

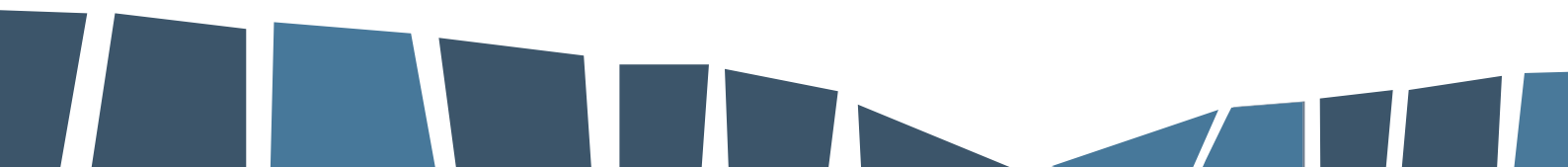
Improving cancer treatment options for rural residents

Exploring the role of a regional radiotherapy centre in Western Australia

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We pay respect to the traditional owners of the land on which the interviews were conducted and respect to their elders, past and present.

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Competing Interests

Dr Siddhartha Baxi is Medical Director of South West Radiation Oncology Service. He was involved in the planning of this research but was not involved in any interviews with patients or service providers (other than himself as a participant) or in the analysis of data.

Executive Summary

Our study set out to explore the impact which the South West Radiation Oncology Service (the Service) has had since it was established in Bunbury as Western Australia's first rural radiotherapy service. We interviewed a broad range of service providers and rural cancer patients, who all had radiotherapy treatment at the Service, to achieve our aims.

Key Findings

- Patients were very positive about the quality of the treatment and care they had received at the Service.
- Aboriginal participants were equally positive in their comments about the Service, but service providers noted the small numbers of Aboriginal patients attending for treatment.
- Participants praised the assistance with travel, accommodation, and emotional support.
- The convenience of having a local radiotherapy facility close to home influenced the decision of some patients to go ahead with the recommended treatment.
- Some cancer patients were still travelling to Perth because of the broader range of services and more specialised skills offered there and lower level of additional costs.
- Suggestions for improvement were to increase allied health support and continue to raise awareness of the Service locally.
- Other recommendations included providing better follow-up support for when treatment has finished and improving the processes and procedures for recording Indigenous status.

Radiation patients speak up

By **SHANELLE MILLER**

RADIATION patients in Bunbury have been asked to speak up about their experiences with local treatment and the impact of the Bunbury Radiation Oncology Centre.

The Bunbury centre opened in 2011 and was the first radiotherapy service available in regional Western Australia.

Anecdotal evidence has suggested that some Bunbury patients are still being treated in Perth and a University of Western Australia research team wants to know why.

Chief investigator Professor Sandi Thompson said it was important that cancer patients in regional areas knew the Bunbury service was available and that it was comparable to

treatment received in Perth.

"There have been studies that showed some people can think that the treatment will be better if they travel to a major city," Professor Thompson said.

"We know for a fact that there are poorer cancer outcomes in rural areas, attributed to travel and the out-of-pocket costs that come with leaving home."

Professor Thompson said there were effective initiatives in place in Bunbury to make life easier for cancer patients, like the chemotherapy unit at St John of God Bunbury hospital and the South West Cancer Accommodation Centre in Dalyellup.

"This research will have significance far beyond WA – while there will be compli-

ments for the services, there's also bound to be insights that could lead to improvements," she said.

The information will be collected through one-on-one interviews, either in person or over the phone.

For more information contact study coordinator Shelley Cheetham on (08) 9346 7246 or shelley.cheetham@uwa.edu.au

Introduction

Background

Radiotherapy is a very effective way to treat cancer. It has been identified as having played a part in the successful outcome of 40% of cancer cases that have been cured.¹ As radiotherapy centres need infrastructure and expert staff, most centres are located in cities with large populations.² This means that rural residents with cancer, who are recommended to have radiotherapy, must often travel large distances and incur additional costs if they are to have this type of treatment. These difficulties have been identified as contributing to the poorer outcomes for rural cancer patients compared with cancer patients who live in cities.³

To make it easier for rural cancer patients in Western Australia (WA) to have radiotherapy treatment, the South West Radiation Oncology Service (the Service) was opened in Bunbury in 2011.⁴ This is the first regional radiotherapy service in WA and means that many cancer patients living in the South West region no longer have to travel to Perth for treatment.⁴

The Service is operated by Genesis Cancer Care, a private provider of radiotherapy services. It was built on the South West Health Campus which allows the Service to work with the two hospitals based on the Health Campus, Bunbury Regional Hospital and St John of God Bunbury Hospital.⁵ The Service works with these hospitals, and with many other health care professionals, to form a network which offers a wide range of services to rural cancer patients.⁵

As of 2016, the Service provides radiotherapy treatment to around 550 patients per year, most of whom are treated as out-patients.⁴ Treatment is available for most cancers found in patients in the South West region, for example breast, colon, lung, and prostate. However, patients with more complex needs and children continue to be treated in Perth as the Service currently does not have the facilities to treat these patients.

A number of support services work with the staff at the Service and the South West Health Campus to give the patients extra support. These support services include Cancer Council WA, McGrath Foundation funded breast cancer nurses, the Patient Assisted Travel Scheme (PATS), SolarisCare (providing support and complementary therapies), South West Aboriginal Medical Service (SWAMS) and WA Country Health Service (WACHS). These services provide information and assistance with travel and accommodation, as well as providing emotional support.



South West Cancer Accommodation Centre

Research Aim

Given the importance of WA's first rural radiotherapy service, our study set out to explore the impact its establishment in Bunbury has had, from the perspectives of both rural cancer patients and service providers.

In particular, we examined what participants in our study thought of the following:

1. The accessibility and quality of care provided at the regional radiotherapy service.
2. The support provided to patients.
3. The care given to Aboriginal patients.
4. How treatment decisions are made.
5. The reasons why some patients continue to travel to Perth for radiotherapy treatment.
6. Ideas for improving services for rural cancer patients.

Methodology

We used semi-structured interviews with service providers and cancer patients to achieve our aims.

Sampling

We identified two groups of potential participants. The first group consisted of adults living in Bunbury or the South West region who had been diagnosed with cancer. People in this group had been recommended to receive radiotherapy treatment and could have received it either in Bunbury or Perth. We also interviewed a broad range of service providers involved in the treatment and care of people with cancer. These included staff from primary care and those working in chemotherapy, radiotherapy, allied health, and cancer support services.

Recruitment

Staff at the Service, and at a number of the cancer support services, invited patients to take part and provided them with information about the study. A broad range of participants were recruited so that males and females with different cancer types were included.

Service providers were personally invited by colleagues or investigators. A meeting was also held at the Service to provide information about the study.

Data Collection

All participants gave informed consent before being interviewed. We also obtained their permission to record the interview.

Interviews explored relevant topics for cancer patients. These related to their cancer treatment, including their experience of radiotherapy and why they had opted to take up radiotherapy. We also asked why they had radiotherapy in Perth or Bunbury, their opinion of the Service, any factors that had made getting treatment easier or more difficult, the support they received and any ideas for improvement.

Service providers were asked to describe their role and how long they had worked in the region. We also asked them for their views on the following – the quality of services provided and on the level of use of the Service; the extent to which patients were involved in making decisions about their cancer treatment; why patients might go to Perth for radiotherapy; difficulties associated with accessing radiotherapy in Bunbury; and any ideas for service improvement. Service providers were also asked to comment specifically on any issues they had experienced when caring for Aboriginal people.

Interviews were generally held at a place suitable for the participant but, for convenience, 12 interviews (six with service providers and six with patients) occurred by phone.

Data Analysis

All recorded interviews were transcribed word for word. The transcripts were then analysed by comparing participants' views to identify any that were the same and those that differed. This data analysis process required reading and re-reading, immersion in the data, coding, creating categories and identifying themes. The themes that emerged were discussed and agreed among the team involved in the research.

Ethics and Confidentiality

Approval to carry out this study was obtained from the Human Research Ethics Committee at the University of Western Australia, the WA Country Health Service (WACHS) Human Research Ethics Committee, and the Western Australian Aboriginal Health Ethics Committee.

Results

We interviewed 38 participants, 21 service providers and 17 patients. Interviews took place between August 2015 and July 2016.

Twelve of the service providers were female and nine male. The service providers included five nurses, eight doctors (made up of specialists and general practitioners (GPs), four staff members/ volunteers from support organisations, an allied health professional, an Aboriginal Health Worker, a radiation therapist and a senior manager). Participants were drawn from the Service, St John of God Bunbury Hospital, WACHS, SWAMS, Cancer Council WA, SolarisCare and a number of GP practices.

The 17 cancer patients (12 females and five males) had all had radiotherapy treatment at the Service. They ranged in age from 25 to 72 years and had a variety of cancer diagnoses - breast, prostate and skin cancers were the most common.

The findings in response to 6 questions are summarised below:

1. How satisfactory is the radiotherapy service?

Patients were very positive about their experiences at the Service. They praised the quality of the care provided and noted the convenience of receiving treatment locally. In the words of one patient:

I was happy to be in Bunbury...I had no reason to want to go to Perth... (Female patient)

Participants (both patients and service providers) identified a number of reasons why there was general satisfaction with the regional radiotherapy service. These were as follows:

Convenience

Participants said that the main benefit of receiving treatment in Bunbury was the location of the Service closer to where patients lived. All facilities were located on-site which added to the convenience. This compared favourably with the alternative of having to travel to Perth. Patients and service providers said that the convenient parking and light traffic in Bunbury meant that it was much easier to have treatment at the Service rather than experience the 'hassle' of getting to Perth.

Being able to stay close to family while having treatment locally was another advantage. As one participant said, avoiding ‘dislocation’ from home was one less stressor for patients. Commitments to family, work, and pets were all reasons why remaining locally for treatment was preferable. In addition, patients could either stay at the local accommodation provided for patients, or travel home every day if they lived close enough. One service provider summed up the advantages of receiving treatment close to home:

I think it is a no-brainer...convalescing at home, very little travel, your partner can be near you
(Male service provider)

Financial considerations

A further benefit of receiving treatment within the region was that certain out-of-pocket costs could be avoided. The patients who could stay living at home had no accommodation costs. In addition, there was free on-site parking at the Service, unlike in Perth where parking could be expensive.

Quality service

All patients, without exception, praised the ‘excellent’ quality of the service provided. As well as being recognised for their professional skills and expertise, staff were praised for their caring attitude and level of compassion. Patients used words such as ‘wonderful’, ‘fabulous’, ‘amazing’, ‘marvellous’ and ‘welcoming’ to describe the supportive atmosphere at the Service.

Service providers and patients emphasised the efficiency of the Service and the patient-centred approach to care that was offered. This was noted particularly in the way the Service coordinated referrals and followed up appointments quickly. The ‘streamlined’ service offered in Bunbury was made easier by everything being located on the same campus. Many patients mentioned the short waiting times. They also noted the flexible appointment scheduling system which tried to accommodate patients’ preferences. Some patients who had previously been treated in Perth said that they found the Service in Bunbury to be more accommodating.



South West Radiation Oncology Service staff

A selection of comments offered by service providers and patients about the quality service provided is set out in Table 1 below.

Table 1: Participants' Comments on the Quality of Service Delivered

Skilled/experienced professionals

And I had the operation here because we've got a good specialist here, and he is very, very good actually. (Female patient)

I think the quality of the radiotherapy service is excellent. I think the actual technical skills and the staff there and all that side of things is very good... (Male service provider)

... he was so thorough, so very thorough. I felt very comfortable with him because I knew exactly every day what I was going to be doing. (Female patient)

Efficient service

... they can actually access the service a lot easier than in metropolitan areas which is a huge benefit of course. (Female service provider)

But they are really terrific and smooth running there, very, very efficient, and once again you don't wait. (Female patient)

There was never an issue where they didn't meet my request. (Female patient)

Friendly staff

What a breath of fresh air! You walk into the office and the girls, 'Hello!' and smile, you know, 'Welcome!' (Male patient)

... I can't really fault anything about them. They were just all wonderful, right down to the receptionist, the radiation people. I think it was absolutely wonderful. (Female patient)

And I can't speak highly enough of [Name of Service Provider] and his crew. I was welcome to go back there anytime... (Male patient)

... you just walk in [to a Perth treatment centre] and you walk out, and you have got a no-name face, whereas down here it is more personal. (Female service provider)

General

... there is nobody I know now going to Perth ... (Male service provider)

Genesis Cancer Care patient satisfaction surveys

As with all sites operated by Genesis Cancer Care, patient satisfaction surveys are conducted at the Service. Patients are invited to complete the voluntary survey usually while waiting at the Service for treatment. Most responses are positive and are consistent with our research findings about patient satisfaction. It was reported that a number of changes had occurred within the Service as a result of patient feedback, such as placing tables in the waiting room, having a chair in the change room and efforts to improve communication with patients. An example of this is notifying patients if appointment delays are anticipated.

2. Is the support provided adequate?

Considerable support for patients to assist them when undergoing medical treatment at the Service was reported by both patients and service providers. Patients were usually aware of what support was available but it was reported that sometimes GPs lacked the appropriate information to tell patients. This happened particularly with less common forms of cancer that they may only occasionally encounter. Nurses were identified as playing a particularly important role in letting patients know about the relevant support services. As one service provider said:

The nurses are really switched on with that. (Male service provider)

The main types of support identified were:

Accommodation

Having accommodation close to the Service was a key factor allowing many patients who lived further away to have their treatment. This was acknowledged by many participants, summed up in the comment:

Since the accommodation has been here it has made life a bit easier... (Female service provider)

Previously, patients had to make alternative arrangements, such as staying with relatives. Or they may not have been able to go ahead with their treatment at all. One patient expressed her appreciation:

... I am just so grateful that I did have that [accommodation]. (Female patient)

Transport

Lack of suitable transport could be a problem for patients referred to Bunbury for treatment. Many patients did not have family to drive them to treatment or were not physically able to drive themselves. Furthermore, lack of money made regular travel by car more difficult for some patients.

Given these challenges, the transport provided by the various organisations (including the voluntary service arranged by support bodies, such as St John of God Bunbury Hospital, Cancer Council WA Dot's Place and SWAMS, and the service from Peel Health Campus at Mandurah) was greatly welcomed. This appreciation is clear from the comment made about the bus service between Busselton Hospital and the South West Health Campus which was described as:

... a godsend for everybody down there. (Female service provider)



Dot's Place

Emotional support

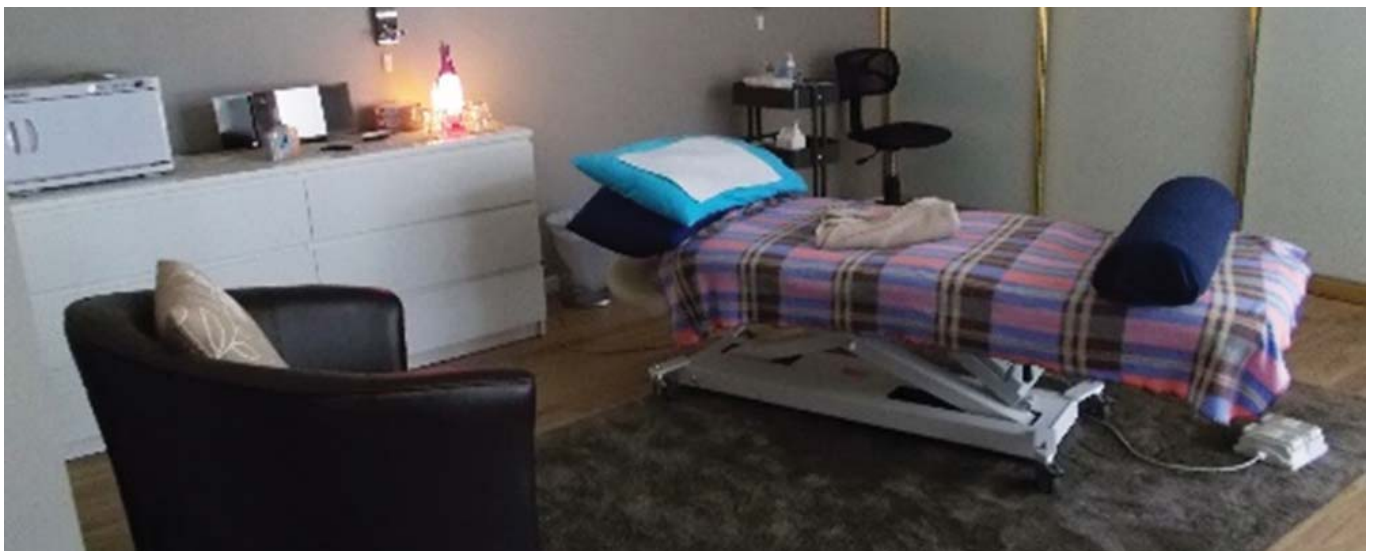
Participants noted the importance of having someone (other than family members) to talk to and of not 'bottling' things up. There was particular praise for the support and advice given by the Breast Cancer Nurses:

For a month or two I didn't know whether I was coming or going... She was able to talk to me, because I was a mess. But she was great. (Female patient)

The emotional support provided by all staff at Dot's Place was highlighted by many patients as being 'absolutely brilliant'. Many patients found the support groups to be especially valuable as it was helpful to talk with others who were going through similar experiences. Groups, such as a partners' support group, a lymphodema support group, and a prostate cancer support group were mentioned.

The programs offered by a number of organisations (in particular SolarisCare), such as exercise programs, massage, meditation and reflexology, were also praised. As one participant said, they helped patients to:

... relax through a mirage of horrible times. (Female service provider)



SolarisCare

3. What are the experiences of Aboriginal cancer patients?

We interviewed three Aboriginal patients with cancer. Many service providers noted that they treated very few Aboriginal patients at the Service. This is supported by statistics from the Service which showed that Aboriginal people attended in small numbers. The figures showed that less than 1% of patients who presented for treatment at the Service every year identified as Aboriginal. Overall, the Aboriginal community makes up about 2% of the total population of the South West region.

One reason suggested for the low numbers in the statistics was that Aboriginal patients were not being identified. This is despite efforts having been made at the Service to improve data collection systems. Another reason was that Aboriginal patients may be presenting late to their GP. By this time, if their cancer is more advanced their treatment may be more complex and radiotherapy treatment no longer an option. Alternatively, they may prefer to be treated in Perth where all treatment services are covered within the public health system, not necessarily the case at the Service. There was little to suggest that those patients who were interviewed had concerns about lack of cultural safety, however, it is possible this could be an issue which keeps some Aboriginal patients from attending in Bunbury.

The Aboriginal participants in our study were all positive in their comments about the Service, particularly the convenient location and the welcoming and supportive staff. This was summed up by one patient who said:

... the sisters there at radiation helped me.....I can't thank them enough. (Female patient)

Once again, the particularly supportive staff at Dot's Place were singled out for praise. The local Aboriginal services – SWAMS and GP Down South Aboriginal Health Service – were also noted for their attentiveness.

4. How are decisions about treatment made?

Although most patients said that they felt involved in the decision-making process, they generally followed the advice given by their doctors. A number of service providers felt that although patients can refuse treatment, they don't often exercise this right:

... [patients] feel that they don't get the choice, when in actual fact the choice is there... (Female service provider)

A number of service providers said that having the radiotherapy facility available locally helped influence some patients to go ahead with their treatment. Previously, patients had sometimes refused treatment if it meant time and expense travelling to Perth:

...patients are now willing to consider it because it is there, whereas before I literally would have patients saying, 'No, I'm not doing that' even if it was the best thing for their health. (Female service provider)



Radiotherapy

5. Why do some patients still travel to Perth for treatment?

Participants identified a number of reasons to explain why patients may still travel to Perth for radiotherapy treatment, for example, if the patient is a child as the Service does not treat paediatric cases. Some patients need a certain type of radiotherapy procedure which is not available at the Service or they have a particular type of cancer, such as head and neck cancer, that needs specialised support which the Service cannot yet provide.

Some service providers commented that a few local doctors, GPs in particular, chose to send patients to Perth who could be treated in Bunbury. And sometimes it was the patient's decision to travel to Perth for treatment for family reasons. Or because treatment in Perth would avoid potential additional expenses which are associated with the public/private system in Bunbury and where patients may be charged for some interventions and scans.

6. How could rural cancer services be improved?

The Genesis Cancer Care patient satisfaction surveys, which were carried out between December 2015 and May 2016, show that patients felt that the Service delivered is excellent. There were a few suggestions for improvement but these related to minor issues.

In our study, most suggestions for improving cancer treatment services related to the support available to patients. This was particularly in relation to the need for improved allied health support. Most pressing was the lack of social workers at the Service with nurses often relied upon to fill this gap:

[Nurses] do an amazing amount of social work that is unrecognised but vital to patients' well-being... (Female service provider)

A service provider noted that a discharge planner could be a useful addition to the Service. A number of patients said that they had experienced difficulties after discharge and commented that they found it difficult 'letting go of the care'. A discharge planner could help patients re-adjust to life as a rural cancer survivor and ensure follow-up support was in place for when treatment finished.

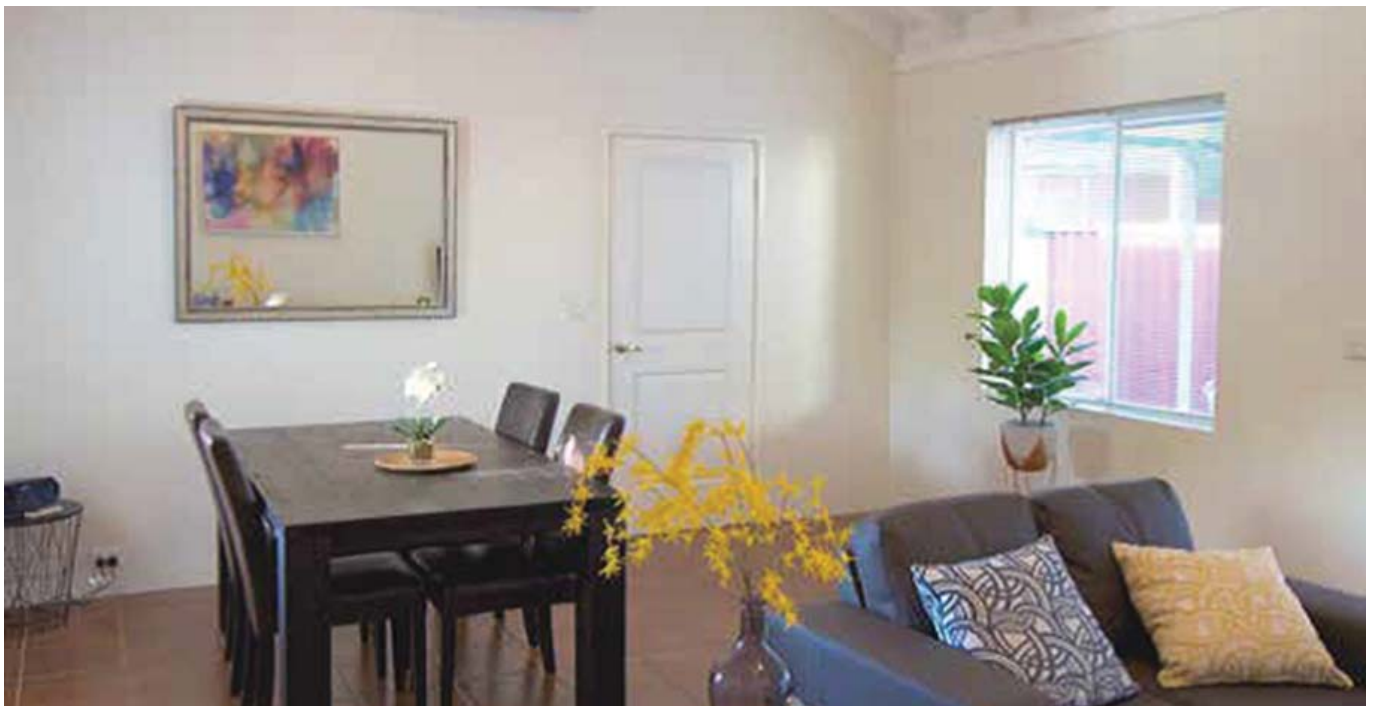
Although a huge amount of work has already been done to raise the profile of the Service in the South West, participants said that these efforts need to continue. The treatment and the wider support services available to patients warranted being publicised so that all interested parties are aware of what the Service has to offer.

Discussion

Patients were very positive about the quality of the treatment and care they had received at the Service. Most participants noted the assistance with travel, accommodation, and emotional support. This appreciation came from both service providers and patients. Having a local radiotherapy facility allowed patients to remain at (or close to) home while receiving treatment. This influenced the decision of some patients to go ahead with the recommended treatment. However, some cancer patients were still travelling to Perth because of the broader range of services and more specialised skills offered there and lower level of additional costs charged by the public facilities in the city. Suggestions for improvement were to increase allied health support and continue to raise awareness of the Service locally.

Overall, cancer patients living in rural areas have poorer outcomes than patients from urban areas⁶ This difference is partly due to the lack of cancer services in rural areas. A regional radiotherapy service does not always remove all difficulties faced by rural cancer patients. But it can make radiotherapy treatment more acceptable by reducing the time and distance needed to travel to obtain care² Our study confirmed that the convenient regional location of the Service made treatment more accessible to patients and increased the likelihood of some taking up recommended treatment. It also met their preference for being treated in a local, familiar environment. Participants overwhelmingly confirmed that the Service delivered high quality care which was centred on the needs of the patient.

The Aboriginal participants were just as positive about the quality of the service. The low numbers of Aboriginal patients at the Service is also found at other radiotherapy treatment facilities throughout Australia⁷ This raises wider issues of concern. Many service providers were keen to understand why there were so few Aboriginal patients and wanted to put steps in place to address the situation. Further work needs to be done to make sure that accurate data on Indigenous identity is recorded. It is important that service providers know who the Aboriginal patients are and give them the support they need. It is also vital that service providers maintain a culturally safe and respectful organisation to encourage Aboriginal patients to attend.



Kalimera House

Providing assistance with travel and accommodation eased some of the burden of treatment. Many participants said that this was a factor which allowed patients to have their treatment. As well as this type of support, it is particularly important that rural cancer patients are also given emotional support.⁸ Some participants reported they had found the diagnosis of cancer to be 'overwhelming'.

Our study found considerable support existed for rural cancer patients in the area. However, patients need to be aware of what is available in order to use the support. Usually it is the responsibility of social workers to put patients in touch with the relevant support services. But, due to the lack of social workers available to radiotherapy patients at the Service, this was often left to nurses. Arguably, better access to social workers could help connect radiotherapy patients with the appropriate support services.

Where we did find a few examples concerning a lack of knowledge about support services, these mainly related to GPs who are often the main source of information for patients.⁹ As GPs may have few patients with cancer, they may not be as well-informed about the available support as those directly involved in cancer care. For maximum use of support services, it is important that all available support is publicised to GPs as well as to patients.

Although praising the support available to patients before and during their treatment, a few participants said that they had felt abandoned after their treatment had finished. They admitted struggling to cope with the change from intensive treatment and care, to having very little support. The difficulties which rural cancer survivors face getting follow-up care have been noted as a particular concern.⁸ A discharge planner to help patients make the transition to life as a rural cancer survivor was suggested. A resource such as this could help ensure that the long-term well-being of cancer patients living in rural communities is not neglected.

One reason why patients continue to be treated elsewhere was because some health professionals may not know about the services offered on the Bunbury Health Campus. Therefore, it is essential they are aware of the expertise available locally. In this way, it is likely that they will refer local cancer patients who require radiotherapy treatment to the Service. Efforts should continue to promote the Service amongst service providers in the South West to increase confidence in the quality of the service offered. This would encourage referrals and maximise usage of these facilities.

We identified a number of valid reasons to explain why some patients travelled to Perth for treatment. However, the quality of the radiotherapy service provided in Bunbury was not questioned. This highlights how important it is to promote the excellent services that are available locally. Staff must be assisted in their efforts to publicise the Service amongst health professionals and community members. It is particularly important that members of the Aboriginal community are made aware of the Service. Some patients were influenced to go ahead with radiotherapy treatment because of the local availability of this treatment, demonstrating that the Service has succeeded in achieving one of its key objectives.

Conclusions

Our study found that this facility in the South West of WA has made it easier for rural cancer patients to receive radiotherapy treatment. The convenient location of the Service has overcome some of the barriers faced by regional cancer patients, particularly those related to inconvenience and costs which can affect patient decisions around treatment. Increased access to radiotherapy treatment for rural cancer patients is likely to contribute to improving the outcomes of rural cancer patients.

The favourable comments made by our participants show how successful the regional service has been both in delivering quality radiotherapy treatment, and in developing support systems for comprehensive care. In addition, our finding that most patients choose to remain in Bunbury for treatment shows that the local community has confidence in the skills and expertise of staff at the Service.

Recommendations

- 1. Continue to promote the Service throughout the South West community (patients and health professionals) to raise awareness and increase referrals to the Service.**
- 2. Provide a social work service for radiotherapy patients to connect these patients with the appropriate support services.**
- 3. Establish mechanisms to keep patients and GPs informed of the patient support that is offered and ensure that all available support is being used.**
- 4. Put in place improved discharge planning arrangements which provide follow-up support for rural cancer patients around their ongoing needs.**
- 5. Improve the processes and procedures in place for recording Indigenous status to enable service providers to capture more accurate data.**
- 6. Undertake a health economic investigation to explore the out-of-pocket costs associated with cancer treatment for rural patients under various treatment scenarios and the impact of the private-public partnership arrangement.**

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