NSW Health

Listening to Aboriginal men about their Radiation Therapy stories in Western NSW.

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Contents

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Ethics

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Abbreviations

- RT = Radiation Therapy.
- Linac = Linear Accelerator.
- WNSWLHD = Western NSW Local Health District.
- CWACN = Central West Aboriginal Cancer Network.

Keywords

Radiation

Aboriginal

Phenomenology

Kapati

Treatment

Journey

Barriers

Education

Cultural

Stories

Abstract

Background

Embracing Aboriginal perspectives plays a crucial role in reducing the disparities in cancer outcomes. The scarcity of research surrounding the experiences of Aboriginal men who have undergone radiation therapy highlights unaddressed needs and barriers. Understanding the challenges unique to this population can lead to interventions that are more effective and culturally sensitive.

Aims

This project aimed to understand the experiences of Aboriginal men who had undergone radiation therapy treatment in Western New South Wales to address knowledge gaps in communities, and disparities in treatment and outcomes.

Methods

Phenomenology, combined with an Indigenist approach, was used to understand the participants' subjective experiences. The research team comprised of five members including two identifying as Aboriginal to ensure research rigour. Six Aboriginal men who had received radiation therapy treatment or follow-up within the last five years were interviewed either via telephone, or in-person. Open coding of the interview transcripts, and initial isolation of themes was performed by a single team member before a more collaborative thematic analysis approach was undertaken.

Results

The study revealed the unique cancer journeys of participants and highlighted the need for personalised care. Family support played a crucial role in their experiences, and the need for dedicated Aboriginal Health Workers or Care Coordinators was stressed. Mistrust of the healthcare system, financial constraints and geographical isolation were some of the barriers noted. Participants emphasised the importance of raising awareness and improving education about cancer, as well as screening, treatment, and survivorship in ways that are culturally sensitive.

Conclusions

Despite the positive accounts, persisting barriers for this community were highlighted in this study. The insights into the participants' experiences will guide future research and interventions to allow for equitable healthcare delivery, and improved health-seeking behaviours in Aboriginal men.

Executive Summary

Introduction

Aboriginal Australians are 20% less likely to survive a cancer diagnosis. Research that simply describes this difference is limited in its ability to help close this survival gap. Approaches that work with community in holistic and culturally respectful ways are required to better understand the needs and barriers for Aboriginal patients to access vital cancer treatments. In the Western NSWLHD such research was performed by listening to the stories of six aboriginal men that had accessed the Radiation Therapy service located in Orange. Kapati, an indigenous narrative enquiry technique that utilises storytelling and yarning, was used to capture the experience of each man, with common themes and ideas linked and framed through the story of the project logo in order to best portray their cancer journey. This research aims to improve the understanding of the Radiation Therapy needs of Aboriginal men in Western NSW and translate this knowledge into service improvements that can make a difference in cancer outcomes for local aboriginal communities.

Key Findings

This research revealed the unique cancer journey of each man and highlighted the need for personalised and culturally-centred care. Despite positive accounts, the men shared insights into aspects of their journey that proved difficult and offered pragmatic solutions that could improve access to cancer treatments. Family support played a crucial role in their experiences and the need for dedicated Aboriginal Health Workers or Care Coordinators in Radiation Therapy centres was stressed as vital to help navigate the overall cancer journey. Mistrust of the healthcare system, fear of cancer, financial constraints and geographical isolation were some of the barriers noted. The men also emphasised the importance of raising awareness and improving education about cancer, as well as screening, treatment and survivorship in ways that are culturally sensitive.

Recommendations

The key findings of this research indicate that the Radiation Oncology service should continue to listen to Aboriginal patients and their needs, perform culturally appropriate cancer education for Aboriginal communities and have dedicated Aboriginal Health practitioners to support the cancer journey of Aboriginal patients. The service should look at further research opportunities by repeating the project with Aboriginal women and also to investigate the impact of the new Radiation Therapy centre in Dubbo.

Concluding Comment:

This research provides invaluable insights into what Aboriginal men need to overcome to access and complete a treatment course of Radiation Therapy. These insights will drive tailored interventions that will look to improve cancer outcomes for Aboriginal Australians.

Introduction

On average, Indigenous Australians are 20% less likely to survive five years after diagnosis of cancer compared to Non-Indigenous Australians[1]. Research into culturally appropriate and centered strategies aimed at cancer outcomes for Indigenous Australians is required to help reduce the difference. Research of this nature is especially pertinent in the Western NSW LHD (WNSWLHD) where a significantly higher proportion of its population (11%) identify as aboriginal compared to the NSW state average of 3.6%[2]. In 2011, the WNSWLHD opened a Radiation Therapy service in the Western NSW regional city of Orange leading to improved utilisation of this specialised cancer treatment, especially by men[3]. The service is located within the Wiradjuri Nation, the largest Aboriginal Nation in NSW, but research into the experience of Aboriginal men that have accessed this cancer treatment has not yet been performed.

To better understand the journey Aboriginal men have had with Radiation Therapy, a phenomenological qualitative research methodology with an Indigenist approach will be used. Phenomenology will enable the project to describe the men's experience with the service from their own perspective and combining this methodology with an Indigenist approach will ensure the research is decolonised, respectful and inclusive of the Aboriginal community where the research is to be undertaken.

Participants will be men identifying as Aboriginal that have had Radiation Therapy in the WNSWLHD. The men will be interviewed using Kapati, a narrative enquiry technique that utilises storytelling and yarning as culturally appropriate ways to collect information. Coding and thematic analysis of the data will be performed to better understand the common experiences of the men, identify any needs that were not met and how the service could be adapted to address these gaps. Participation and verification with the local Aboriginal community will occur throughout the data collection, analysis and distribution of the research to ensure appropriate reflexivity and appropriate power relations occur.

Listening to the Radiation Therapy stories of Aboriginal men will endeavour to improve the treatment journey for future patients and translate to better cancer outcomes for Aboriginal communities in Western NSW.

Literature Review

Radiation Therapy is a highly targeted treatment that uses radiation to kill cancer cells and stops them from growing and multiplying. Radiation Therapy uses advanced technology to treat many types of cancer both safely and effectively and contributes to more than half of cancer cures. [4]

In Australia overall cancer survival has been improving over the last 30 years with 70% of all people now diagnosed with cancer surviving at least five years. However outcomes are not evenly spread across the population with Aboriginal and Torres Strait Islander people (hereafter Aboriginal Australians as recommended by the Aboriginal Health and Medical Research Council of NSW) having a 54% 5 year approximate relative survival rate for all cancers combined compared to 68% for non-Aboriginal Australians.[1] Cancer is the leading broad cause of death for Aboriginal Australians who have a higher incidence of fatal, screen-detectable and preventable cancers[5] and have more advanced disease when diagnosed, more co-morbidities and are less likely to receive specific or adequate cancer treatments[6,7].

Research that merely continues to describe the differences in cancer outcomes is now limited in its use.[6] A holistic and respectful approach is required to better understand cultural differences in attitudes to cancer and its treatment in order to improve cancer survival for Aboriginal Australians.[8] In Western NSW this can be done by listening to Aboriginal men about their Radiation Therapy stories to get a better understanding of their cancer journey and the barriers men face accessing this vital treatment. This research will address a gap in understanding the particular experiences of Aboriginal men whom could be better engaged with cancer diagnosis and treatment.[9] The need for such research is indicated by a systemic review by Dasgupta et al[10] which found that while some of the poorer survival faced by Aboriginal cancer patients can be explained substantial disparities likely to be related to Aboriginal determinants remain and approaches to better understand these are required to inform evidence-based action. Additionally, for NSW, Rodger et al[11] looked at treatment patterns for Aboriginal men and found them to be less likely to have surgery or radiotherapy for prostate cancer than other Australian men and suggests tailored programs are needed to ensure Aboriginal men have equitable access to best care.

The Western NSW Local Health District opened its first Radiation Therapy department at Orange Health Service in 2011. The service has saved patients travelling to Sydney to receive such specialised treatment and facing the associated burdens of distance, travel, accommodation and support that comes with this. The radiation oncology information system indicates that of these patients approximately 5% were aboriginal and only around 40% of aboriginal patients were men.

To date, no research investigating the Radiation Therapy needs of Aboriginal men has been performed in the Western NSWLHD. Taylor et al.[12] indicates to develop appropriate models of cancer care focus is first needed on how cancer service providers currently deliver services to their Aboriginal patients and on ways in which they can improve to better meet their needs. Studies have been performed in other cancer care settings that have assessed their service through the experiences of Aboriginal patients. Reilly et al. [13] in South Australia looked at how care co-ordination influenced Aboriginal cancer treatment, finding continuity of care may potentially improve cancer journeys, while Shahid et al. [14] looked at the experiences of Aboriginal people in Western Australia accessing cancer services and treatment concluding logistical, infrastructure and cultural safety issues must be addressed to improve cancer outcomes. Thompson et al. [15] interviewed urban, rural and remote Aboriginal people affected by cancer to assist those planning cancer services to ensure they meet the needs of Aboriginal patients and Taylor et al. [16] explored how three cancer services performed when compared to two national best practice guidelines. Prior[17] in Queensland explored why Aboriginal women participated in cancer screening and highlights the need for a culture-centred approach that decentres the authority of conventional services and instead gives prominence to Aboriginal cultural values as a focal point in cancer control. In the field of Radiation Therapy, the Alan Walker Cancer Care Centre in Darwin has done extensive work around culture and creating many initiatives in areas such as staff training, patient focused care and patient education which have led to improved treatment compliance for their Aboriginal patients.[18]

Consequently, it is imperative to start research in our own local area to assist with the development of appropriate models of cancer care through a better understanding of how the Radiation Therapy service can meet the needs and improve outcomes for Aboriginal men in Western NSW.

Study Aim

The overarching aim of this research is to improve the understanding of the Radiation Therapy needs of Aboriginal Men in Western NSW and translate this knowledge into practice improvements that will reduce barriers for accessing such vital cancer treatment. Listening to the stories of Aboriginal men aims to give them a voice in the way the Radiation Therapy service is provided for their community.

Objectives

The objective of this research is to:

1. Identify the cultural needs of Aboriginal men undergoing radiation treatment.
2. Identify the barriers to accessing the cancer service.
3. Identify the service gaps that currently exist.
4. Identify the changes that would lead to an improved Radiation Therapy story.

Methods

Population and Participant Recruitment

Aboriginal men that have had Radiation Therapy or follow-up consultation post treatment in the WNSWLHD in the last 5 years were invited to participate in the research. Permission was given by the Radiation Oncology Management group, who are the custodians of the Radiation Therapy data, to access the men's details in the Radiation Oncology electronic medical record. Patients that are deceased are flagged in this record and thus helped to avoid unnecessary and distressing contact with the families of patients that have passed.

Cultural experts in the research team advised to invite men to participate in the research by phoning them directly and to explain why the research is being performed and why it is important for their community. The recruitment was performed by the Principal Researcher and a Co-Researcher, who is also an Aboriginal Health Practitioner, to reduce the potential impact of existing relationships or power relations with the Principal Researcher.

Participation was voluntary. If a potential participant did not wish to take part at initial contact this was noted and they were not included in any follow up. If a participant decided to take part and later changed his mind, he was able to withdraw at any stage. A potential participant's decision about being in the study would not affect their ongoing health care or relationship with the Central West Cancer Care Centre. This was clearly stated in a participant information sheet that was available for potential participants. For men that indicated an interest to participate, the Research team sent them a Participant Information Sheet electronically or in paper form. Potential participants had time after initial contact (approximately 2 weeks) to decide if they wanted to participate in the study to remove any time pressure around their decision and to allow time for reflection and family discussion to occur. Potential participants were encouraged to discuss their decision to participate with a family member or a support person and were informed that if they do wish to participate a family member or support person can be present during the interview process as well.

A verbal consent was completed before each participant began the research interviews indicating that they had been given sufficient information about the project and the implications of taking part enabling them to make an informed decision to participate. The consent was acquired as a separate recording to the research interviews and are securely stored on a drive of the computer network hosted by the WNSWLHD and only accessible by the Principal Researcher.

No financial incentive was offered for participating in the project as this could have resulted in pressure on individuals to consent. Additionally, the interviews were offered to be performed over the phone to reduce any travel, time and financial burden that could be encountered with face-to-face interviews with the participants. As a token of appreciation for their shared knowledge and time each participant was provided with some Rugby League equipment and clothing.

Purposeful sampling was predominately employed with eligibility being all Aboriginal men who have had Radiation Therapy or follow-up consultation post treatment in the last 5 years. There was also some snowball sampling with one participant being nominated by an Aboriginal Health Care worker when made aware of the project. The sample number recruited was 6.

Data Collection

The men were be interviewed using Kapati, an indigenous narrative enquiry technique that utilises storytelling and yarning as culturally appropriate ways to collect information.[19] The interviews were performed by an Aboriginal Health Practitioner (Co-Researcher) with the Principal Researcher. This combination of cultural knowledge on the interview panel helped cover any queries around the Radiation Therapy concepts while also providing cultural safety and navigation for the participants. The research team included local Aboriginal men who gave direction on how to work with community and ensured appropriate power relations occurred by decolonising ay non-Aboriginal interpretation or understandings of the stories by the Principal Researcher.

The interviews were recorded with a digital Dictaphone, with five of the interviews occurring over the phone while one participant's preference was to interview in person. The interviews were started with the researchers asking the participant to describe their Radiation Therapy story. A guide was developed to assist the researchers when performing the interviews (see Appendix 1) and contained semi-structured questions that could be used to explore themes and gain a better understanding around certain aspects of the participant's treatment journey. Recordings ranged from 15 to 30 minutes in duration and the interviews were performed over a 5-month period.

Ownership and control over the data collected was provided to participants through subsequent follow up meetings to verify the interpretation of their stories and knowledge was correct and respectful. Additionally a hard copy of the final project report will be provided to all participants.

Data Management and Statistical Analysis

The interviews were recorded with a digital Dictaphone as this reduces the chances of loss or theft that can occur with tape systems. The data collected was downloaded and stored on a secure drive of the computer network hosted by the WNSWLHD. Access to the WNSWLHD network is password protected and only the Principal Researcher has access to the drive where the data will be stored. Each participant recording was de-identified by removing or masking personal information in the file names and transcripts to further ensure the privacy of the participants.

The interview audio was transcribed to allow coding and thematic analysis of the data. The transcripts were printed, read several times, and an open coding process was completed for each interview by a Medical Student (Co-Researcher) with guidance from a Senior Research Lecturer (Co-Researcher). The transcripts were then cut up to break the data into discrete parts, labelled with codes and then collated into draft themes for group discussion to occur. The collaborative consultation process took a full day of round table reflection of the categories and transcripts by the research team and allowed for the themes to be arranged and connected in a way to best represent the telling of each participants' stories. Further research rigour and reflexivity occurred through follow up meetings with each participant to verify the research interpretations and findings.

The study data, consent and interview recordings will be stored for at least 5 years upon on the secure computer network hosted by the WNSWLHD. Following the five years of retention, data will be destroyed by deleting all the electronic files stored on the network. Any future use or disposure of the data gathered by this project will require consultation with the Central West Aboriginal Cancer Network (CWACN) who have partnered with this project as the community reference group. Such consultation is required to maintain respect as the information gathered by this project may be of cultural significance.

Results

All participants were from small or medium rural towns at least 50 kilometres from the nearest regional centre and 86 kilometres from the treatment service. The age range of participants was from 57 to 71 years of age. Prostate cancer represents a large proportion of diagnoses in men who receive Radiation Therapy at Orange Health Service, which was reflected in this sample group, and overall accounts for around 20% of all treatment courses delivered at the centre. P5 provided a different experience in that he had Head and Neck cancer. Characteristics of each participant can be found in Table 1.

Participant	Age	Distance to Treatment (km)	MMM Category of Hometown	Treatment Location	Cancer Diagnosis
P1	66	86	5	Orange Health Service	Prostate
P2	71	105	5	Orange Health Service	Prostate
P3	71	105	5	Orange Health Service	Prostate
P4	61	104	5	Orange Health Service	Prostate
P5	56	121	4	Orange Health Service	Head & Neck
P6	57	105	5	Orange Health Service	Prostate

Table 1: Patient Characteristics (Age, Distance to treatment and Modified Monash Model (MMM) category of hometown) & Medical Factors in Treatment Decision-Making (location of treatment and type of cancer diagnosis).

This study highlighted five themes generated from the men's stories, the first being the participants' learnings, and how treatment acted as a learning experience for them. The second theme was the barriers and facilitators to accessing care. Family as a support system during the cancer journey was seen as both a possible barrier and facilitator and is an important factor when considering why an Aboriginal man might choose to attend treatment. Other identifiable barriers and facilitators included access to services and fear of the healthcare system. The third theme related to the participants' experiences whilst in the healthcare system and how their interactions with staff impacted their journey. Theme four identified five key domains of cancer treatment that the men believed required more education, these being screening, diagnosis, cancer itself, radiation therapy, and survivorship. A link was found between this need for education with the participants' learnings or knowledge acquisition (Theme 1) and assisting with fear as a barrier to treatment (Theme 2). The final theme evolves around delivering education in culturally acceptable ways. This linked into family and community support (Theme 2) as leveraging these can enhance the impact of education initiatives. The concept map in Figure 1 revolves around the cancer journey and details the flow of themes highlighted in this study.

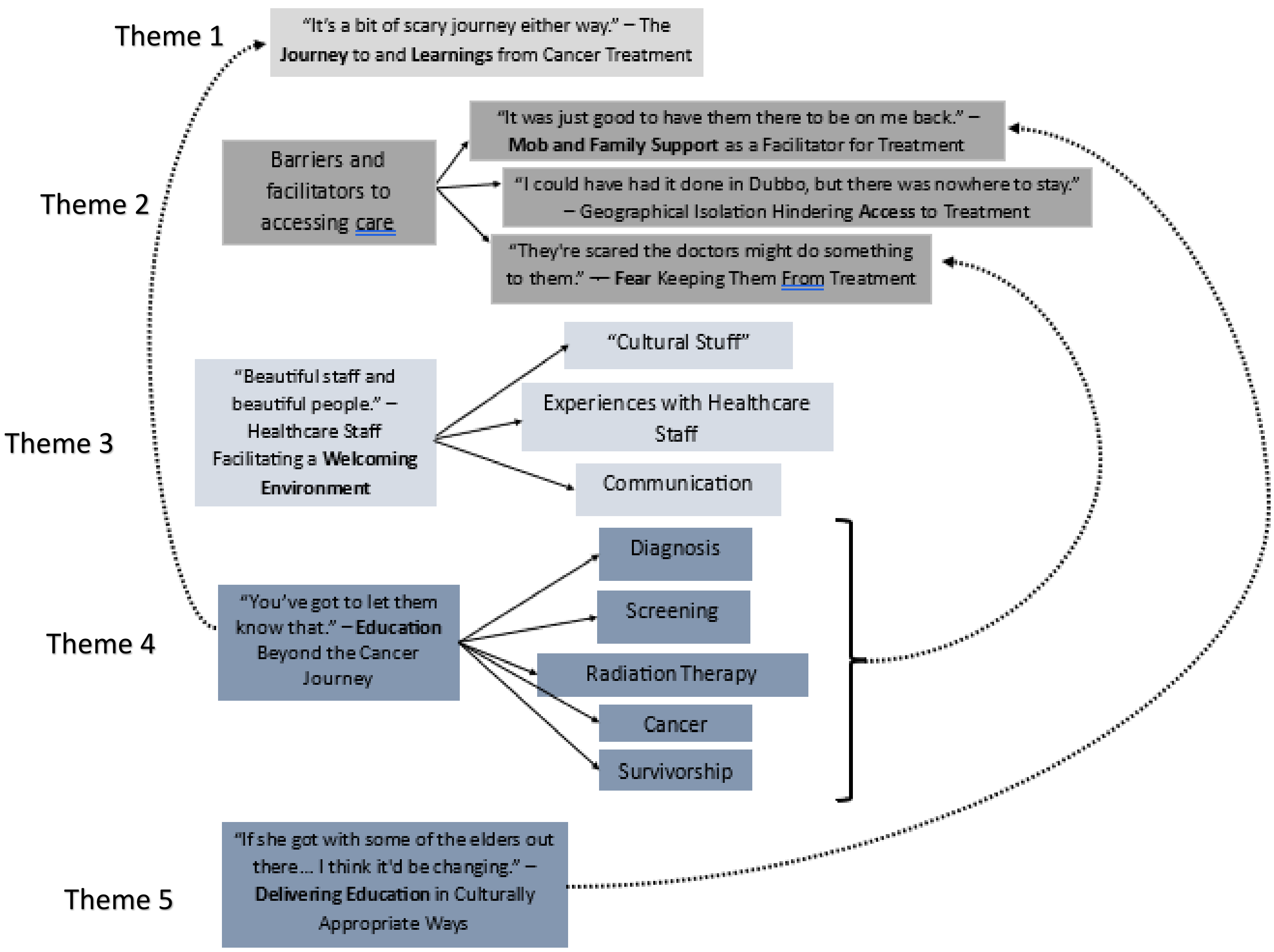

Figure 1: Flow of the patient story and links between different themes.

The story of the logo used as the centrepiece of this study (see Appendix 2) was used to frame and connect the themes identified in this study to best portray the cancer journey of the men. It symbolises through its circular and u-shaped elements individuals coming together to support patients and families impacted by cancer. The themes of family and community support, as well as the experiences in the healthcare system are implicated here. The incorporation of the sun represents hope and fresh starts, and the rays illustrate each patient's distinctive journey and how stakeholders can better support individuals to overcome barriers to treatment. Revealing how the participants' stories might be used to improve education and practices, and positively influence cancer outcomes for Aboriginal peoples, is linked to the hope.

Theme 1: The Journey To, and Learnings From, Cancer Treatment

Despite the fear and uncertainty that surrounded a cancer diagnosis, all six participants were able to generously share their own varied, but ultimately positive stories. The lessons learnt by the men through their experience with the cancer treatment process are split into categories and best visualised in Table 2.

Lesson	Quotes
The Importance of Early Intervention	*"Like I say, I think I was lucky, it could have been a lot worse if I hadn't of noticed it when I did. So that early intervention, even if you're not quite sure of what it could be. It could be something totally, not even related to cancer. It's always good to go and get it checked out anyhow."* ***(P5)*** *"Maybe I wouldn't have done anything only that I lost the weight. I lost 5kg. But I was lucky because they told me that it was just sitting there dormant but didn't move which was good to know. I had it when I was having open heart surgery. I didn't know."* ***(P3)***
The Importance of Acting Promptly	*"I know some people that have died from the prostate cancer because they left it too late."* ***(P3)*** *"I knew I had to get the operation done because at the first time when the doctor said it was a mild prostate cancer…but when the operation was taken, it was even worse…"* ***(P6)***
Fear of Cancer	*"I think people are frightened. As soon as you say 'cancer' you're frightened. I was at the start when I knew they couldn't operate."* ***(P3)*** *"I suppose they don't like bringing it up. It's like somebody on drugs, once they get the habit they can't get over it. It's a shame to talk about things like that, but it's real."* ***(P2)*** *"Some people, yeah, I don't know, just don't want to know about it."* ***(P3)***

Coping with the Diagnosis	*"I was very young to have prostate cancer, I was very shocked."* ***(P6)*** *"I did panic a bit. I said "Well what are you going to do?" Then when they said "You do the radiation" I went to Orange, seen Dr [Radiation Oncologist], had all the tests done. They put me through the machines and I said "This is quite simple" but it's the fear of it all."* ***(P3)***
Appreciation of Treatment	*"And I started my radiation and I think the radiation saved my life."* ***(P2)***
A Humbling Experience	***Interviewer:*** *"It sounds like it's been a bit of a life changing event really."* ***(P3):*** *"Yeah it was. Brought you back down to earth."*

Table 2: Theme One: Learnings and Lessons from Their Cancer Journeys, with Illustrative Quotes

Theme 1 highlights that through their experience the men have learnt the importance of seeking early medical advice and accessing appropriate intervention for their cancer. It also comments on some of the psychosocial and cultural factors that had to be overcome after a cancer diagnosis and how these impacted each participant during his treatment. A specific example was seen in P3's story where he referred to the initial panic surrounding his diagnosis, about overcoming fear at different stages and ultimately the humbling experience that was his cancer journey.

Theme 2: Barriers and Facilitators to Treatment

Theme 2 highlights barriers and facilitators raised by the men around treatment and encompasses three sub-themes which were recognised as factors that might be implicated in why Aboriginal men may or may not choose to attend services.

i. Mob and Family Support as a Facilitator for Treatment

It is important to recognise the pivotal role family and community support play in facilitating cancer treatment for Aboriginal men. Family is often prioritised above self, and existing caregiving responsibilities that patients might have can make it challenging to attend treatment sessions. This underscores a complex decision-making process and highlights the interplay between family dynamics and accessing healthcare.

> *"I ended up with prostate cancer. Got it early, but my partner at the time, she got diagnosed with aggressive breast cancer. So, I put mine on the back burner to look after her…"* **(P4)**

The involvement of loved ones in the treatment journey as both practical and emotional support significantly eased the burden of a cancer diagnosis for these men. Furthermore, encouragement from family provided the motivation some of them needed to treat their cancer.

> *"…me kids you know, [said] 'you got it early, you're probably lucky, you'll go and get it done, and everything'll be right.' Sort of more encouraging words."* ***(P5)***

> *"One of the biggest one who helped was my partner…I was lucky I wasn't on me own, so she took me through it and that."* ***(P6)***

Leaving these support networks behind to attend treatment services could prove to be a barrier for some. It was emphasised the significance of having a dedicated Aboriginal Health Worker, or Care Coordinator, who could understand such barriers, and the cultural factors unique to Aboriginal individuals.

> *"I'd say probably the feeling of being away from their people, being alone. The information maybe can be overwhelming and scary at times as well. You are in a strange place."* ***(P5)***

> *"If you've got any questions… you can get them [Aboriginal Health Worker] to come in and see you instead of having to wait for days… especially when you're going through other stuff too as well."* ***(P5)***

Furthermore, by having *"a woman [to] talk to the woman, and a bloke could talk to the blokes,"* ***(P2)*** alluded to how many Aboriginal men could be more comfortable speaking with another man about sensitive issues.

ii. <u>Geographical Isolation Hindering Access to Treatment</u>

Financial and geographical barriers present significant obstacles for Aboriginal people to access treatment. Whilst services like Marrabinya (a multi-disciplinary program that supports Aboriginal Australians with chronic disease) can assist with these hurdles for some, they do not cover an exhaustive area.

> *"Unfortunately all them services are not available in every community and little towns like that."* ***(P5)***

Reimbursement for travel and accommodation was only a portion of what it might cost to, for example, drive each day for treatment, at 40c per kilometre of travel in a private car.

> *"… [it] was only about two weeks for the travel… I had a few bob put away so didn't get affected but I know a lot of people that would have."* ***(P3)***

For very remote areas, this access to treatment is a barrier that is somewhat secondary to access screening services. Without the infrastructure, medical expertise and education in place to facilitate health-seeking behaviours, the disparity in healthcare outcomes will continue to disproportionately impact these remote communities.

> *"Like you go away out near Ivanhoe… There's no doctor there, and you wouldn't know who had cancer… because none of them go to a doctor. And the nearest doctor is a 100 and something k's away…"* **(P2)**

For those that could access dedicated support services such as Marrabinya, this helped to alleviate logistical and practical challenges, and acted as a significant facilitator of treatment.

> *"I went through Marrabinya and a beautiful lady there…she looked after me well, made sure the accommodation was all set up, me fuel. I travelled back and forwards every week."* **(P4)**

iii. Fear Keeping Them From Treatment

Another barrier was a certain fear and mistrust of the healthcare system that stemmed from community experiences of racism in culturally unsafe health services. Similarly, there was a belief that doctors can only be trusted to deliver bad news, making interactions with medical staff a confronting and upsetting experience.

> *"You know, I've known Aboriginal blokes and women, won't even go near a hospital. They're scared the doctors might do something to them."* **(P2)**

> *"They were just afraid that the doctors will find something wrong, and I was exactly the same"* **(P4)**

In a dialogue between **(P2)** and the interviewers, the participant said, *"you can't see your same doctor",* emphasising and rounding out a conversation about how the lack of continuity of care in rural areas can sow mistrust and frustration with the healthcare system.

Theme 3: Healthcare Staff Facilitating a Welcoming Environment

It's essential to highlight in a cancer journey the importance of personalised healthcare that maintains a level of cultural sensitivity. Theme 3 refers to the practices of the healthcare staff that enabled engagement in treatment and made for positive experiences overall. Simple gestures like playing music in the treatment bunker were quoted as beneficial to *"take your mind off things,"* ***(P1)***. The significance of building strong patient-provider relationships is shown in how the participants' voice that their treatment experiences were made positive by the staff they encountered: *"the staff knew me. They were great."* ***(P1)***.

Incorporating cultural elements into the treatment facilities allowed for Aboriginal patients to feel more at ease and provided a connection to cultural identity. It was thought that more could be done in this regard, acknowledging that this connection to culture is important to many Aboriginal people.

> *"I didn't mind going out and sitting near the bar-be-que there and the rock and the Wiradjuri totems and all that… it was for me more a bit peaceful and that."* **(P5)**

Hospital environments are known to be lonely and difficult to navigate, particularly for those who must travel far from home. Tailoring communication to the patient and using explanations devoid of medical jargon were highlighted as crucial components to building patient rapport. These factors made the service feel less isolating and ensured a positive treatment experience.

> *"And explain to them, don't throw stupid words at them because that just frightens you, I can tell you that now."* **(P4)**

Theme 4: Education Beyond the Cancer Journey

There is a plethora of educational materials regarding the aspects of the cancer journey for the general population, but the men felt there was a deficit in those specifically targeted at Aboriginal people. Theme 4 highlights five components of the journey (listed in Table 3) where the men felt education requires improvement or a need to raise awareness of resources available.

Lesson	Quotes
Screening	*"It's already a shame there's not more Aboriginal people in, information out there for Aboriginal people and that. About the situation and what to look for."* **(P5)** *"If you get it early enough, they can treat it before you have to have your prostate taken out or your bowel or anything. So that's what they've got to learn you know it's okay to get a blood test done."* **(P4)**
Diagnosis	*"But you've got to let them know that, "Okay you've got cancer but you can beat it." "You've got tonsillitis, we're going to take your tonsils out," you know. And the medical, like what they do with medical science and all that now is completely different, but black fellas don't understand that."* **(P4)** *"And maybe if them things were made a little bit easier then maybe men would be "Well you know it's not that bad, sooner you go down and do it and get back."* **(P5)** *"We've got care systems and that but it's a bit of a struggle because you don't know where to go, where the information is."* **(P5)**
Cancer	*"I would say when you tell somebody, you've got cancer. They look at you and say, you look too fit and that."* **(P2)** *"No I had never considered it, like never actually thought about it. Like getting caught with it, with the disease or anything like that."* **(P6)** *"I don't think they realise how dangerous it is. I think if we had a few more spokesman to go out to these places, and have a conference for anyone, black or white, and tell them how dangerous it is."* **(P2)**

Radiation Therapy	*“We still never knew about radiation or anything. So there is still some more education to be done, but how do you do it is a different thing.”* ***(P4)*** ***Interviewer:*** *And did you know about radiation therapy before this happened?* ***(P5):*** *No, no not really.* ***Interviewer****: It’s sort of a bit of specialised treatment, isn’t it?* ***(P5)****: Yeah and not knowing [is] a bit scary* *“It’d be hard to get it out to the communities’ way out west.”* ***(P4)***
Survivorship	***Interviewer:*** *What do you think would help Aboriginal men and men in general after they finish their treatments? What support do you think would help men that are going to come through in the future?* ***(P1):*** *I don't know, mate. Just a bit of information about it and stuff like that.* ***Interviewer:*** *Do you think it'd be good to have support groups around, but even for the Aboriginal men, we could set up an Aboriginal Support Group for men as well?* ***(P1):*** *Yeah.* ***Interviewer:*** *Do you think that'd be helpful to talk to men in a group?* ***(P1):*** *Yeah, I think it would.* ***Interviewer:*** *If you go through similar experiences and that, you can talk about it.* ***(P1):*** *Yeah. You talk about it.*

Table 3: Theme Four: Important Aspects of the Cancer Journey where Information and Education Needs Improving

The need the men expressed for targeted information encompassed all stages of the cancer journey. Screening can facilitate early detection and treatment of disease however a lack of proper education proves a significant impediment to engaging in these services.

> *“When I got those cancer kits[1] in the mail, the first lot, I used to throw them away.”* ***(P3)***

Empowering individuals with the information they need to treat their illness ties in with the call the men made for more educational efforts to raise awareness of cancer in the first instance. Raising awareness about cancer links somewhat with a general prevalence of fear and stigma that surrounds a cancer diagnosis.

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[1] Referring here to the nationwide Bowel Cancer Screening Program that provides free screening kits to all Australians over the age of 50.

> *“When you tell them “Oh you’ve got cancer,” well that’s when it hits and you think, “oh, you know, I’m going to die.”* ***(P4)***

It also remained a concern amongst participants the lack of awareness around the specialised cancer treatments.

> *“…so you know they’d be able to just say, “This is treatable” without having an operation or you can just go straight into radiation and get it all done”* ***(P4)***

In the survivorship portion of cancer treatment, there is still a need for support to be delivered in a culturally safe way, and for information about this part of the journey to be readily available. Sharing experiences and discussing the challenges in a safe place was thought to be a beneficial way of continuing education and decreasing stigma around cancer.

> *“…but if someone will actually say, “Oh yes, look okay, we’ve got somebody here mate, from my own community here mate who has been through all this”, I would have a talk to them about it yes for sure.”* ***(P6)***

Theme 5: Delivering Education in Culturally Appropriate Ways

The 5th and final Theme found in this study looks at how the education needs flagged in Theme 4 could be best delivered to Aboriginal men. The importance of using trusted and respected community members to pass on information and share their experiences was seen as imperative by the men to increasing engagement. They also indicated the education needs to be performed in ways that are accessible and culturally sensitive to the community.

> *“If she [Aboriginal Health Worker] got with some of the elders out there, and got them to speak to some of the younger men… I think it'd be changing.”* ***(P2)***

> *“Once one of the Uncles … if one of them gets it and its been treated and he’s back home and he’s fine and he can spread the word too. That helps”* ***(P4)***

Using these community members was highlighted as an influential way to encourage others to prioritise their health. Pragmatic suggestions also involved using Aboriginal organisations already founded in the community. This has capacity to drive positive changes in attitudes and behaviours towards healthcare.

> *“You could have a meeting if it’s one a week or once a month… [at] the WINS office… that’s an Aboriginal place,”* ***(P3)***

Discussion

This research has provided an enhanced understanding of the experiences of Aboriginal men who have undergone Radiation Therapy in Western New South Wales. The participants were able to share various insights into the aspects of their journey that proved difficult whilst acknowledging their overall treatment experience to have been one of learning and growth. Listening to the men enabled this research to identify common themes which were connected using the flow of the storylines and painted a picture of their Radiation Therapy journey.

Throughout the interviews the men highlighted how their treatment served as an educational experience, having learnt about the importance of early intervention, about acting promptly against cancer rather than fearing the diagnosis and how they now had a better understanding of cancer treatments and the benefits of them. The men indicated how these learnings now proudly allowed them to use this new knowledge to encourage better cancer awareness and health-seeking behaviours in other members of their families and community.

> *"I recommend anyone over 30 right up till they're 70 or older, to go get tested…I said to my son, just a finger up your backside, could save your life"* ***(P2)***

The men told of barriers they faced when accessing cancer care and provided pragmatic solutions that could improve the treatment journey. The WNSWLHD is the largest geographical health district in NSW and the men felt isolation from family to attend the treatment centre was a barrier to seeking care as it was hard to leave the support and networks of their communities. It has been explored how a connection to land and home remains crucial to feelings of 'wellness' in Aboriginal people.[20] The men felt having Aboriginal people in the cancer service workforce, such as an Aboriginal Cancer Care Coordinator, would make for a more welcoming and comfortable treatment experience.

The stories indicated a connection to family as being a crucial component of Aboriginal culture and illustrated the significant impact a cancer diagnosis can have on these support networks. In other studies, the presence of family was quoted to be more beneficial than having treatment, and ensuring they are supported as an extension of the patient is essential.[21] Sometimes, however, these kinship connections can provide another barrier to engaging in care at the opportune times. Supporting family members through their own problems, or returning home for culturally significant events or responsibilities in their community such as 'Sorry Business' (a term commonly used in Aboriginal communities to refer to the grieving process and cultural protocols surrounding the death of a person)[22] is seen as far more important than remaining in town for treatment.[23, 24] The men indicated that this calls for an amount of flexibility within the system, and ties into the positive impact a dedicated Aboriginal Cancer Care Coordinator could have in outpatient cancer services. It was further reiterated in this research the benefits of having someone who would be more understanding of Aboriginal culture and the biopsychosocial factors that could be impacting an Aboriginal man beyond just their diagnosis.[13, 15, 25, 26] Aboriginal Health Workers have the unique opportunity to provide a crucial link between healthcare staff and the patient. They can prevent cultural misunderstandings and provide support when a patient is required to travel far from home.[13]

> *"…it's probably hard to keep in contact with your family, especially if you're a long way from home…if you've got someone that can work in between there and make a contact, a bit a lonely thing to go through on your own"* ***(P5)***

The financial and logistical burdens of travel and accommodation was also difficult to navigate and the men indicated the importance of raising awareness early of services that could assist with funding and management of these issues. Increasing knowledge in the community of programs, such as Marrabinya, was seen as important in alleviating barriers around transport, finances and accommodation.[15] These programs are in place to assist with easing the practical difficulties, but work needs to be done to increase awareness of them.

It was raised that fear and mistrust of health services also hindered men from seeking treatment and personal disillusionment with healthcare has been known to spread through Aboriginal communities, influencing how others might see screening and services.[20] The men felt this could be overcome by addressing gaps in cancer care education for communities. The men suggested avoiding the use of detailed medical terminology and explanations and to provide simple, clear and targeted information in the identified areas of need.

> *"…when you're getting alphabet words thrown at you, we don't understand it. We don't know. The easier it is to explain it, then the easier it is for them to understand"* ***(P4)***

Healthcare staff building rapport and fostering strong patient-provider relationships was shown to have positive impacts on the treatment experiences of the men. In other studies, feelings of anxiety, worry and isolation were some of the most commonly expressed examples of needs services could not attend to.[27] This research demonstrated various experiences that spoke of flexibility and familiarity with the staff that streamlined treatment. The efforts staff made to create a comfortable environment decreased feelings of nervousness surrounding radiation therapy and the availability of dedicated spaces provided a connection to culture they might otherwise be missing whilst away from home. This was a theme that seemed to relay experiences that were generally quite positive, and showed the staff integrated a level of personalised and culturally safe care into their practices.

> *"…She said, 'what music do you like?', I said, 'I like old country. Like Tammy and all that stuff" so they were playing that for me…it made a lot of difference"* ***(P1)***

The research highlighted the need for delivering education in culturally appropriate ways around diagnosis, screening, Radiation Therapy, cancer and survivorship is essential to improve the uptake of services by Aboriginal men. An interesting observation was how the methods suggested by the men on how to best deliver this education did not involve doctors, nurses or other healthcare staff going out to spread awareness to the community. To these participants, it was crucial that education for Aboriginal people be delivered by Aboriginal people. Using local Aboriginal Health Workers or patients who have returned home having had their cancer successfully treated, 'survivor stars' as such, were some of the trusted community members these participants believed could properly deliver these educational campaigns. Leveraging existing Aboriginal organisations to promote and host such discussion in the community was another pragmatic suggestion to promote positive healthcare-seeking attitudes and behaviours. It was suggested that even just increasing discussion about cancer would allow communities to begin work at destigmatising it, and ultimately improve outcomes for Aboriginal Australians.

> *"encourage the young mob to you know, check themselves…I've been through it, if I can do it, you can do it…if you get people in there so they're not so scared'"* **(P5)**

Limitations and Strengths

A small sample size did have the potential to limit the generalisability of these findings because it might not adequately represent the diversity in western New South Wales. There also could be other potential themes and barriers relevant to Aboriginal men this research didn't reach, and these perspectives cannot be included. As a small population group, the sample may be susceptible to selection bias, and the applicability of these findings could be limited to the population of western New South Wales as healthcare systems, cultural contexts and resources vary widely, even from state to state. It should be noted that the sample size was limited by the nature of Aboriginal men only making up a very small percentage of patients that accessed the service and those that had died, had palliative or complex treatment issues were also not considered.

A strength of this research was in the design, with cultural advice sort from many sources to acknowledge the values of cultural continuity, equity and to balance the collective and individual concepts used to develop this project. Within WNSWLHD, then Director of Aboriginal Health and Wellbeing, Brendon Cutmore and the Orange Health Service Aboriginal Health Practitioner Men's Business, Damon Bell, were important cultural advisors on the development of this research and being co-researchers ensured oversight was provided throughout the whole life cycle of the project. As local cultural leaders Brendon and Damon were able to advise on the most appropriate way to contact participants, how to capture their stories and were consulted on the interpretation of findings. Additionally a follow-up meeting with each participant to discuss the summation of the findings occurred. This consultation ensured research rigour and appropriate translation of the findings providing reciprocity for the Aboriginal community.

The CWACN was also engaged as a reference group for this project. This network is comprised of local specialist health care providers such as the Orange Health Service Aboriginal Health Practitioners, NSW Cancer Council and Orange Aboriginal Medical Service and performs community programs around cancer education and wellbeing. CWACN was consulted on how to perform the research in a respectful and responsible manner to best meet local cultural needs and on how to provide mutual benefits for communities in the Central West. The reference group was also integral in developing the voluntary consent form and patient information sheet to ensure readability and cultural respect as well as advising on how to address any unintended consequences that could arise for participants.

As part of the HETI Rural Research program, education was provided on the historical cultural views of research being exploitive and how to incorporate Aboriginal methodologies such as yarning and Kapati into the design to make the research more inclusive and best capture the stories of Aboriginal men that have had Radiation Therapy.

Addressing cultural continuity, equity, reciprocity, respect, and responsibility in developing this project demonstrates a commitment to spirit and integrity which links all the values together.[28] This research looks to create spirit by connecting generations using the knowledge of past patients to improve the future cancer journey for others and to bring integrity into our health system by developing service practices that acknowledge and embrace Aboriginal values and culture.

Conclusion

This research was undertaken to address service gaps and understand the experiences of Aboriginal men undergoing Radiation Therapy. Despite the positive accounts, the results do highlight persisting barriers for this community. The invaluable insights the participants offered will drive further research and the development of tailored interventions in Radiation Therapy services. These insights hold widespread significance for healthcare practitioners, policymakers and advocates for the Aboriginal community who aim to promote the delivery of equitable healthcare. The translation of these findings into definitive action will allow for a shift towards cancer care that is more culturally sensitive and inclusive. It will also allow for the development of targeted educational campaigns that destigmatise cancer and contribute to better health-seeking behaviours, particularly in rural and isolated communities. Listening to the Radiation Stories of Aboriginal men has given them a voice in how this specialised cancer treatment can best serve their communities and culture.

Recommendations

Given the major findings of this study, it is recommended that the Radiation Oncology service:

- Continue to listen to Aboriginal patients and their needs.
- Perform culturally appropriate education for Aboriginal communities around diagnosis, screening, Radiation Therapy, cancer and survivorship.
- Provide dedicated male and female Aboriginal Health Practitioners for cancer services.

Suggestions for further research:

- Repeat the study with Aboriginal women.
- Repeat the study with men that have attended the new Radiation Therapy treatment centre that has opened in Dubbo.

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Appendix 1

Listening to Aboriginal men about their Radiation Therapy stories in Western NSW.

Interview Guide

1. Before start Interview

- Introduce Interviewers & go through the interview steps.
- Ensure consent has been signed and Participant Information Sheet has been provided.
- Remind the participant the conversation will be recorded and they can stop at any time.
- Remind participant they can have family with them.
- Check if participant has any questions before starting.

2. Starting Interview

- Acknowledgement of Country.
- Start yarning by asking the participant:
  "…tell us your story with Radiation Therapy".

3. During Interview

The following semi-structured questions can be utilised if required to get more detailed understanding or information around certain aspects of the treatment journey:

- **"What are your thoughts about cancer"**
- **"What do you think about Radiation Therapy as a treatment"**
- **"What impact did your treatment have on your family?"**
- **"Was the treatment building culturally welcoming?"**
- **"How about the information you were given, what was that like?"**
- **"How were the treatment staff, were they able to help you with cultural needs?"**
- **"What do you thinks prevents Aboriginal men from having Radiation Therapy?"**
- **"How could we make it easier for community to access this treatment"**
- **"What support do you think would help Aboriginal men after they have finished their treatment?**

4. End of Interview

- Explain the yarn will be listened back to and common themes and thoughts identified.
- Arrange a follow-up meeting to discuss findings and how best to provide final report to the participant.
- Thank participant for sharing their time, story and knowledge - provide a choice of NRL equipment as acknowledgement of this.

Appendix 2

The Logo!

The Logo that forms the centrepiece on the forms used in the project is the logo of the Central West Aboriginal Cancer Network, who have granted permission for its use in this research. The logo was created by local Aboriginal male artist, Sandon Gibbs O'Neill, who explains that the logo represents a sense of community with the circle and u-shapes. It shows different people coming together to support each individual and family impacted by cancer. The link to the sun reflects hope and to take each day as a new day. The Sun's rays also show the different journey every person takes when experiencing cancer and how the network will support them on their unique journey.

The logo explains in picture, much better than in words, what this research is all about!