

Close, but still too far. The experience of Australian people with cancer commuting from a regional to a capital city for radiotherapy treatment

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This paper reports the findings of a study undertaken in November 2001 on the experiences of 17 rural people from the regional city of Toowoomba who had been diagnosed with cancer and were required to travel to the capital city of Queensland (Brisbane) for radiotherapy. The interviews were tape recorded; the recordings were transcribed verbatim and analysed for emergent themes and subthemes, following verification by the participants that the transcription was a true record of their experience. The major themes that arose from the study were (1) the burden of travel; (2) the difficulties of living in accommodation that is not one's own home; (3) the financial burden caused by the need to relocate or travel to and from Brisbane; (4) the lack of closeness to family and friends; (5) and feelings of being a burden on others. The findings suggest that at a time of stress, an increasing burden is placed on cancer clients and their families if they are required to travel for radiotherapy. Health professionals who read the results of this study should be aware of the isolation of rural people who have to live in an unfamiliar environment at a time of great stress. Support mechanisms should be put into place in these referral centres to deal with these stressors.

Keywords: radiotherapy, travel, rural people, financial, psychosocial.

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INTRODUCTION

Data published by the Australian Institute of Health and Welfare (2000) indicate that approximately one in three men and one in four women are at risk of developing cancer during their lifetime and that in Australia, the incidence of cancer is rising at an average of 2.1% per year.

People newly diagnosed with cancer, in consultation with their treating physician, face having to make decisions with regard to various medical treatment options, which

generally include surgery, chemotherapy, and/or radiotherapy. Each treatment modality provides a different method of cancer control and may be implemented individually or in combination with other treatment modalities. Given that these treatment modalities might be prescribed, people from rural areas may be disadvantaged in terms of accessibility and availability of treatment facilities (Australian Health Ministers' Conference 1999). In Toowoomba, a regional city located in southern Queensland, Australia with a population of 91 187 in June 2002 (Australian Bureau of Statistics 2003), the current services for people with cancer include surgery and chemotherapy, both of which are performed in the city's lone public hospital and two private hospitals. Radiotherapy as a treatment option is not available in Toowoomba, requiring people in need of this service to travel approximately 150 kilometres to the capital city of Brisbane.

LITERATURE REVIEW

Because of the centralization of specialist cancer services in major cities, relocation for radiotherapy treatment is often required (McGrath 1998). Despite the availability of several radiotherapy treatment facilities in regional areas, such as Townsville and Nambour in Queensland, the majority of rural people have to travel for radiotherapy treatment. The issue of centralization of specialist services is not a uniquely Australian phenomenon, as similar developments are experienced in Britain, the USA, and Canada (Payne *et al.* 2000). Given the global nature of the problem, it is surprising that only limited research has been carried out to identify the issues facing people with cancer in relation to relocation for treatment (Payne *et al.* 2000). Furthermore, it has been suggested that previous published research is contradictory and inconclusive. For example, Payne *et al.* (2000) note that although the distance that people are forced to travel for radiotherapy can increase psychological distress, there is no conclusive evidence that this factor can influence either compliance with treatment or the choice to initiate or continue with treatment.

Few studies have been conducted in Australia in this regard. However, those that have been carried out provide evidence that people with cancer perceive relocation for treatment as inconvenient and a practical hardship. For example, a study conducted by Davis *et al.* (1998) of 80 women with breast cancer from rural and remote New South Wales reported lack of social and practical support, as well as isolation, as a major concern. Other issues raised included lack of information about travel subsidies and disruption to family and work. A study conducted by McGrath (1999) into the experience of people with haematological malignancies who had to relocate for specialist treatment reported issues including the hardships associated with the unique stressors; the emotional challenges associated with relocation; and the benefits of being provided with supported accommodation.

Evidence of the physical and psychosocial effects of travel (car, bus, train, or airplane) and safety issues arising from travelling whilst suffering from radiotherapy side effects is scant. This study aimed to gather data on the travel experiences of rural people. For those people who live in Toowoomba, there were three options for accessing Brisbane – by

airplane, by car, and by bus. None of the participants in this study accessed their radiotherapy treatment by airplane (and in 2003 there is no longer an airplane service to Brisbane); therefore, this paper focuses on the effects of car and bus travel. Whilst the driving distance of this trip is approximately 2 h each way, the participants who travelled on the ‘ambulance bus’ left Toowoomba at 7.45 AM and would return at approximately 4.30 PM – a 9 h-day for several minutes of treatment.

METHOD

The research question was: What are the experiences of people who travel from Toowoomba to Brisbane for radiotherapy?

Sample and setting

Participant recruitment was conducted through various treatment facilities and media releases. The most successful recruitment strategy was through ‘snowballing’. This is a technique where a participant who met the inclusion criteria was located and, after his or her interview, provided the name of another person who also met the inclusion criteria (Offredy 2000; Oppenheim 2000). Although it is recognized that this method of recruitment can result in a sampling bias (Offredy 2000), it was particularly ensured that the recruited participants had different types of cancers (see Table 1), were from different socioeconomic backgrounds, and had different work histories (i.e., some were homemakers, some self-employed, and others employees). The inclusion criteria for this study were (1) people who had experienced cancer and travelled to Brisbane, Queensland for radiotherapy and (2) people who were able to give informed consent.

Table 1 Description of participants’ medical diagnoses

<i>Diagnosis</i>	<i>No. of participants</i>	<i>%</i>
Breast cancer	11	65
Prostate cancer	1	6
Multiple myeloma	2	11
Melanoma	1	6
Rectal cancer	1	6
Head and neck cancer	1	6
Total	17	100

A total of 20 participants were recruited into this study. Contrary to the findings of Payne *et al* (2000), three of the participants had chosen not to undergo radiotherapy because of the cost of travel and/or disconnection from their families. This paper outlines the responses of the 17 participants who did travel for treatment.

Data collection

Once the participants were contacted by the research team, a Plain Language Statement and consent form was posted to their nominated address. One week after the postage of

the material, the participants were contacted by telephone to ensure that they could provide informed consent and to organize a suitable place for the interview. Some interviews took place in the participant's home; others took place at The University of Southern Queensland. The semistructured interviews lasted between 45 and 60 min and were audio recorded. The interviews were independently transcribed verbatim. The transcripts were posted to the participants, and a member of the research team contacted the participant by telephone to ensure that the transcript was a true record of the participant's experience. Any changes to be made in the transcript were carried out at this time.

Limitations to the study

The original inclusion criteria required that the participants were undergoing radiotherapy treatment at the time of the study. The feedback received during the call for participants suggested that people who experienced radiotherapy previously also wished to be included in the study. We were aware that these participants would be remembering their experiences with radiotherapy retrospectively. It is acknowledged that some may see this as a possible limitation to this study. Although this perspective is true when researchers are grounded in a positivist philosophy where concepts are formalized as constructs, this is not the same when the research is grounded in interpretative epistemology, which asserts that 'memory processes and retrieval of information are always reconstructed rather than recalled' (Crowe 1998, p. 342). It is this reconstruction that the interview method of data collection is well positioned to examine the participant's meaning-making processes and outcomes within the cultural context and experience. As Bourdieu (1986, p. 70) stated, narratives of experience are 'always inspired, at least in part, by a concern to give meaning, to justify, to define a logic that is both retrospective and prospective, a consistency and a constancy, by establishing intelligible relations . . . between successive states'. Thus, in this study the focus was to draw out the meaning subscribed to by the participants who have lived the experience rather than a description of the experience of commuting from a regional to a capital city for radiotherapy treatment. The final time frame in which people received their radiotherapy treatment ranged from 1988 to the time of data collection. The time frames in which these 17 participants received treatment were

- eight people (47%) received treatment in 2001
- two people (12%) received treatment in 2000
- seven people (41%) received treatment in 1999 and previous years

The data analysis did not reveal any differences in the themes arising from these three groups; essentially all of the participants' experiences were similar.

Data analysis

Thematic data analyses were conducted by two teams of researchers for increased reliability of the emergent themes. Data were analysed by using six cycles: content

analysis; coding of interview texts; comparison through the process of indexing; re-analysis through text search and study of the index nodes; re-interpretation of data; and reconfirming each team's preliminary analysis.

Ethics

Ethical approval for the study was obtained from The University of Southern Queensland, Royal Brisbane Hospital, Queensland Radium Institute, Toowoomba Health Service, St Andrew's Toowoomba Hospital Toowoomba, St Vincent's Hospital Toowoomba, Breast Screen Queensland, and the Queensland Cancer Fund.

RESULTS

Demographic data

Of the total 17 participants in this study, 14 (82%) were women and three (18%) were men, with ages ranging from 36 to 80 years. The average age was 58. Table 1 outlines the participants' diagnoses.

Participants from Toowoomba travelled an average of 150 km each way to access radiotherapy services in Brisbane. Ten people (59%) underwent treatment at the Queensland Radium Institute at the Royal Brisbane Hospital as a public patient, and seven people (41%) were treated at the Wesley Hospital as private patients.

Table 2 Major themes of the study

<i>Theme</i>	<i>Number</i>	<i>%</i>
Travel	17	100
Being a burden on others	14	82
Accommodation	11	65
Financial burden	9	53
Lack of closeness to family and friends	7	41

Thematic data

Thematic analysis of the interviews revealed five major themes. These are outlined in Table 2.

The burden of travel

Seven (41%) of the 17 people attending radiotherapy opted to commute to Brisbane on a daily basis. In contrast, 10 (59%) stayed in Brisbane for the duration of their treatment or travelled home on the weekend. Daily commuting allowed six participants to maintain some degree of home life and familiarity. Three participants noted that being at home ensured the continued support of family and friends. For example:

I think that's another fact of why I'm travelling back and forwards is, . . . I [think I] would miss the children, but I don't know if really at this stage, I want to be away from my children, or my husband or my support, it's you know, to be down there, you're basically alone, you've sort of got friends down in Brisbane, but it's not the same – it really isn't.

Travelling on a daily basis to stay close to the family often required a great deal of organization. One participant described the daily ritual of having to organize her children in order for her to travel to treatment:

Well, it's very disruptive for the children, they're all at school, we don't have family here, so we've been fortunate that we've got some very good friends who've offered, they pick the children up in the afternoon and they look after them, it's usually four hours that we're away, and they have the children for four hours, it been very disruptive to them, but I suppose on the other hand, they know that I'm coming home at night, you know, they're still getting to see me, whereas if I was staying down there, it would be a week at a time that they wouldn't be able to see me. It has been disruptive to them, also to my husband's work; he's fortunate he's able to get away a little bit early.

Choosing to travel by car had some negative aspects. Four (57%) of the seven commuters reported difficulties and safety concerns during travelling due to the side effects of radiotherapy, such as burning, tiredness, or pain. As one participant said:

I mean, even from a safety aspect, it is distracting when you have pain and you're feeling unwell, to drive, and especially when you're driving to Brisbane . . .

The side effects suffered by one participant reached a point where commuting was no longer possible and necessitated her to remain in Brisbane for the remainder of her treatment. She explained:

I did three weeks going from here, I'd work till three o'clock, get in the car and I'd drive down to Brisbane, I'd have radium and come straight back. I did the same the next day and I did that for three weeks, but then it just got too much, and I started to burn, I just had to stay down there for the last three weeks to finish it.

Similar to the data obtained in the literature review, the participants from Toowoomba generally disliked staying in or travelling to Brisbane. One participant's comment is a typical example:

And the other thing is, going into a big city, which a lot of us hate Brisbane anyway, going into an unknown area, you know, that's another thing, you're round in an environment that is traffic everywhere and people everywhere, it's an ongoing thing.

The three participants (18%) who chose to travel by ambulance bus reported that it was a long and tiring day. They left the Toowoomba Hospital at 7.45 AM and would return at about 4.30 PM. After the radiotherapy treatment was finished for the day, the participants had lengthy waiting periods until the bus was ready to leave Brisbane to return to Toowoomba. One woman recalled:

Sometimes you had to wait, but it didn't really matter, because if you didn't wait then, you waited the other end anyway, because like we would get there at 11 o'clock and sometimes the bus would leave between half past one and half past two. It just depended where they had to go and where they had to pick people up from. So you waited, it didn't matter if you waited there, 'cause you still had to wait the other end. So I used to take my lunch with me and they had a room where you could, where you waited for the ambulance there, and I'd sit down there with my book, but towards the end I was sleeping more, because it makes you very tired.

All three participants commented that a 10–15 minute treatment resulted in having to be away from home for an entire day. One positive aspect that all three participants who travelled by ambulance bus mentioned was that the service was free.

Living in accommodation that is not one's own home

Accommodation options varied for the 11 participants who stayed in Brisbane. Fifty-four per cent ($n = 6$) stayed in motel or hostel accommodation and 46% ($n = 5$) stayed in private accommodation with family members or friends. Participants and their carers ($n = 9$) often discussed missing the comforts and familiarity of the home environment as well as being unable to continue with 'normal' life:

Oh, there's nothing like being in your own bed for one thing and the comfort of your own home and of course, your friends are at that time, supporting you so much, so if you've got to go to Brisbane, you really don't have anybody there, unless you've got a few rellies or something like that, and so you don't have the support from your friends . . .

A positive aspect about staying in accommodation in Brisbane was the quality of services provided in some of the hostel/lodge placements. Those who stayed in accommodation provided by the Queensland Cancer Fund ($n = 3$) reported very high satisfaction with the organizational and social arrangements. Suggestions were made that this type of service should also be provided if Toowoomba would receive a radiotherapy unit. For example:

Yes, and the units are, they actually had craft days and art days and movie days and barbecues, and so you sort of, it was like living in a little holiday type complex, they had all these things that you could do, if you wanted to. You know, even if you needed to go shopping, they had volunteers that would come and take you shopping, and they had volunteers that would come round to talk to you and that sort of thing. So you certainly weren't neglected.

One participant commented on the close bonds she had formed with some of the people she stayed with and how supporting each other had been of great benefit:

And I found that we had a lot of company, even in the waiting room, and some of the patients who were staying with relatives and that would come in and they'd say, gee, I wish we'd stayed, because you lot are having fun, you know, because we were happy when we went in, and, and they often envied us, because we had, had each other's company, which meant a lot.

This participant is also a practising registered nurse who now uses some of her first-hand experience to help cancer patients in her care. She commented:

Well, for someone who didn't know anything about radiation, it certainly was an eye opener, and you know, I've, as I said, often been of support to other people, patients that have come in who, like me, have no idea. It was a fear of not knowing what you're going to do and where you're going to stay. That was the biggest thing. Yes, that was the biggest fear, and I find that with patients that come through, that suddenly they've got, they're told they've got to go and have radiation, they have no idea where they're going to stay. Accommodation is a big thing.

The financial burden

Nine participants (53%) reported that travel or relocation to Brisbane for radiotherapy treatment placed additional financial strain on the individual and their family. Two participants were eligible for Veteran Affairs benefits and all their costs were covered. Six (35%) did not discuss the issue of financial burden because most or all of their travel and accommodation costs were covered by the Patient Transport Subsidy Scheme (PTSS).

Loss of, or reduced wages were reported as stressful by six participants. For example, some people did not have enough leave left because most had already been used when participants were undergoing surgery. Thus, one of them said, 'Well see I didn't have sick leave or rec leave to have . . . am supporting myself because I'm divorced, so I had to work'.

Two participants continued to work part-time at the beginning of their treatment, but were not able to maintain this because of the strain of travel and side effects. As one participant commented:

I'd probably be able to work a little bit more, because the fatigue factor wouldn't be there from the travelling. You know, most of the studies say that radiotherapy in itself isn't the tiring part, it's the preparation. I suppose I'd still get tired, which is sort of to get over there and all this, but there wouldn't be that extreme travelling time, which we've got at the moment and the added costs too.

One participant reported receiving financial help from her family because she was unable to work during her treatment. Other financial burdens reported included increased fuel costs, wear and tear on the vehicle, maintaining two places of residence (home and temporary accommodation), and increased food costs. For example:

It's not, it's not cheap, it is an expensive little event. I suppose we're lucky we've got an economical car, but it's money that you know, okay if you buy petrol weekly, usually, but we're having to fill up a couple times a week. So, and we're already financially disadvantaged because I'm not working as much as I would've. I've used all of my entitlements up so holiday leave and sickness leave, that's all been used. So, yeah, it's difficult.

Fifteen per cent of participants ($n = 3$) made comments regarding costs incurred through treatment as a private client. Gap payments caused significant financial strain, especially because private health insurance does not cover treatment given as an outpatient in a hospital. As one participant noted:

Probably what I'd like to, really I think someone should address one day, is the fact that your private health fund doesn't cover radiation. When you're an outpatient you're not covered at all, so it's a very costly business on top of everything else. That probably doesn't come into it coming here, but it certainly adds to the cost because you can only claim so much on Medicare, and then there's nothing else because you're an outpatient. and I think someone should really address that. Because I think my last, the first lot over and above was about 15 hundred dollars, and probably, no bit lower, 13, about 15 this time. That's on top, on your rebate from Medicare. So it's a very expensive business.

Seven out of the 17 participants (41%) who received radiotherapy made comments with regard to the PTSS scheme but reported few problems. Reimbursements were received for all or part of the travel costs, as well as accommodation. Travelling costs incurred by family members visiting participants on the weekend were not covered by the scheme. One person commented:

They were actually very good, I must say. As soon as I'd finished treatment I just had to get my, the oncologist to sign the thing, and put it in, and it was paid within the week I think, it was very good. That was great.

One participant who commuted to Brisbane daily but did not feel comfortable driving in the inner city traffic chose to park his car in the outer suburbs and to take the train into the city. As a result, he said, 'It cost us a lot on the train all the time . . . Yeah, we didn't get any reimbursements for that'.

The lack of closeness to family and friends

Despite the fact that the majority of the participants who stayed in accommodation from Monday to Friday traveled home on the weekend had family members come to Brisbane over the weekend or were accompanied during their stay by a family member or friend, seven (41%) reported separation from their family and friends as a negative aspect of being away from home during their treatment. Because this separation came at a time when the cancer clients reported feeling vulnerable and in need of support and closeness for their emotional and physical well-being, it added more stress to the whole experience.

Whereas, you know, I had, used to get phone calls all the time, which was great, and I made phone calls, but you didn't really see anybody you knew, you know?

Several people were unable to be accompanied and were thus faced with having to cope on their own. One woman described her situation: 'None of my family could get off six weeks to go and stay in Brisbane. So I went alone . . .'

Participants with family expressed sadness at having to leave their children at home, as well as the unsettling situation this created in their home environment. One participant's elderly parents had to live in with the family in order to help out with household chores:

Well . . . my mother and mother-in-law actually had to come, and they are quite elderly, both of them, so they took it in turns at coming and looking after the kids.
..

Another participant described the daily ritual of having to organize her children in order for her to travel to treatment:

Well, it's very disruptive for the children, they're all at school, we don't have family here, so we've been fortunate that we've got some very good friends who've offered, they pick the children up in the afternoon and they look after them, it's usually four hours that we're away, and they have the children for four hours, it been very disruptive to them, but I suppose on the other hand, they know that I'm coming home at night, you know, they're still getting to see me, whereas if I was staying down there, it would be a week at a time that they wouldn't be able to see me.

The burden on family and friends

Fourteen participants (70%) acknowledged the crucial role of family members and/or friends in providing support during their radiotherapy treatment. The majority ($n = 10$) of cancer clients were accompanied by a family member or friend who faced similar burdens to those experienced by the participants. Two participants who stayed with family in Brisbane for the duration of their treatment reflected on how it felt living in someone else's household for a considerable amount of time. Issues raised were the additional food cost incurred for the host household and the inconvenience for everyone involved. One participant explained:

It was, even I noticed that when I was even staying with my sister. You are aware of being in another person's home, and I did also stay with a friend . . . , . . . but I didn't want to impose on their family, and all those sort of things, you know? And you're conscious of being in somebody else's house, so that's the last week then, we opted just to drive down every day, but no, it was certainly different, you know, makes you aware of, you know, where you are and what you're doing.

One carer who is also chronically ill but did not want to let her husband travel on his own due to his forgetfulness was faced with having to accompany him, despite the fact that it was also very strenuous for her. They commented:

Oh, travelling knocks me around, you wouldn't think it does, but it does. It knocks me in the head.

The need for a radiotherapy treatment centre in Toowoomba

There was overwhelming support from participants for the establishment of a radiotherapy unit in Toowoomba. One hundred per cent ($n = 17$) of the participants commented on how their experience or decision would have been different if they had the opportunity to have radiotherapy treatment in Toowoomba. Travelling to Brisbane for treatment came at a great financial and personal cost and significant disruption to the individual's and their family's life. It comes at a time when stability, support, and the comforts of the home environment are significant influences upon the person's recovery.

Oh, tremendously different. 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.

DISCUSSION AND CONCLUSION

The findings of this study demonstrate the difficulties people with cancer from Toowoomba experience when having to travel for radiotherapy treatment in Brisbane. These difficulties are increasingly recognized at a policy level (Australian Health Ministers' Conference 1999). For example, the report of the Radiation Oncology Inquiry (Commonwealth Department of Health and Ageing 2002) acknowledged that because of time commitment and expense, radiotherapy is 'inherently inconvenient'; however, the same report views travelling as an unavoidable consequence of centralization of services. Thus, rural people, who are already considered a disadvantaged group within Australia (Australian Institute of Health and Welfare 1998; Australian Institute of Health and Welfare 2004), will be further disadvantaged should they be diagnosed with a cancer that requires radiotherapy.

The study results suggest that some people are not in a position (either financially or emotionally) to relocate to Brisbane for the duration of their treatment. In these cases, these people drove a minimum of 4 h-return each day for their treatment. Further, for

those people who chose to commute using the ambulance bus, the fatigue of approximately a 9 h-day, added to the fatigue from radiotherapy, became overwhelming as their treatment progressed. In some cases, people were forced to relocate to Brisbane to be able to complete their treatment.

An important aspect with regard to travelling that has not been clearly identified in the literature is the range of problems that radiotherapy side effects cause for a person having to travel. Burns and blistering from radiotherapy make it difficult for women with breast cancer to wear a seat belt, and anyone who had treatment to the lower region of their body found the pain of sitting in the car or bus agonizing. Fatigue is a particularly problematic issue for people who have no one to drive them, and the implications for safety need to be considered.

However, it must be recognized that, for some, there were benefits in commuting, such as being able to maintain a family life and to receive the continued support from family and friends.

Although it is acknowledged that in a large country such as Australia – which has the major part of its population located within capital cities or in coastal areas adjacent to capital cities – it is not cost-effective to establish radiotherapy centres in small rural towns (Payne *et al.* 2000), it was apparent from the stories of the 17 participants in this study that the experience of radiotherapy increased their psychological stress (Davis *et al.* 1998; Payne *et al.* 2000). Additionally, participants who accessed the private, rather than the public, hospital system found the cost of radiotherapy a financial strain. It should be noted that none of the participants who accessed the private system were aware that exactly the same services were available in the public system free of charge. In addition, several participants noted that they were financially disadvantaged due to the lack of ability to access employer paid leave for either themselves or their spouse. On the positive side, there is evidence of employers who introduced flexible work hours to assist the family during their radiotherapy experience. Additionally, the Toowoomba participants in this study did not report any difficulties accessing the PTSS (McGrath 1999; Sidoti 1999).

The study has many messages for health professionals who are involved with rural people who travel for their radiotherapy. Recommendations from this study include that health professionals

- 1 ensure people are given a choice between public or private radiotherapy (not find out after they have incurred the costs that another option was available);
- 2 ensure that rural people are provided with information – before their radiotherapy treatment – on what facilities are available (e.g., accommodation, travel subsidies). This should be done when the patient makes their booking for their planning treatment;
- 3 explore with patients and their carers during radiotherapy treatment any psychosocial problems that may occur, such as feelings of social isolation and

financial hardship, rather than just focusing on the physical side effects of the radiotherapy.

In conclusion, it can be argued from these results that travel for radiotherapy places an extra burden on families already undergoing severe stress related to their cancer diagnosis and treatment. The recommendations above, if implemented, would overcome some of these disadvantages.

Note: In 2003, the Australian government provided funding for a radiotherapy unit in Toowoomba. The unit will be operational in 2005.

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