

Psychosocial wellbeing and supportive care needs of cancer patients living in urban and rural/regional areas: **A systematic review.**

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Abstract

Purpose

To describe what is known about levels of morbidity and the experience and needs of people with cancer, and their carers, living in rural areas.

Methods

A search of online databases for English language papers describing or assessing the prevalence of psychosocial morbidity or needs in a population of rural or regional cancer patients. Excluded: intervention studies, discussion of service delivery, effectiveness of support groups or support via videoconferencing, concentrated on medical outcomes or survival rates, reported differences in the uptake of cancer screening, or concentrated on health attitudes or treatment decision making.

Results

There were 37 studies included in the review, including 25 quantitative studies (all surveys), 11 of which included a control group of urban patients, and 12 qualitative studies. Until recently, most studies had methodological short-comings. Only two prospective studies were identified, most studies focused on breast cancer and few addressed psychological morbidity. The majority of controlled studies reported worse

outcomes for rural patients, who appear to have higher needs in the domains of physical/daily living. This may reflect more limited access to resources, a more self-sufficient lifestyle and personal characteristics, for example, being more stoical and less likely to ask for help. The need to travel for treatment caused many practical, emotional and financial problems for patients and burdened them with additional worry concerning family and work commitments. Some patients reported benefits in sharing experiences with others also forced to stay away from home, but most agreed that staying at home was preferable.

Conclusion

This review highlights that whilst we are beginning to get some insight into the needs of people with cancer in rural areas, much is still unknown. Population-based, prospective studies including people with heterogenous cancers from rural and urban settings are needed.

Key Words

Cancer, rural, healthcare needs, carers

Introduction

Quality cancer care is now viewed as involving more than just the delivery of anti-cancer therapy, and increasingly includes addressing patients' supportive care needs. Supportive care can be defined as care that helps a person with cancer and their family cope with cancer and its treatment, from pre-diagnosis through the process of diagnosis and treatment to cure, continuing illness or death and into bereavement [1]. Patients living in rural and regional areas are likely to have unique supportive care needs.

Approximately 2.3% of Australians live in remote or very remote areas and 29% live in regional areas of Australia [2]. Definitions of what constitutes rural, remote and regional vary. For example, the Australian Bureau of Statistics (ABS) endorsed measure of remoteness, ARIA+ [3], is an unambiguously geographical approach based on road distance measurements to the nearest service centres of varying sizes. ARIA+ classifies places into five categories: very remote, remote, moderately accessible, accessible, highly accessible. Other definitions are based on population size, or refer to wide open spaces in which agriculture is practiced. Unfortunately, most studies comparing outcomes for remote, rural, regional and urban settings do not define what they mean by these terms, making comparisons difficult. Further, the meaning of such terms and the scales used to define them, are likely to vary across countries of different sizes. Clearly a remote area in Australia will be very different to a remote area in England! While such definitional vagueness complicates interpretation of studies and comparisons across studies, there remains inherent value in comparisons of urban versus rural/regional populations to ensure that the needs of rural/regional/remote populations are understood and met.

Research has revealed evidence of significant disparities in cancer survival between urban and regional or rural patients [4,5]. Contributing factors may include geographic isolation, delayed diagnosis, inadequate transportation, health workforce shortages and a higher proportion of people of lower socioeconomic status [4,5]. Cancer services are fewer in these areas, and most patients have to travel significant distances to access cancer care, which may influence their treatment decisions; e.g., in a study of 1,453 NSW cancer survivors, 10% reported they had had to live temporarily away from home to receive cancer treatment and 15% had to travel more than 2 hours to receive radiotherapy [6].

Psychosocial morbidity and unmet needs may also be greater in rural/regional residing cancer patients, in part due to isolation from information and support services, extra demands/ expectations placed upon them and the larger number of roles that they might play [7-11]. Such patients may also be reluctant to accept services even when offered, due to a stoic and 'matter of fact' approach to life, concerns about privacy in a small community, and practical considerations such as availability of transport, financial issues and farm, small business and family needs [8-11].

In 2005, the Clinical Oncological Society of Australia (COSA) commissioned the first national survey to map regional and rural oncology services in Australia. Suboptimal service levels (clinical and supportive care services) were recognised in all regional and rural areas [12]. Sub-optimal services are likely to compound the challenges experienced by rural cancer patients. To improve service delivery, a clear understanding of the supportive care needs of rural cancer patients and families, both unique and shared with their urban counterparts, is required.

The purpose of the present review is to describe what is known about the experience and supportive care needs of people with cancer, and their carers, living in rural areas.

Methods

Search Strategy

A systematic search of three electronic bibliographic databases was conducted in the second week of March 2011. The following databases were searched; RURAL: Rural and Remote Health Database via Informit Online (1996 - 2006), PsycINFO via OvidSP (1806-present) and Medline (1950-present). The search was limited to studies in the English language involving people over 18 years of age. The reference lists and authors of obtained studies were searched for additional studies.

The following search term was used to search in topic (Medline), keyword (PsycINFO) and any field (RURAL):

cancer* AND (qol or (quality life) or wellbeing or well-being or psycho* or social or emoti* or adjust* or depress* or anx* or (unmet need*) or need* or morbidity or distress) AND (Rural or regional or remote or travel) NOT (child* or indigenous* or aborigi* or screening*).

The inclusion criteria were studies assessing psychosocial morbidity or supportive care needs in a population of rural or regional cancer patients. Studies were eligible if they compared cancer patients from rural areas with patients from urban areas in terms of

psychosocial outcomes or supportive care needs; or discussed these issues for rural cancer patients or their carers alone. Study participants had to include adult cancer patients, adult cancer survivors, or cancer patients in palliative care. Studies of family members or friends who were caring for cancer patients were also included. The setting had to be described as a regional or rural area(s) of Australia or as a rural area for other countries of the developed world. Both quantitative and qualitative studies were included in the review.

Studies were excluded if their focus was not on reporting the prevalence of psychosocial morbidity or supportive care needs; i.e. they were intervention studies, discussed service delivery, discussed the effectiveness of support groups or support via video-conferencing, concentrated on medical outcomes or survival rates, reported differences in the uptake of cancer screening, or concentrated on health attitudes or treatment decision making. Studies were also excluded if they studied psychosocial outcomes in the indigenous cancer population, as the issues and challenges facing this population were thought to be unique. Finally, studies were excluded if they were conducted in non developed countries, because the cancer services and conditions in these areas may be vastly different to those in developed countries.

The selected papers were graded using adapted checklists for the quantitative studies [13] and qualitative studies [14]. JS and PB graded a random sample of 10 papers, five qualitative and five quantitative. Where reviewers disagreed on methodological aspects, the article was discussed until consensus was reached. After that a further six studies were assessed by both reviewers and a kappa score was calculated. The study quality checklist used for the quantitative studies covered 20 items and an

excellent kappa score of $K= 0.857$ was reached. The list for the qualitative studies covered 34 items and a good score of $K= 0.617$ was reached. The remaining studies were rated by JS alone.

The percentage of items on which studies were rated as including essential quality characteristics was calculated. Studies which achieved less than 40% were classified of poor methodology quality. Studies reaching a percentage from 40% to 70% were classified of good quality. Studies reaching a score higher than 70% were classified being of very good quality.

Results

Of 21218 identified papers, 98 were retrieved for full text screening and 37 met the inclusion criteria (see Figure1). Of these 37 papers, 16 were Australian studies and 21 were from a developed country including USA, Canada, Norway and the UK. All but two studies were cross-sectional.

There were 25 quantitative studies (all surveys), 11 of which included a control group of urban patients, and 12 qualitative studies. Study samples consisted mainly of breast cancer patients; 15 studies included only breast cancer patients, four studies had mainly breast cancer patients and three had breast and prostate cancer patients. Two surveys included gynecological cancer patients, another focused on colorectal cancer patients, nine included heterogeneous cancer types and three did not specify type of cancer. Twenty-four focused on the active treatment phase, 13 on cancer survivors. Eight studies included the perspectives of carers.

Due to the very disparate nature of designs and measures used, meta-analysis was not possible. Few studies clearly defined rurality, although this was more common in recent studies. This made it even more difficult to compare study results, since rurality in countries as large and sparse as Australia may mean very different things to rurality in smaller, more densely populated countries such as UK. Below we present the results of quantitative papers with a control group, then quantitative papers without a control group, qualitative papers with a control group, and qualitative papers without a control group.

Quantitative studies with control groups

Quantitative studies with a control group are presented in Table 1. There were 11 quantitative studies with a control group [15-25]. Three addressed emotional issues, one travel issues and the remainder the general needs and quality of life of cancer survivors. Only one was longitudinal [16].

Table 1 about here.

Of seven studies exploring needs and quality of life, four (three Australian and one US) reported poorer outcomes for rural patients [19,21, 22, 24], one (US) found that urban patients had more needs than rural patients [23], and two (one Australian and one US) found no differences between groups [20,25]. Daily living, physical functioning and symptoms were most likely to be worse in rural samples.

One US study of 116 heterogenous cancer patients [17] compared rates of emotional morbidity between urban and rural cancer patients; rural patients reported significantly

poorer mental health functioning (effect size – ES= 0.45), higher levels of anxiety (ES=0.70) and depression (ES=0.47), greater distress (ES+0.41) and more emotional problems (ES=0.47) than nonrural cancer survivors. There was no difference between groups for positive mental health outcomes such as benefit finding.

Factors promoting lower depression in women with breast cancer were explored in two papers, one from Australia, the other from US. Active coping and positive reinterpretation [16] and the belief that one's health is determined by powerful others [15] were protective for women in rural areas, while behavioural engagement [16] and the belief that internal factors are responsible for health/illness [15] were protective for urban women.

Patients living away from home [16], while noting the helpful contribution of staff in their accommodation, were significantly more likely to report dissatisfaction with accommodation than patients who stayed in their home (Mann Whitney $u=202$, $p=0.016$). Patients who stayed at home while receiving treatment in this US study, also described a better sense of normality. One study comparing patients living in Guernsey who had to travel to England for treatment with those living in England close to the treatment centre [18] found that whilst patients who were able to stay at home valued maintaining normality in their lives, patients who travelled actually perceived themselves to have better social support. They benefited from contact with other people in the same situation as themselves in the accommodation centres. However, some patients who travelled for treatment, who were responsible for the care of another, worried that their absence would negatively affect that person. Dealing with treatment side effects in an unfamiliar environment was also seen as difficult by patients.

Quantitative studies with no control group

There were 14 quantitative studies without a control group, three on emotional aspects, three on travel issues and eight on needs and quality of life, all in the active phase of treatment [9,11, 26-37]. Only one study [35] was longitudinal.

Table 2 about here.

These papers described a range of concerns and challenges for rural patients and their families, including physical symptoms, fears and financial difficulties [26-28]. Caregivers often felt more worried than patients [28]. One US study [27] found that patients experiencing other stressful events, and who lacked self efficacy, were more likely to have poor mental health outcomes.

The studies focusing on needs and quality of life in the active treatment phase showed general agreement that patients in rural areas have significant information, financial and support needs, particularly those forced to travel for treatment and leave the support of their family and local community. About 5-30% of the samples reported needing help with a range of issues.

One US study [37] compared their results with a previous study [49] which was conducted five years previously on an urban sample with similar characteristics (but with higher education). While differences were few, good physical care, knowing when to call the physician, and a need to be well organized were only highlighted by rural patients.

This was thought to be a reflection of the more stoic nature of people in rural communities who are less likely to ask for help and have many other responsibilities, such as their own businesses, so need to be organized.

Caregivers from US rural communities had more needs than patients in the areas of side effects of treatments, the symptoms to expect as the disease progressed, help to communicate with the patient, and for comfort and support from other family members [37]. Caregivers indicated more need areas than patients, reporting needs in the areas of personal care, activity management, involvement with health care and interpersonal involvement, although patients identified more total needs than carers [37]. Another Australian study [29] focused on carers' issues during palliative care, and emphasised high family needs for information, equipment and 24-hour care.

The single longitudinal study, with a sample of 89 Australian women with breast cancer [35], reported that most needs decreased significantly between 1 and 3 months post diagnosis, although sexuality needs increased over this timeframe. The most common reported needs at one month post diagnosis were psychological: worries for those closest to you, fears about the cancer spreading, fears about the cancer returning and anxiety about having treatment. Three months post diagnosis physical and daily living issues were more common, especially lack of energy and tiredness.

Many families reported travel was a challenge, identifying the following as needing improvement: access to information and support prior to leaving home, and for someone to help them decipher the information, access to information about supportive care services while away from home, and sensitivity to personal needs in making

arrangements for travel [11,29,30]. One Canadian study [30] compared patients who unexpectedly had to travel when it became clear that their local centre could not provide treatment in a timely manner, with patients who expected to travel because of their distance from a city, and patients who lived in an urban environment and did not have to travel. Some patients travelled daily, sometimes for quite long distances, to receive treatment, and others travelled to the treatment centre and found accommodated there. Patients reported benefits and drawbacks to being away from home, but all patients found waiting for care most distressing, and that the idea, experience and costs of travel were distressing and difficult to manage. Another Australian study which explored patient and carer needs separately [9], found that carers had higher levels of anxiety about travel than patients and reported the disruption to family life of forced travel difficult to manage.

Almost half of one US sample [37] expressed dissatisfaction with the financial burden of travel, with more women than men reporting dissatisfaction with travel arrangements. Staying in the city during treatment is more expensive in addition to telephone calls and maintaining the rural household [29]. In the Australian study by Davis et al. [11] in 1998, only 39% of the participants received financial assistance, 19% of whom had trouble claiming the money for which they were eligible. In 2003 [36], the same researchers found that 47% of the women had received financial assistance, and 13% had difficulties organising or claiming financial assistance, indicating that only small improvements had been realised since the earlier study.

However, other studies reported that patients found positive aspects of travel. Some participants felt that being away from all responsibilities gave them the opportunity

to rest without feeling guilty [38]. Patients in Canada were overall satisfied with the care provided in their accommodation [30].

Qualitative studies with control groups

Three qualitative studies with control groups, exploring respectively travel issues, needs and quality of life during active treatment, and needs and psychological morbidity in survivorship, were identified.

Table 3 about here.

A qualitative study of patients with colorectal cancer in Scotland [39] found some urban/rural differences in care, but highlighted that people from each community also responded differently to care. For example, delays in presentation were more common in rural communities, but most rural patients were happy to wait for their GP to act on their behalf, whereas their urban counterparts were more insistent. Rural patients also reported that a system that moved very quickly made things feel more impersonal, whereas the urban patients liked this.

Survivors [40] reported that transition of care or shared care was especially important to rural patients, so they had support and surveillance when they needed it. Patients in this Canadian study [40] reported that more rural patients received their care from their family practitioner than their urban counterparts. The authors felt this was appropriate since rural patients need someone to turn to who is close by for medical advice and surveillance. Some patients felt that follow-up that consisted of just an

examination, rather than invasive tests, was inferior. This was especially true for rural patients who had to travel some distance just for this physical exam.

A Canadian study on travel issues [38] confirmed the challenges of travel reported in quantitative studies. Four themes emerged: (1) waiting was the most difficult part of the experience. Throughout diagnosis and treatment patients described many times when they struggled with waiting for answers and information; (2) the idea of travelling for treatment was distressing; (3) travelling for treatment was tiring and posed difficulties for patients; and (4) being away from home had both benefits and drawbacks. However, participants also saw positive aspects of travel, perceiving it as a way to get their treatment quicker [38].

Qualitative studies without control groups

Nine qualitative studies without control groups were identified, six exploring needs and quality of life during active treatment and three exploring needs and psychological morbidity in survivorship.

Table 4 about here.

Two qualitative studies from Queensland, Australia, [8, 41] found that patients' concerns centred on their family coping with their absence from family and business responsibilities, separation from family and the strain put on family relationships, and

financial issues. Participants suggested a 24-hour information hotline or a more comprehensive list of services was needed [8].

One Canadian study [42] looked at people who chose to have their chemotherapy treatment at a local outreach service who would previously have gone to a regional centre. Most participants thought the benefits of being local outweighed any disadvantages, the main disadvantage being not having access to biomedical expertise. Another Australian study [46] highlighted that living in a rural area can have benefits, such as the support of a close community, and these were felt to outweigh the negatives.

Other studies [10,43] highlighted difficulties with travel, noting a need for help with accommodation, obtaining travel assistance, general information, transport and how to access supportive services whilst away from home. Some patients felt that they had to disclose their diagnosis wider than they perhaps might have liked. Disrupting family and work life was an issue, and participants worried about how to maintain these responsibilities whilst they were away. Many reported that they felt they were a burden to their friends and family.

Discussion

Many studies included in this review have limitations which indicate a need for new, well designed, studies. Results are difficult to compare as the settings were often weakly defined [e.g. 34] and self developed measurement tools were often used, without prior psychometric testing of the instrument [e.g. 26]. The demographic and disease characteristics of the participants were often not well described. Studies either did not measure the time since recurrence [e.g. 32] or collected no information about current

cancer treatment [e.g. 11]. The possibility for bias in the recruitment process was noted in many studies [e.g. 35,40]. Almost all the studies (including population based studies with a control group) used a cross sectional design, leading to a lack of measurement of long term outcomes and an inability to explore causality. From 37 reviewed studies 22 were mainly or entirely on breast cancer patients, which limits the generalizability of results presented in this review. Further, rurality was rarely well defined. Similar methodological problems were noted in a wider review of studies reporting unmet supportive care needs in cancer patients [48].

Only one study included urban and rural general population control groups as well as directly comparing urban and rural cancer populations [19]. While the number of more rigorous, population-based studies with an urban control group has increased in the past few years, most have measured unmet needs or quality of life, with only one study addressing psychological morbidity [17]. More research is needed for different cancer types and addressing psychosocial morbidity.

Nonetheless, the studies described here shed some light on disparities between urban and rural cancer patients. While results of the seven studies including a control group were inconsistent, with one finding that urban patients had more needs than rural patients [23], and two finding no differences between groups [20,25], the majority (four) reported poorer outcomes for rural patients, including higher psychological morbidity and poorer quality of life [19,21, 22, 24]. Daily living, physical functioning and symptoms were most likely to be worse in rural samples, suggesting less effective supportive care in rural areas, while information needs were high in all samples. Such differences may reflect differences in the characteristics of the rural community in terms of needing to be

self sufficient and finding it difficult to ask others for help. Many patients however, felt that there were benefits to living in a rural community and that these outweighed any negatives.

The single longitudinal study conducted in this area on needs, noted that needs change as the disease progresses [16]. Whilst in the early days post diagnosis needs might revolve around providing information and support to allay fears and anxieties about the cancer spreading, once treatment commences needs focus more around the practical issues of being able to perform activities of daily living, and it is in this area that rural patients in particular report greater challenges and requiring greater support. None of the studies distinguish between information and education, or address how patients would like to receive education or information. However, in one study patients suggested that a telephone helpline would be of benefit [8].

Many rural patients and families reported rural-specific challenges, particularly those caused by the need to travel to receive cancer treatments. Whether this was travelling daily or staying away from home for periods of time, families reported financial, emotional and relationship challenges associated with travel. However, some patients valued the greater expertise available in urban settings and some found the support of staff and others in the same situation available in accommodation centres was helpful. It is therefore important that the choice of where to receive treatment remains, but patients and their carers clearly signalled a need for more information and financial and emotional support to help them to make this choice and manage travel.

Interestingly, one small study found that urban and rural women with breast cancer differed in the coping styles which were protective against depression. Active

coping, positive reinterpretation and the belief that one's health is determined by powerful others were protective for women in rural areas while behavioural engagement and the belief that internal factors are responsible for health/illness were protective for urban women [15,16]. While requiring replication and examination of the applicability of findings to other cancer types, this suggests that interventions for urban and rural women might best focus on supporting different coping strategies.

Limitations This review focused on descriptive studies of rural/urban differences and did not include intervention studies. A previous review has examined some of the innovative solutions [50].

. We excluded non-English papers and are therefore unable to comment on similarities of experience in rural patients in non-English-speaking countries. Finally, dissimilarities in measures, samples and designs precluded meta-analysis, so that comparisons between studies are conceptual, rather than statistical.

Conclusion

The importance of providing high quality, accessible health services to people with cancer living in rural areas, particularly in large countries with rural areas many miles from regional and urban centres, such as Australia, is obviously of high importance. This review indicates that in the area of supportive care, especially daily living needs, physical functioning and informational and emotional support, patients may not currently be receiving such a service. Such results were consistent across countries, suggesting this is a universal issue. Well-designed, prospective studies of people with heterogeneous

cancers with control groups and using standardised measures and reporting methods are needed.

Conflict of interest

The authors do not have any conflicts of interest to declare.

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