ORIGINAL RESEARCH



'The best thing since sliced bread': Patient experiences of teleoncology in western NSW

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Abstract

Objective: This study explored experiences of rural cancer patients who were receiving treatments by remote video-assisted chemotherapy (RVAC) or participating in clinical trials remotely.

Setting: Participants lived in Coonabarabran or Dubbo in western NSW.

Participants: Seven cancer patients undergoing treatment for breast, bladder or colon cancer, renal cell carcinoma or lymphoma.

Design: Appreciative inquiry informed this qualitative study. Semi-structured interviews were conducted between July 2018 and January 2019 and thematically analysed.

Results: The patient experience of teleoncology was overwhelmingly positive. Patients explained the value of relationships that developed with the local and virtual care team. Patients felt they received better care if they saw the same on-cologist for the duration of their treatment and felt RVAC had accommodated this. Teleoncology allowed patients to remain independent because they were able to maintain their usual support mechanisms including family, friends and health care team. Patients described the reduced physical and emotional travel burden in addition to reduction in travel time and cost.

Conclusions: These findings highlight the acceptability of teleoncology for rural patients as chemotherapy can be added to the health care and social and emotional supports, which exist in their hometown. Expansion of teleoncology should be codesigned with local communities with a focus on establishing care teams with consistent staffing to build trust between the treating team and the patient. These relationships improve the patient experience and enhance patient independence, which is a desirable attribute of cancer survivorship. Recruitment to clinical trials using teleoncology is acceptable and should be factored into trial development.

K E Y W O R D S

cancer, oncology, qualitative research, remote, rural, telehealth, telemedicine

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1 | INTRODUCTION

People in rural and remote Australia have generally poorer cancer outcomes than those living in more densely populated areas. All-cancer survival rates demonstrate just over half (55%) of people who live in very remote areas lived 5 years past their cancer diagnosis, whilst almost two-thirds (63%) of people living in major cities were alive five-year post-diagnosis.¹ Differences in survival rates have been attributed to social determinants of health, an increase in risk factors associated with cancer such as smoking, obesity and alcohol consumption and poorer access to health services.¹⁻⁴ With unfavourable economies of scale associated with running specialised medical services in remote locations, teleoncology is emerging as a feasible means of circumventing this inequity of access.⁵ Teleoncology is also being trialled to improve access to clinical trials for these populations.⁶⁻⁸

Teleoncology is a subset of telehealth, which facilitates consultations and supervision of remote cancer therapy delivery, including chemotherapy and immunotherapy, through videoconferencing. A range of teleoncology models operate in Australia, but all depend on health care providers in smaller, more remote facilities to administer cancer therapies and manage any complications of these agents under the supervision of specialist cancer centres. An established Queensland service requires patients to travel from their remote town to tertiary centres for initial consultations and chemotherapy and then receive follow-up consultations and low-risk treatment via teleoncology.⁹ This service has been identified as safe¹⁰ and acceptable to staff and patients.^{11–13}

In New South Wales (NSW), a novel remote videoassisted chemotherapy (RVAC) service established in 2017 links the remote town of Coonabarabran (Modified Monash Model 5¹⁴) with the regional cancer centre located in Dubbo (Modified Monash Model 3¹⁴) 160km away. The RVAC service allows cancer patients to receive low- and medium-risk cancer therapies in Coonabarabran Hospital as an outpatient. These therapies are supervised by specialist chemotherapy nurses in Dubbo via fully integrated telehealth services and administered by community or ward-based nurses with training in chemotherapy handling. Patients see their treating oncologist either by teleoncology or in-person during outreach clinics to Coonabarabran. The RVAC service has been proven to be safe¹⁵ and resulted in a threefold increase in referrals from patients living in the Coonabarabran district to the regional cancer centre (incidence proportion was calculated by number of referrals from Coonabarabran per annum divided by town population)¹⁶ although the effect on utilisation of cancer treatments and outcomes is yet to be realised.¹⁷

What is already known on this subject:

- Cancer outcomes are generally poorer for people who live in rural and remote areas, partly because of the extensive travel required to access cancer treatments
- Teleoncology has been used successfully to reduce travel time and associated financial burden for patients in rural and remote areas
- Knowledge of patient perspectives and experiences of teleoncology are sparse but would assist in refinement of future patient-centred models of care, including increased opportunities for rural people to join clinical trials

What this paper adds:

- Patients were overwhelmingly positive about teleoncology, which they saw as additional care offered locally complementing their existing local health care and social and emotional supports
- Patients explained the value of relationships that developed with the care team both at their local site and over video link, which they perceived to be beneficial to their care across their cancer journeys
- These relationships improve the patient experience and enhance patient independence, which is a desirable attribute of cancer survivorship

Teleoncology has reduced travel distance and costs for cancer patients,^{5,12} but little is understood about the patient perspective of receiving teleoncology and how services can be improved to meet the needs of people living in rural and remote areas. One qualitative study undertaken on the Townsville Teleoncology model found that staff in the patient's hometown were crucial to positive patient experiences of teleoncology as they served important roles in filling in gaps in communication, undertaking examinations and solving technical problems.¹¹

Literature concerning patient perspectives of clinical trial participation for teleoncology is also limited. A quantitative study in rural Queensland found isolated patients were interested in clinical trial participation but were limited by cost of travel and need of family support during treatment.⁶ Another study in the United States involved six consultations with 15 clinical trial participants via teleconferencing over a period of 6 months and showed high satisfaction rates across the cohort. All patients completed all required consultations and agreed they were likely to participate in a telemedicine clinical trial in the future.⁷

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A 'teletrial' (telemedicine clinical trial) framework for regional Victoria has been implemented to improve access of rural people to clinical trials⁸ and has been described by patients in a mixed methods study as acceptable and valuable.¹⁸ Access to clinical trials via teleoncology has recently become possible in NSW with colorectal cancer patients in Dubbo now able to join a clinical trial based in Orange.¹⁹

This study explores rural patient experiences of accessing cancer treatments through RVAC or participating in clinical trials remotely. The novel RVAC model and scarcity of in-depth qualitative data regarding teleoncology make this study unique to the literature. Understanding patient experiences of teleoncology will help inform how the existing and future models can be adapted and improved to accommodate patient preferences and expectations and has broad applicability to other rural and remote health services.

2 **METHODS**

Semi-structured interviews were used in this qualitative study to explore patient experiences. Interview questions, analysis and recommendations used in this study were informed by appreciative inquiry, an approach which identifies strengths and focuses on positive and incremental improvement.²⁰

Patients from Coonabarabran receiving RVAC from Dubbo or patients participating in the ASCOLT clinical trial remotely from Dubbo in the six-month period from July 2018 to January 2019 were invited to join the study. Patients were identified using the local radiation and chemotherapy databases and specific telehealth billing numbers for teleoncology services. Patients were excluded if it was believed that conducting interviews would interfere with the delivery of their care or if participation was deemed too burdensome due to poor health. This was determined by an oncologist (Rob Zielinski or Florian Honeyball) familiar with the patients' history and current health status. Patients who may also have had surgery, radiation therapy and high-risk chemotherapies in regional or urban centres, which required extensive travel from their hometown were eligible for the study.

Patients were posted a patient information sheet and consent form by the principal investigator (Sid Pye) who had no prior relationship with participants. Follow-up was made via telephone (Sid Pye) to organise an interview time. Thirteen patients were invited to participate and six declined, leaving seven participants.

Data were collected using semi-structured interviews conducted over the telephone. Interview schedules were customised for teleoncology or clinical trial patients. Interviews ranged between 20 and 40 min and were audio recorded using an external recorder and transcribed by an online transcription service. Before interviews began, verbal consent was gained and recorded as a separate audio file to de-identify the audio transcripts.

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Transcripts were open coded, and thematic analysis was used to transform the data.²¹ Data collection, coding and analysis were conducted by a single investigator (Sid Pye) who was new to qualitative research. Supervision from an experienced qualitative researcher (Emma Webster) included checking of coding and revision and critique of themes. Emerging themes were presented to novice and experienced research colleagues at a research meeting for discussion to assist with defining and refining themes. Care was taken to anonymise participants due to the size of the communities they were drawn from.

Preparation of this manuscript has been guided by the Standards for Reporting Qualitative Research.²²

3 RESULTS

Patients were undergoing treatment for breast, bladder or colon cancer, renal cell carcinoma or lymphoma. Five patients were male and two were female, and their ages ranged from 39 to 71 years. Analysis of the data identified five themes; acceptability of teleoncology, role of teleoncology in strengthening relationships, access to support networks in hometown, reduced travel burden and trial experience.

3.1 Acceptability of teleoncology: '... it's the best thing since sliced bread' P2

Patient impressions of teleoncology were overwhelmingly positive with all reporting they would receive treatment in the same way in the future.

> Damn lucky for the technology... it's the best thing since sliced bread.

P2

No patient described any initial discomfort at the idea of receiving treatment over videoconferencing, with two of the patients interviewed describing previous teleconferencing experiences in education and justice contexts. Management of the videoconferencing equipment is navigated by health care workers during teleoncology sessions, and patients did not comment on any difficulties using the technology. Some patients talked about feeling reassured by routine health assessments taken during teleoncology sessions such as evaluation of vital signs and verification of medications and other safety checks. Although there were no explicit concerns about breaches of privacy, one patient felt that more care could have been taken when treatment for more than one patient was in progress simultaneously. Patients perceived conversations about palliative care held via teleoncology as reassuring and facilitate appropriate time to make plans.

3.2 | Role of teleoncology in strengthening relationships: '... it's a huge leap forward' P4

Patients reported that teleoncology enabled them to build relationships with the same care team, which they perceived beneficial to their ongoing care. These relationships gave confidence and comfort during their cancer treatment.

> ...it's been pretty nice with the nurses and you can have a bit of a laugh with them and that makes it a lot easier too.

> > P3

Patients described how seeing familiar faces both in the local clinic and on the screen helped them feel at ease.

...when I'm just sitting in the chair waiting for the injection and I see all the faces I know walking past the cameras and stuff, and that is really nice too, to know them

P4

One patient expressed frustration at being consulted by different doctors at each (in-person) consultation and how teleoncology had allowed connection with the same oncologist.

> ...we had lots of locums, and some of them really - I would have been better off talking to (the same) specialist via video conferencing and talking to them one-on-one. So, it's a huge leap forward.

> > P4

Patients described how forming trusting relationships with their treating teams locally and with their oncologist allowed for discussion of difficult topics. One patient explained how teleoncology would allow them to receive palliative care at home.

We've discussed sort of end-of-life stuff and all of that jazz. And yeah, so I'll be comfy here

and I'd prefer to be here and not to have to move at the end

P4

Whilst some patients felt there was little difference between seeing their oncologist in-person or by videoconference others expressed their preference for an in-person consultation. However, teleoncology was always favoured over the inconvenience of having to travel to the regional centre for a consultation.

3.3 | Access to support networks in hometown: 'This time around I'm never left on my own' P4

Patients described feeling more independent when receiving treatment by teleoncology in their hometown as this reduced their reliance on family, friends and government services to provide transport and accommodation. Government and institutional financial assistance for travel was considered adequate although some patients reported they could have been better supported for accommodation. The main financial support utilised was the Isolated Patients Travel and Accommodation Assistance Scheme, with assistance from not-for-profit organisations such as Can Assist and The Leukaemia Foundation. Some patients accessed hospital-provided accommodation, which they described as being both affordable and comfortable.

> ...(accommodation provided) was probably better than any other motel we've stayed near [Regional Hospital]

> > P5

Receiving treatment in their hometown meant patients had access to existing support networks, and most patients described the social and emotional supports provided by friends and family as well as their treating team.

This time around I'm never left on my own P4

Patients felt well informed regarding their illness and their treatment; however, some mentioned that access to services was delayed because information concerning what services or supports were available was not communicated during the initial treatment consultations. Some patients also reported receiving counselling.

3.4 | Reduced travel burden: '(travel) has been quite wearing and tearing physically and financially' P1

Patients appreciated reductions in travel time and expenses as a result of using teleoncology. All patients interviewed had some experience of travelling to receive an aspect of their cancer care, which could be up 6 h one way if treatment was in Sydney, contributing to financial and time pressures and physical and emotional strain.

I've had to travel about 200 kilometres away to my nearest cancer centre, which has been quite wearing and tearing physically and financially

P1

One patient described their experience of travelling home after major abdominal surgery.

... they (family) brought me back through (home) over the next couple of days because I couldn't spend too long in the car. Like, this time around I had 57 staples holding me back together...

P6

Another patient described the physical and emotional strain of managing their treatment and tending extra duties on the farm during a time of drought.

> I had to go to [Regional Hospital] for six weeks (of treatment). So, that was a big thing, and at the time I was a farmer and was in a drought... so that was pretty full on.

> > P4

3.5 | Trial experience: 'It was a lot more convenient... to do the teleconference side of things' P6

Two patients interviewed were participating in the ASCOLT trial¹⁹ via teleoncology. Both patients found it convenient, well organised and flexible.

It was a lot more convenient being able to do the teleconference side of things

P6

One patient believed the experience was superior to their normal consultations because the trial team could afford them more time. You could spend the time with them on there and actually talk to them and discuss these things rather than just sort of in and out the door

P6

Both patients had good trial literacy and were altruistic in their motivations. Patients reported no major medication difficulties with taking their trial medications although one patient had taken the wrong dose for a period. Both patients indicated they would participate in clinical trials through teleoncology in the future and for one patient, participation in the clinical trial would not have been possible if teleoncology was not available.

> Yeah initially, I wasn't (on the trial) because it wasn't an option... (as) it was visits to [Regional Hospital] or whatever. Now, it's via the video conferencing (I have joined).

> > P7

4 | DISCUSSION

This study used semi-structured interviews to explore the perspectives of seven rural cancer patients who were receiving chemotherapy or participating in clinical trials via teleoncology. The patient experience of teleoncology was overwhelmingly positive. Patients valued seeing the same oncologist for the duration of their care under the RVAC model. Teleoncology also allowed patients to maintain access to usual support mechanisms including family, friends and people who had been part of their health care team before their cancer journey had begun. Patients reported teleoncology reduced the travel burden, which extended beyond travel time and cost to include the emotional burden of being away from home. These findings highlight the acceptability of teleoncology for rural patients because chemotherapy can be added to the health care and social and emotional supports, which exist in their hometown.

Previous studies have established that teleoncology reduces travel time and cost for rural patients and their families.^{5,11,12} Our study supports these findings and extends our understanding of the emotional burdens, which arise from travel as a result of not being able to attend to usual responsibilities such as farming or family commitments. Our study also extends understanding of the importance of established relationships between the patient and health care provider before a cancer diagnosis. Whilst this does build patient confidence in teleoncology by navigating technology and enhancing communication between the specialist and patient,¹¹ it also explains the importance of feeling cared for by people in their hometown who knew them before their cancer diagnosis, complemented by the addition of multidisciplinary cancer specialists to provide treatment and palliation (where required) contributed to positive patient experiences of care. The patient perception of superior care when being looked after by a single oncologist can also be explained by the establishment of trusting relationships. The benefit of establishing and maintaining trusting relationships has also been described by cancer survivors' in their engagement with telehealth for follow-up and remote monitoring.²³

Teleoncology delivered in the local hospital setting was easy and practical for patients to use as technology was managed by health care workers. Receiving teleoncology close to home also improved social supports for patients undergoing treatment by reducing the time spent away from support networks such as friends and family. Patients felt more independent as they were less reliant on government services and family members for travel and finances. This independence is considered a desirable element in cancer survivorship.²³

This forms the first qualitative study of the patient experience of a teleoncology service, which combines in-person oncologist visits to see the patient in their hometown with delivery of remote video-assisted chemotherapy. The appreciative inquiry framework helped detail strengths of RVAC in establishing and maintaining patient and health care provider relationships. Future adaptations to enhance the patient experience could link patients to services for social and financial supports in initial treatment consultations, which could be facilitated (in-person or telehealth) by a social worker. Future service development of remote sites could pay more attention to privacy needs where multiple patients are receiving treatment simultaneously is warranted.

In adopting a RVAC service, respect needs to be given to the unique nature of each rural town. Trust and relationships were central to perceptions of being cared for. Efforts to augment patient-health care provider relationships to build trust should, therefore, be contextdependent and guided by local community input. Whilst an Aboriginal perspective was not explored in this study, cultural advice and guidance is likely to be of key importance in rural communities, many of which are home to significant proportions of Aboriginal peoples. Studies undertaken in Queensland have indicated teleoncology was suitable for Aboriginal patients but that there were also likely to be unique needs such as accommodating between four and six family members during delivery of chemotherapy treatments and including Aboriginal Health Workers as part of the care team at the remote site.^{5,13}

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Patient perspectives of clinical trial participation via teleoncology were positive with no issues raised in terms of communication or major confusion with medications consistent with Galsky et al.⁷ Our findings also resonate with those of Lee et al.¹⁸ regarding reduction in travel burdens and valued addition of oncology staff to their hometown care team. Travel for patients joining clinical trials in NSW averaged 4602 kms and cost \$1079 in accommodation per patient.²⁴ Teleoncology can provide rural patients with equitable access to clinical trials and should be routinely considered in all clinical trial frameworks appropriate to the Australian context have recently been published.⁸

Although only seven interviews were conducted, the interview process allowed for an in-depth exploration of patients' experience of teleoncology. The advantage of using a qualitative approach was that it gave patients the opportunity to express their perceptions and opinions and for the investigator to dynamically uncover their reasoning. A further unintended strength was that all participants had experience of travelling for in-person chemotherapy treatments as well as teleoncology chemotherapy treatments. This provided a useful perspective of the differences between the treatment modalities.

This study was limited by a small sample size, which included only two participants contributing to the clinical trials data. Sample size was limited by available patients and time to collect and analyse more data and meant it was not possible to determine whether saturation of themes had occurred.

5 | CONCLUSION

Teleoncology improves access to cancer care for rural patients because it reduces the time, cost and emotional burden of accessing lifesaving treatment and because it supports ongoing relationships between the patient and the care team. Teleoncology decreases time away from family and friends, which augments the support received during treatment and improves patient independence which is a desirable quality of cancer survivorship. These attributes mean that teleoncology makes a positive contribution to patient-centred care.

The tripling of referrals for cancer treatments by teleoncology coupled with the significant psychosocial impacts identified in this study makes a compelling argument to expand teleoncology services to additional rural and remote towns where cancer treatments are currently unavailable. Expansion in other centres should be contextdependent and codesigned with local input, especially where communities are home to Aboriginal peoples. New 96 WILEY- AJRH & Rurd H

services should aim to build on existing trust and enhance these relationships in rostering of specialist health care providers to enhance continuity of care and improve the patient experience.

Teleoncology was well received by clinical trial patients and is likely to increase the participation of rural people in future trials where teleoncology is routinely considered. Determining whether increased referrals for teleoncology result in increased access to chemotherapy needs to be investigated alongside cancer outcomes for teleoncology patients. In parallel to service expansion and quantitative investigation of associated cancer outcomes, ongoing qualitative research is needed to further explore patient experiences. Research on patient perceptions of the value of palliative care delivered through telehealth is also warranted.

AUTHOR CONTRIBUTIONS

The idea for this study came from discussion between EW, FH and RZ. SP prepared a research protocol and ethics application under the supervision of EW, FH and RZ. FH and RZ assisted SP with data collection. SP analysed data supervised by EW. Manuscript development was led by SP supported by EW, FH and RZ. All authors have reviewed numerous versions and approved the submitted manuscript.

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CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

ETHICAL APPROVAL

Ethics approval was received from Greater Western Human Research Ethics Committee HREC/18/GWA HS/69.

DISCLOSURE

This study was not funded. This research has not been published elsewhere in part or in full.

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