diagnosis and inferior cancer care appear to contribute to this.⁶

Although not all associated with survival, general documented examples of poorer cancer care and barriers to supportive care services in rural and remote areas include:

- reduced 'state of the art' diagnosis
- less local cancer services compared to metropolitan areas, particularly those offering complementary therapies, follow-up and supportive care
- lower probability of patients completing treatment
- few local cancer support networks
- geographical distance/isolation and lack of transportation to specialty care.^{6,14,19}

Needs of rural cancer patients

Although there is a paucity of literature on the impact of place of residence on the needs of cancer patients,³ relevant conclusions can be drawn from what is available. A summary of the results of recent studies focusing on the needs of rural patients is presented below.

In a study conducted in 1993, the self-identified needs and concerns of persons with cancer and their families living in rural America were analysed via questionnaire.²⁵ Categories of coping, knowledge, interpersonal relationships, treatment effects, life view, depression, loneliness and support were examined.²⁵ Concerns raised included lack of specialist cancer centres in rural towns, inadequate support groups, (particularly those offering financial and transportation assistance and group and spiritual support), and inadequate information on areas of coping, treatments and side effects.²⁵ Lack of home health care to assist with treatment side effects was also raised, with a link made between the additional responsibilities that this places on rural family members caring for the patient.²⁵ This is an important issue to address, as previous studies have indicated that formal health care providers in rural areas are not as heavily relied upon as they are in metropolitan areas.²⁵ This is as patients tend to obtain support from family and close friends and from their own self-help and reliance.²⁵

Between the years 1995-96, 229 women suffering from breast cancer in NSW, Australia, were randomly sampled to assess the prevalence and predictors of their perceived unmet needs.³ Particular focus was on impact of location. Using the *Breast Cancer Patients' Needs Questionnaire* (BR-CPNQ), which is

a valid survey that explores patients' perceived needs across five domains, women with breast cancer described unmet needs in a variety of areas, including information and psychological domains.³ The major difference in needs that existed between both populations lay in the physical and daily living category.³ In this, rural women were more likely to testify some need for help compared to urban women.³ The authors concluded that this might be a reflection of the additional strain placed on women in rural areas and the considerable number of roles that they fulfil.¹³

A published report exists on the needs of cancer patients and their families living in rural areas in Queensland, Australia, following completion of the *Supportive Care Needs Survey* between March 1999 and December 2000.⁷ Issues raised by participants included the impact of cancer on routine and lifestyle, its negative effect on family functioning and concerns over tiredness and lack of choice of treatment location.⁷ Financial pressure of disease, future financial concerns, and worry related to cancer recurrence were also mentioned.⁷ In this study, anxiety and depression were reported as being higher than would be expected in the normal population; a result most likely exacerbated by reduced access to counseling and other local services addressing psychological issues.⁷

In 2003, Martin-McDonald *et al.*²⁴ investigated the issues related to Queensland rural patients with cancer whose choice of radiation therapy treatment required travel to and accommodation at a metropolitan area. Rural patients indicated that, during the course of their treatment, they felt vulnerable and in high need of support, closeness and comfort which only loved ones and a familiar environment could offer.²⁴ Financial burdens noted included: loss of income, increased fuel costs, parking costs at the treatment centre and accommodation costs.²⁴ Over half of those interviewed commented that relocation or travel to the city for treatment caused financial strain on both themselves and their family.²⁴ During weekends and times when treatment was not active, some returned home to continue with their work.²⁴ Motivation for this work ethic was influenced by the financial pressure caused by their absence, as well as the stress such absence placed on their businesses and partners.²⁴

Strategies that address the needs expressed

As discussed, the needs of all patients with cancer are wide and varied. The quest to meet these needs is great, and often necessitates specialised strategies, particularly in rural areas where resources are more limited.²

Girgis and Burton² state that evaluating the physical symptoms and unmet needs of those diagnosed with cancer can only result in care improvement if: (a) the multidisciplinary team is conscious of the physical and psychosocial difficulties of individual patients; and (b) strategies are in place to address such issues.

In an effort to develop and improve the care of patients with cancer in NSW, funding has recently been received from the NSW Cancer Institute to implement a system assessing the psychological wellbeing of patients.¹¹ In this arrangement, a terminal server hosting a web-based survey and database will reside at the Centre for Health Research and Psycho-oncology (CHeRP), with computers displaying this survey installed in the oncology outpatient waiting rooms of participating cancer centres.¹¹ The survey, consisting of valid and reliable self-report measures of anxiety, distress, depression and perceived needs, will be completed by cancer patients on their first treatment visit, mid-treatment visit and first post-treatment review visit¹¹. After each survey comple-

tion, results will be printed, (with the patient's permission), and placed in their medical file for follow-up by the health care team.¹¹ Printed results will include a synopsis of the patient's psychological wellbeing, incorporating score interpretation and a warning for those requiring some sort of psychosocial care or referral.¹¹ The degree of care required is based on a pre-determined algorithm of possible responses to the psychosocial measures and is intended to make certain that psychosocial resources are assigned in a systematic way and modified to each patient's needs.¹¹

To recognise suitable clinical pathways and referral systems for patients with different psychological, social and living needs, literature suggests the organisation of multidisciplinary workshops to ensure that actual management and referral processes (i.e. to social workers, psychologists, cancer support groups) are in place across a centre.² Team meetings held in cancer departments are also beneficial as they increase awareness of the most recent information of a patient's condition, medication, needs and emotional state.²⁶ Weekly multidisciplinary team assessment meetings are commonly held in both rural and metropolitan cancer centres in Australia.

For patients and their caregivers, support groups are helpful in assisting in the discussion of problems and potential solutions.¹⁹ For example, community support groups allow individuals to associate with others in the community facing cancer-related issues.¹⁹ Services reducing physical and daily-living strains, such as meals on wheels, home cleaning, garden maintenance and child day care, are also beneficial to patients and/or their families. Although such emotional and home help support services are widely in existence in urban areas,²⁷ they are often difficult to start and maintain in rural areas.¹⁹ Literature suggests that local agencies or church groups could initiate such services, as these organisations are more trusted and acceptable to persons in rural areas.¹⁹

Provision of information is vital for all aspects of cancer care, but in particular in the decision-making process in regards to treatment and in obtaining informed consent.¹⁰ Patients and their families should have access to written and verbal information on all aspects of a particular cancer that is diagnosed, including details about the disease, its symptoms, prognosis, side-effects of treatment, palliation and community resources.²⁸ In the case of rural patients receiving treatment in metropolitan areas, further information is required on travel and accommodation subsidies.²⁸ Families also often need to be prepared for caring for a sick relative, particularly if the condition progresses to the point where knowledge is required about end of life care.²⁸

Being given information decreases fear and empowers an individual by increasing authority and control.²⁸ Suggested information provision strategies include booklets and videotapes as well as the organisation of group education programs to deal with topics such as the nature of cancer, common treatments, side-effects and support available.²⁹ In Australia, such materials are currently produced and distributed to patients by organisations such as The Cancer Council.²⁷ Additionally, some health professionals use videos in their waiting rooms to offer their patients information.²⁹

For a more individualised approach to communication of information from health professionals to family members, a suggested strategy put forward by literature is for nurses to teach and demonstrate skills that family members may require in caring for the patient at home.³⁰ Such responsibility calls for co-operation of all members of the multidisciplinary team,

particularly doctors who would be required to support nurses in such roles and encourage family members to seek information from them.³⁰ Mobile care units, through which high-quality cancer care is provided by nurses on an ongoing basis, have also been recommended by literature for both rural and metropolitan residents.¹⁹ Examples of home nursing services currently available in Victoria, Australia, include the Royal District Nursing Service, Kerang District Nursing Service and the Buchan Bush Nursing Centre.²⁷

A relatively new approach for the provision of cancer information is the use of internet kiosks. Such kiosks are common in the United States, where secure and accurate resource information on cancer is provided in traditional pharmacies and cancer centres.³¹ In rural areas, where access to information is limited, this approach would be extremely valuable and useful.

Other potential strategies to support the cancer-related information needs of both rural and urban residents include telephone access, with major medical centres providing 24-hour-a-day information, assistance, communication and support.²⁵

For housebound and isolated rural residents, social support services run by churches and volunteers through telephones may also assist and help the patient to cope.¹⁹ *Cancer Connect* services, where cancer patients are put in telephone contact with specially trained volunteers who have also experienced cancer and its treatment, are currently available in most Australian states.²⁷

For those requiring financial and material support, there are many services available in Australia.²⁷ Financial assistance schemes are currently in place and are continuing to be implemented by various community agencies.^{2,27}

Many major cancer treatment centres also have access to short-term accommodation available for patients and their families²⁷. In Victoria, a travel and accommodation subsidy scheme, called the Victorian Patient Transport Assistance Scheme (VPTAS), exists to support rural and remote patients with travel and accommodation costs encountered when traveling long distances (i.e. more than 100 km from home to the treatment centre).²⁷

To recruit and retain health care professionals in rural practice, literature suggests a range of incentives.¹⁹ These include reducing student loans, offering scholarships with stipends in return for services and increasing pay rates.¹⁹ Such incentives are currently in place in many Australian rural health centres.

Conclusion

This paper has discussed examples, derived from the literature, of the perceived needs of cancer patients living in both rural and urban areas.

In summary, the needs of cancer patients are wide and varied and cross many domains. The cancer experience of rural residents is often further intensified by separation from home and loved ones, reduced social support and financial burden.

Meeting the needs of cancer patients is challenging, but can be achieved with team awareness of the physical and psychosocial difficulties of individual patients, community and government based initiatives and support to health care professionals.

Acknowledgements

The authors would like to thank the following for their advice, guidance and support in writing this paper: Lily Obradovic, Jim Frantzis, Mark Middleton, Steve Medwell, Mary Lynton-Moll, Allison Boyes, Andrew Gray, Judy Andrews, Associate Professor Afaf Girgis, Laura Spiteri, Aldo Rolfo, Min Ku, and to all unmentioned staff at ROC and BAROC.

References

- 1 Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. *Cancer* 2000; 88 (1): 226–37.
- 2 Girgis A and Burton L. Cancer patients' supportive care needs: strategies for assessment and intervention. *NSW Pub Health Bull* 2000; 12 (10): 269–72.
- 3 Girgis A, Boyes A, Sanson-Fisher RW, Burrows S. Perceived needs of women diagnosed with breast cancer: rural versus urban location. *ANZ J Pub Health* 2000; 24 (2): 166–73.
- 4 Foot G, Sanson-Fisher R. Measuring the Unmet Needs of People Living with Cancer. *Cancer Forum* 1995; 19 (2): 131–135.
- 5 Wikipedia. The Free Encyclopedia. Rural. [web page on the Internet]. 2004. [cited 2005 May 7]. Available from: <http://en.wikipedia.org/wiki/Rural>.
- 6 Jong KE, Vale JV, Armstrong BK. Rural inequalities in cancer care and outcome. *Med J Aust* 2005; 182 (1): 13.
- 7 Clavarino AM, Lowe JB, Carmont S, Balanda K. The needs of cancer patients and their families from rural and remote areas of Queensland. *Aust J Rural Health* 2002; 10: 188–195.
- 8 myDNA Media. Side Effects of Cancer Treatment. [web page on Internet]. 2005. [cited 2005 May 10]. Available from: http://www.mydna.com/health/breast_cancer/treatment/side_effects.html.
- 9 University of California Regents. Medical Care & Info [web page on the Internet] 2000. [cited 2005 May 10]. Available from: http://cc.ucsf.edu/cis/ask_cis_q06.html.
- 10 Ziegler L, Newell R, Stafford N, Lewin R. A literature review of head and neck cancer patients' information needs, experiences and views regarding decision-making. *Eur J Cancer Care* 2004; 13: 119–126.
- 11 Girgis A, Boyes A. A 4-step model to facilitate the provision of more integrated, coordinated and patient-focused psychosocial care for cancer patients. Proceedings of the 10th Annual National Health Outcomes Conference; 2004 Sept 15–16; Canberra, Australia. Wollongong: Australian Health Outcomes Collaboration; 2004.
- 12 Gustafson DH, Taylor JO, Thompson S, Chesney P. Assessing the needs of breast cancer patients and their families. *Qual Man Heal Car* 1993; 2 (1): 6–17.
- 13 Center for Mental Health Services Research. CMHSR Measures Collection. Supportive Care Needs Survey (SCNS). [web page on Internet]. 2005. [cited 2005 August 12]. Available from: <http://gwbweb.wustl.edu/cmhsr/measure/e25.html>.
- 14 Koopman C, Angell K, Turner-Cob JM, Kreshka M, Donnelly P, McCoy R *et al.* Distress, Coping and Social Support Among Rural Women Recently Diagnosed with Primary Breast Cancer. *Breast J* 2001; 7 (1): 25–33.
- 15 Houts PS, Yasko JM, Kahn SB, Schelzel GW, Marconi KM. Unmet Psychological, Social and Economic Needs of Persons With Cancer in Pennsylvania. *Cancer* 1986; 58: 2355–61.
- 16 Walton VA, Romans-Clarkson SE, Mullen PE. Improvements urban and rural women wish to see in their health care services. *NZ Med J* 1988; 101: 80–82.
- 17 Guadagnoli E, Mor V. Daily Living Needs of Cancer Outpatients. *J Comm Heal* 1991; 16 (1): 37–47.
- 18 Australian Institute of Health and Welfare. Health in Rural and Remote Australia- Introduction. [web page on the Internet] 1998. [cited 2005 April 25]. Available from: <http://www.aihw.gov.au/publications/health/hrra/hrra-c01.pdf>.
- 19 Given BA, Given CW, Harlan AN. Strategies to Meet the Needs of the Rural Poor. *Semin Oncol Nurs* 1994; 10 (2): 114–122.
- 20 Monroe AC, Ricketts TC, Savitz LA. Cancer in Rural Verses Urban Populations: A Review. *J Rur Health* 1992; 8 (3): 212–220.
- 21 Alston M. Rural Poverty. *Aust Soc Work* 2000; 53 (1): 29–34.
- 22 Elliott TE, Elliott BA, Renier CM, Haller IV. Rural-Urban Differences in Cancer Care. Results from the Lake Superior Rural Cancer Care Project. [web page on the Internet]. 2004. [cited 2005 April 25]. Available from: <http://www.mmaonline.net/publications/MNMed2004/September/Elliott.html>.
- 23 Iredale R, Jones L, Grat J, Deaville J. The edge effect: an exploratory study of some factors affecting referrals to cancer genetic services in rural Wales. *Health Place* 2005; 11: 197–204.
- 24 Martin-McDonald K, Rogers-Clark C, Hegney D, McCarthy A, Pearce S. Experiences of regional and rural people with cancer being treated with

- radiotherapy in a metropolitan centre. *Int J Nurs Prac* 2003; 9: 176–182.
- 25 Sullivan T, Weinert C, Fulton RD. Living with cancer: Self-identified needs of rural dwellers. *Fam Community Health* 1993; 16 (2): 41–9.
- 26 Litcher I. *Communication in Cancer Care*. Edinburgh: Churchill Livingstone, 1987. pp 186.
- 27 The Cancer Council Victoria. *Cancer Services*. Melbourne: The Cancer Council; 2004: 18–23.
- 28 Wilkes L, White K, O’Riordan L. Empowerment through information: supporting rural families of oncology patients in palliative care. *Aust J Rur Health* 2000; 8: 41–46.
- 29 Lloyd M, Bor R. *Communication Skills for Medicine*. Edinburgh: Churchill Livingstone; 2004: pp 52–53.
- 30 Houts PS, Ruseas I, Simmonds MA, Hufford DL. Information needs of families of cancer patients: A literature review and recommendations. *J Cancer Educ* 1991; 6 (4): 255–61.
- 31 Cavotta MF. Cancer Resource Kiosk Initiative. [web page on the internet]. 2005. [cited 8 May 2005]. Available from: <http://www.medicalnewstoday.com/medicalnews.php?newsid=22800>.
-