

✧ RESEARCH PAPER ✧

Experiences of regional and rural people with cancer being treated with radiotherapy in a metropolitan centre

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This paper explores the issues related to rural people with cancer whose choice of radiotherapy treatment necessitated travel and accommodation in a metropolitan centre. Semi-structured interviews with 46 participants, from the Toowoomba and Darling Downs region of Queensland, Australia, were conducted and the data thematically analysed. The specific themes identified were: being away from loved ones, maintaining responsibilities whilst undergoing treatment, emotional stress, burden on significant others, choice about radiotherapy as a treatment, travel and accommodation, and financial burden. This study supports the need for a radiotherapy centre in the location of Toowoomba as a way of providing some equity and access to such treatment for the rural people of Queensland.

Key words: cancer, radiotherapy, regional, rural.

INTRODUCTION

People who develop cancer in the Toowoomba and the Darling Downs health catchment area in Queensland, Australia, are disadvantaged compared to metropolitan cancer patients regarding accessibility to treatment

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options. Current practices in the management of cancer in rural Queensland are influenced by the limited availability of specialist medical services for cancer; and the shortage of general medical practitioners, allied health professionals and specialist cancer nurses.¹

For the purposes of this study, 'rural' was defined according to the Rural, Remote and Metropolitan Areas Classification.² This classification defines areas of Australia according to their population density and degree of remoteness from metropolitan centres. The major categories within the RRMAC are:

1. Capital city (population of greater than 100 000, and in this case, Brisbane).
2. Large rural centre (population of 25 000–99 999).
3. Small rural centre (population 10 000–24 999).
4. Other rural area (population < 10 000).

The aim of this study was to explore the experiences of rural cancer sufferers in relation to the necessity for travel to, and accommodation in, a distant city in order to receive radiotherapy treatment. Additionally, the study also aimed to explore if there was a need for a radiotherapy treatment centre in Toowoomba.

LITERATURE REVIEW

The issue of access to cancer treatment services has been a concern in Australia for many years.³ Current radiotherapy infrastructure is inadequate to meet the needs of the Australian population despite the recognised cost-effectiveness of radiotherapy.³ Therefore, it is important to undertake a needs analysis of cancer service provision that accounts for the health infrastructure and socio-economic factors unique to the various regional and rural communities in an area when considering the introduction of new services.⁴

Being rural means being a long way from anywhere, and close to nothing.^{5,6} Currently, health service delivery is characterized by economic rationalism. The majority of intensive cancer treatment services are therefore located in areas where the cost-benefit ratio per head of population is consistent with the principles of economic rationalism. As a consequence, rural and remote residents are required to travel long distances to access specialist care.⁷ Rural people must therefore meet higher costs than metropolitan people in terms of travel to, and accommodation in, the major centres even though they are generally poorer in terms of income.^{8,9} These factors become increasingly problematic the greater the distance they live from a major centre.

The removal of a rural person to a metropolitan centre for treatment increases their vulnerability at a time when their need for their social support networks is greatest. A commonality of the studies that have examined the importance of family and other social support to people with illnesses is the central role of the family in cancer patients' acceptance of their condition and their subsequent recovery, coping, mental health^{10,11} and rehabilitation.¹²

*Social networks and social support have been found to be beneficial to the health of individuals in a variety of ways; reducing mortality rates, improving recovery from serious illness, and increasing use of preventive health practices.*¹³

Moreover, there are psychosocial and cultural issues common to rural people that determine the choices and timing of treatment. Rural people are generalized as being independent and turning inward for answers⁶ and are likely to postpone specialist treatment until it is socially or economically convenient.^{4,14} It has been suggested that rural people tend to define health in terms of both the ability to perform their work roles and to maintain their productivity.¹⁵ Therefore, delaying a diagnosis and treatment may lead to far more radical treatment due to disease progression, which in turn, entails a much greater burden on the health system.

For all of these reasons, it is reasonable that steps are taken to ensure that health treatments for rural people are as accessible and as near to home as possible, directed towards the maintenance of their functional abilities and cause minimal disruption to their occupational role.⁴

METHODS

Research questions

This project addressed the following research questions:

1. What factors influence the choice of treatment options for regional and rural people from the Toowoomba and the Darling Downs health catchment area who are diagnosed with cancer?
2. What are the issues related to the need to travel from the Toowoomba and Darling Downs health catchment area to Brisbane for radiotherapy?

Sample and setting

Recruitment strategies used key stakeholders, media releases and the 'snowball' technique to obtain a purpo-

sive sample ($n=46$) of men and women who had been diagnosed with cancer, who had chosen either multimodal treatment options, or who elected surgery or radiotherapy treatment in the metropolitan centre of Brisbane.

Data collection

Participants consented to a 60–90 m interview using a semi-structured format. Interviews were undertaken face-to-face in a location of their choice or by telephone (if geographical location restricted personal contact).

Data analysis

The interview data were transcribed verbatim and combed for common themes and patterns of meaning. Two teams each with two researchers independently analysed the data before collation, discussion and consensus for each thematic category which enhanced the rigour of the study.

Ethics

As this was a multi-site project, ethics clearance was obtained from the Human Research and Ethics Committees of the University of Southern Queensland and seven health care institutions. Plain Language Statements and Consent Forms were given to each potential participant for information, explanation and clarification of the study to assist in their decision whether to participate. Each participant was sent a complementary copy of the final report.

RESULTS

Demographic data

Thirty-nine (85%) participants were female and seven (15%) were male. Their ages varied from 36 to 80 years, with the mean age being 58 years. Twenty of the 46 participants (43%) lived in a large rural centre and 26 participants (57%) lived in a small rural centre or other rural area. The distances that participants lived from the treating radiotherapy facilities varied from 150 km ($n=22$; 48%) to 300 km ($n=17$; 37%). The length of time for radiotherapy treatment ranged from 3 to 13 weeks, with the average length being six weeks. Table 1 outlines the participants' diagnoses. Thirty-seven (80%) participants received, or were about to receive, radiotherapy (see Table 2). Of the nine (20%) participants who did not receive radiotherapy, seven (15%) of those were women with breast

Table 1 Diagnoses of participants

Diagnosis	Number of participants	Percentage (%)
Breast cancer	32	69.4
Prostate cancer	3	6.5
Multiple myeloma	2	4.3
Uterine cancer	1	2.2
Endometrial cancer	1	2.2
Non-Hodgkins lymphoma	1	2.2
Salivary duct cancer	1	2.2
Rectal cancer	1	2.2
Throat cancer	1	2.2
Brain tumor	1	2.2
Facial sinus cancer	1	2.2
Melanoma	1	2.2

Table 2 Participants' relationship to radiotherapy treatment

Treatment	Number of participants
Radiotherapy completed	35
Awaiting radiotherapy	2
No radiotherapy	9

cancer who elected to have a mastectomy in preference to a lumpectomy and/or adjuvant therapy. Another two participants did not require radiotherapy as part of their cancer treatment.

Thematic data

The complexity and interrelationship of the themes were labelled as being away from loved ones, maintaining responsibilities while undergoing treatment, emotional stress, burden on significant others, choice not to have radiotherapy, travel and accommodation, and financial burden.

Being away from loved ones

The participants identified that, during the time of their radiotherapy treatment, they felt vulnerable and in great need of support, closeness and the comfort that only loved ones and their familiar surroundings could provide. As one participant stated:

I was on my own, basically without family ... it wasn't the treatment, it didn't worry me, it was just the being away from home that was really, you know, I'm not a city person at all.

Maintaining other responsibilities while undergoing treatment

The need for treatment in a metropolitan centre did not relieve three (8%) of the participants from their work-related responsibilities. So in times when treatment was not active, namely weekends, these participants continued with, or caught up with, their work when they returned home. Motivation to continue to do this was primarily from financial pressures brought on by their absence, as well as the stress on their businesses and partners. One participant explained:

I am involved on the property with this GST (tax) and the BAS (tax statement), so he'd (business partner/husband) stop work or whatever, even have to get extra help in to give him a hand. But yes, disrupts you a bit.

Some participants ($n=5$; 14%) continued familiar responsibilities, such as cooking, cleaning, and babysitting, caring for children or aged parents as a choice, perhaps as a way of maintaining normal routines as much as possible, or because there was no other person to perform those duties.

Emotional stress

Participant responses to the need to travel and be accommodated in a metropolitan centre for several weeks ranged from an attitude that they 'didn't have much choice' to one of emotional distress:

I was a complete mess ... it was very traumatic for me ... I just went to pieces.

The trauma of the whole thing being away from home, being away from the property ... You tend to be a bit of a fish out of water when you go to somewhere like Brisbane if you're a country person.

Burden on significant others

Twenty-six participants (70%) acknowledged the crucial role of support that family members and friends were able to provide. As one participant stated:

If my wife hadn't been with me I don't know how I could have handled it, to be quite honest.

However, while being grateful that a loved one was able to accompany them, 16 (43%) participants experienced an additional burden, in that their treatment also removed their loved ones from home. Some family members unable to accompany the participants ($n=12$; 32%) found the absence of the participant arduous as identified in the following:

... he (husband) wasn't able to come with me and he really had a hard time here at home on his own.

For some participants, being away from their home and family required extensive arrangements for the continuity of their family needs being met. Understandably, for some participants their concern for their carers was uppermost in their mind as this participant said:

You end up being the support, the supportive person, of everybody ... even though you're the one that's meant to be getting all the support, you actually end up doing it.

Choice not to have radiotherapy

Seven (15%) women participants with breast cancer chose not to have a lumpectomy with adjuvant therapies, such as radiotherapy, thus receiving a mastectomy. Several factors influenced this decision, including the choice not to travel to the city for treatment ($n=5$), family concerns ($n=3$), financial reasons ($n=3$) and following the surgeon's advice ($n=2$). One participant explained her choice in the following way:

... eight weeks out away from my life out here ... would have been just too much for my family, myself, and the lack of your support group that you have ... one of the main reasons I decided to have the mastectomy, I didn't want to leave my children with anybody.

Travel and accommodation in a distant city

Thirty-seven (80%) participants attended radiotherapy in the nearest metropolitan centre. Difficulties cited were a general dislike for staying or travelling to the city, unfamiliar city traffic, location and cost of city parking and city transport. One participant summed up these difficulties by stating:

For most people in the country, going to Brisbane was a rather traumatic experience, because you don't want to drive in the traffic

because you don't know where you're going and you don't know the local rules.

Being unable to travel home on the weekends, during treatment-free periods or during the maintenance of radiotherapy equipment, exacerbated a sense of loneliness as nine (24%) participants commented. This was in contrast to seven (15%) participants from Toowoomba who chose to commute to Brisbane on a daily basis in order to maintain home life ($n=6$; 13%) and avail themselves of the supportive network of family and friends ($n=3$; 6.5%). Commuting was not without its difficulties and disturbances to family life, as one participant indicated in the following:

It's very disruptive for the children... it has been disruptive to them, also to my husband's work.

The side-effects of radiotherapy, such as burning, tiredness or pain, made travelling a trial for six (16%) participants. For three (6.5%) participants the side-effects made it difficult, and eventually unsafe, to continue to travel; thus, accommodation in the city became a necessity for the remainder of their treatment.

The three (6.5%) participants who chose to travel with the ambulance bus found the advantage of it being a free service was outweighed by the 9h day necessary for a 15m treatment session.

Twenty-eight (74%) participants opted for accommodation in Brisbane. Of those, 18 (64%) stayed in motels or hostels, 10 (36%) in private accommodation with family members or friends and one (2%) was hospitalized for the duration of treatment. The absence of home comforts was a prominent concern of participants. Many expressed a heightened appreciation of them, such as:

There's nothing like being in your own bed.

Participants ($n=7$; 19%) acknowledged that the most positive aspects of the hostel/lodge placements provided by the Queensland Cancer Fund were the organizational and social arrangements.

They're very good at the Lodge. They are excellent and there's lots of activities

(We) had each other's company which meant a lot.

Financial burden

Twenty-one participants (57%) reported that travel or relocation to Brisbane for radiotherapy treatment caused financial strain on them and their family. Financial burdens were identified as a loss of or reduction in income ($n=7$; 19%), maintaining two households ($n=9$; 19.5%), increased fuel costs and wear and tear of private vehicle ($n=3$; 6.5%), and parking costs at the treatment centre which could be up to \$10/day. As one person stated:

It's not cheap, it is an expensive little event... we're already financially disadvantaged because I'm not working as much as I would've... So yeah, it's difficult.

For those participants who had private health insurance, there was usually a gap between refunds and costs incurred through treatment, with the shortfall causing financial strain.

... it certainly adds to the cost because you can only claim so much... was about 15 hundred dollars... That's on top of your rebate from Medicare. So it's a very expensive business.

Location of choice for a radiotherapy unit

There was overwhelming support from 43 (93%) participants for the establishment of a radiotherapy unit in the city of Toowoomba, mainly because it is more familiar and is usually where rural people within the region have social and family networks. Three participants (7%) were unsure of the benefits of a radiotherapy unit in Toowoomba to them personally, as they were concerned about accommodation needs. However, two other participants were very supportive:

Oh, absolutely tremendously different. Cost-wise, emotionally wise, in every way. If I'd been able to be in my own home and have the treatment here in Toowoomba, it would have been absolutely marvellous.

I can assure (you) that if you could get a (radiotherapy) unit in Toowoomba, it would save a considerable amount of stress and pain to anybody involved.

DISCUSSION

The findings of this study expose the difficulties experienced by rural men and women whose treatment for cancer necessitates travel and accommodation in a distant

city. The specific difficulties identified by the participants in this study included the personal challenges, travel and accommodation arrangements and financial burdens. These difficulties caused some participants a great deal of long-term suffering, which has been labelled as psychological and social morbidity.¹⁶

These data strongly support the argument of the National Radiation Strategy and National Cancer Control Initiative and Utilisation Strategy¹⁷ that transport, access to services and the need to action radiation oncology proposals are urgently needed to help rural Australians with cancer. While rural areas appeared to have made some gains in utilization rates of radiotherapy (from 19% in 1991 to 39% in 1998), uptake still remains remarkably short of the plan to increase the number of newly diagnosed cancer patients receiving radiotherapy to 50%, in line with the recommendations of the Australian Health Ministers' Advisory Council (1999).³

For these rural participants, receiving radiotherapy treatment in a metropolitan centre entailed a journey into an unknown and frightening environment. Their experiences were exacerbated by being separated from their family and friends, the difficulties in receiving reimbursements of costs or, for many, the additional out-of-pocket expenses. Not surprisingly, the participants preferred treatment in a centre that enabled them to stay closer to their home. It has been claimed that living in a rural area can be emotionally protective.^{18,19} These data indicate, however, that in a time of great emotional need, rural people with cancer are left with the undesirable option of being uprooted from their rural home and displaced in a metropolitan centre for life-sustaining therapy.

It should not be overlooked that some participants elected the less conservative treatment option of mastectomy in preference to the disruption of being relocated for several weeks at a metropolitan centre for radiotherapy. This highlights the aversion that some rural people have to metropolitan places, or how strongly they feel that they cannot afford the discontinuity that such displacement brings to their life. This is a concept that may not be easily understood by people who do not come from rural areas themselves, for rural people are strongly connected to the land.²⁰

Again, not surprisingly, the participants expressed a preference for Toowoomba as their place of treatment as they are more familiar with Toowoomba and its environs, often having well established social or family networks

there. This was clearly expressed by all the participants as the following words convey:

It's just the feeling of being . . . taken away from everything you know . . . you feel you're out of it . . . you're on your own at a time when you really should be in a familiar environment.

The findings of this study are consistent with those of the Radiation Oncology Inquiry Report (ROIR)²¹ which argues that current radiotherapy services in Australia are fragmented and inequitable. The ROIR suggests that several critical areas need to be addressed on a national basis in rural areas like Toowoomba. These include current inequity of access to radiotherapy services, shortages of equipment and qualified workers, cost shifting and extended waiting lists. The ROIR indicates that the current situation is worsening and will continue to deteriorate unless effective remedial action is taken in the short term.²¹ Given the urgency and gravity of the Australia-wide situation in radiotherapy service delivery described in this report, it is understandable that the ROIR chose to diminish the significance of the social isolation of rural people receiving treatment at metropolitan centres with the comment that 'little can be done about the social costs'.²¹ The findings of the Toowoomba study make clear, however, that the social costs also have the potential to burden the Australian health system unnecessarily if they continue to be ignored. The ROIR actually argues that fewer rural clients avail themselves of radiotherapy than city dwellers, yet dismisses one of the principal reasons that this situation exists. This study has made it obvious that without addressing the sociocultural and contextual needs of rural clients, this inequity of access will continue.

CONCLUSION

It appears that at a time when the participants' health, and perhaps life, is threatened, and when they would benefit most from the comfort of their loved ones and the security of what is familiar to them, rural people who require radiotherapy are deprived of those very sources of support during a time of intense stress.

Under current treatment arrangements, if rural people with cancer choose to have radiotherapy, they are required to move from their known environment to an unfamiliar, and often disliked, metropolitan environment to forego all the physical, psychological and social comforts of their own home. This disruption occurs at a time of increased

stress, uncertainty and vulnerability. There is a possibility that these events actually are the cause of unnecessary suffering that might not occur if radiotherapy were available closer to their rural homes.

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