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The Experiences of Young People Living with Cancer in Regional and Remote Australia: A Qualitative Study

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Abstract

There is limited qualitative research specifically exploring the experiences of young people living with cancer in nonmetropolitan Australia. This article reports on an in-depth qualitative study exploring young people’s experiences of diagnosis, treatment and post-cancer care and support, focusing on the impact of living in regional and remote Queensland, Australia. Thematically coded data from in-depth interviews was managed using NVivo 12 qualitative software. Connections with place, knowledge, people, support, lifestyle, and peers were key themes. Travelling for treatment interrupted these connections, with participants desiring treatment closer to home. Preventive social work in metropolitan and nonmetropolitan areas that supports maintaining connections for young patients from regional and remote areas is recommended. Further research, including the impact on young Aboriginal and Torres Strait Islander people with cancer and on the role of social workers, will inform improvements in social work practice.

Implications

- Recognising the importance of connections for young people living with cancer from regional and remote areas can inform social work psychosocial assessments in metropolitan and nonmetropolitan settings, assisting social workers to respond appropriately to information young people share and supporting these valued connections.
• Enhancing preventive social work care with young people living with cancer from regional and remote areas will involve direct, regular communication at diagnosis, during and after cancer treatment using appropriate age-specific interventions.

Keywords
Nonmetropolitan, Rural, Young People, Adolescent, Cancer, Social Work

Regional Australian social workers are uniquely positioned to recognise challenges experienced by young people living with cancer in nonmetropolitan areas. Social work has a responsibility to address disadvantage (AASW, 2020), with equity of access to health care a significant international issue for those from nonmetropolitan areas (Idris, 2016). In 2017, 28% of Australians lived outside major cities in nonmetropolitan areas defined as inner regional, outer regional, remote and very remote by Australian Statistical Geography Standard – Remoteness Area [ASGS-RA] classifications (Australian Institute of Health and Welfare, 2020). Regional and remote Australians experience lower levels of education, employment and access to health care, having poorer health outcomes including a higher cancer burden and lower cancer survival rates than metropolitan Australians (AIHW, 2020). Young people 15-24 years from nonmetropolitan areas have higher cancer and mortality rates than those from major cities (AIHW, 2018), further exacerbated by interruptions to developmental milestones and distance to specialist cancer care in metropolitan areas.

Young people’s development includes establishing autonomy from parents, personal values and identity, peer relationships including intimate and sexual relationships and appropriate preparation for the workforce (D’Agostino et al., 2011). A cancer diagnosis during these years interrupts these tasks, with young people with cancer a distinct group
requiring specialised, age-specific services (Zebrack et al., 2016). Geographical distance from specialist cancer care brings long-term familial separations, disruptions to schooling, education, work and to psycho-developmental milestones (Holland et al., 2021). Limited research exists to guide nonmetropolitan oncology social work practice with young people (Sariman et al., 2020). This study aims to address this gap in knowledge by exploring the experiences of young people living with cancer in regional and remote Queensland.

**Living in Nonmetropolitan Australia: Health Outcomes and Young People**

Most specialist cancer services for young people in Queensland are located in Brisbane (Bradford et al., 2018), however over half of Queensland’s estimated resident population live outside Brisbane (ABS, 2021). Delivering services equitably across Queensland is complicated for young cancer patients in nonmetropolitan areas where there is resulting “inconsistency in access to care and divergent experiences for young people” (Holland et al., 2021, p. 2). Proposed advances to models of cancer care for young people from nonmetropolitan areas such as tele-health have been made, however research informing them is predominantly metropolitan based (Sariman et al., 2020). Current models of care (Canteen, 2011, 2017; Christ et al., 2015; Commonwealth of Australia, 2008; Palmer & Thomas, 2008) for young people living with cancer are not informed by nonmetropolitan research. As argued, the voices of young service users from nonmetropolitan areas do not inform social work practice, resulting in practice often reliant on individual practitioner frameworks and models of care not connected to young people in systematic, evidence-based ways.

**Young People with Cancer: Nonmetropolitan Social Work Practice**
Geographical inequities exist in accessing psychosocial support due to distance from major cancer treatment centres (Holland et al., 2021). In this study, all participants, half of whom were from nonmetropolitan areas, encountered at least one barrier to psychosocial care, with inequitable geographical service access (Holland et al., 2021). Another Australian multi-site study supports this finding, noting that of 250 social work oncology cases 60% came from nonmetropolitan areas, suggesting higher demand for psychosocial support based on geographical location (Pockett et al., 2020). Social workers at metropolitan sites saw high numbers of patients from nonmetropolitan locations (Pockett et al., 2020). Although Pockett et al.’s (2020) study re-affirmed the support needs of nonmetropolitan cancer patients their focus was not on young people.

There is limited practice-based research in Australian oncology social work to guide gold-standard care (Pockett et al., 2020). Practitioner led research can assist in addressing gaps between practice and research (Harvey et al., 2013). Our study aimed to explore young people’s experiences at diagnosis, during and after cancer treatment in regional and remote Queensland to better inform social work practice. A qualitative, exploratory design, using a person-in-environment approach that assumes reciprocal relationships between people and their environments was used to ensure the breadth and depth of young people’s experiences were captured (Bretzlaff-Holstein, 2018).

The research questions were: How do young people diagnosed with cancer from regional and remote Queensland describe their experience of living with cancer? What is important to young people living with cancer in regional and remote Queensland when diagnosed with cancer, during cancer treatment and after treatment finishes or when they return home?
Ethics approvals were gained from the Far North Queensland Human Research Ethics Committee (Reference No. HREC/18/QCH/90 – 1260) and James Cook University Human Research Ethics Committee (Reference No. H7789). Pseudonyms were applied to participant responses, and findings are presented in overall themes, with data not reported if it could potentially be linked to participants, to uphold participant privacy.

Methods

Site of Study

The site for this study was a 531-bed regional hospital in Queensland. ASGS-RA classifications, measured by a location’s level of access to services, were used to define regional and remote areas (AIHW, 2020). Inpatient and outpatient cancer services are available at the hospital in paediatric and adult oncology. Adult oncology offers services from diagnosis to treatment completion, including chemotherapy and radiotherapy, with resident adult oncologists and haematologists. However babies, children and young people almost always need to travel to specialist cancer care centres in Brisbane (1390km by plane or 1680km by road) for at least two weeks for initial diagnostic staging and treatment planning, or longer-term treatment for up to nine months, before they are able to return home for maintenance therapy, often needing further travel to Brisbane for treatment or medical reviews. A visiting paediatric oncologist travels to the site six monthly for those no longer requiring Brisbane reviews. Travel is required for stem-cell transplant treatment for all patients.
Sampling and Recruitment

‘Young person’ was defined as an adolescent or young adult aged 15-25 years (Canteen, 2017). Inclusion criteria were young people aged 15-25 years; living in regional and remote Queensland (ASGS-RA classifications) (AIHW, 2020); diagnosed with cancer before age 25; who had received ongoing medical monitoring following active treatment which had been completed at least six months prior to study participation. Exclusion criteria were young people currently undergoing treatment, or 15-18 years and assessed as unable to provide consent. ‘Living with cancer’ refers to someone receiving ongoing medical monitoring post-cancer treatment.

Purposive sampling (Dutta, 2014) was used to derive information-rich data on variant experiences of living with cancer. Study flyers were placed in paediatric, adult and Visiting Medical Officer oncology clinics. Study information was also included in a routine mail-out to service users. Nursing staff were briefed by the first author and provided flyers to eligible potential participants at clinics. Interested young people contacted the first author directly at clinics, by phone or email if they wished to participate and provided written consent after being provided with a Participant Information Sheet outlining the study purpose and methods. The research was undertaken from October 2019 – August 2020.

Data Collection

Semi-structured interviews were conducted by the first author in person, by videoconference or phone after COVID-19 restrictions were in place, averaging one hour. The first author, a Queensland Health social worker, was not clinically working with
participants at interview, however some were past clients. It was explained to participants that the first author was in a research role and that only information shared in the interview would be used. Any prior knowledge would remain confidential. Using a topic guide, participants were asked to reflect on their cancer experiences at diagnosis, treatment and post-cancer care, with emphasis on impacts of living in regional or remote areas. An example of a questions is: “How do you think living in (hometown) affected what happened after your diagnosis?” Interviews were conducted with participants individually or with a relative present at the young person’s request (n=4). The first author asked relatives to comment only when invited by the young person, ensuring participants’ reflections of their cancer experience were depicted in ways they chose (Thompson, 2020). Participants invited relatives to assist with memories when, for example, they were very young at diagnosis. Data collection ceased when no new themes emerged.

**Data Analysis**

Interviews were recorded on a digital recorder and transcribed for analysis. Thematic coding (Ritchie et al., 2014) was used to interpret and report on data. Codes were sorted into categories and organised inductively into themes relevant to the research questions (Smith et al., 2009) and common issues identified by participants. The first author strived to define the essence of participants meanings both intentional and unintentional (Minichiello et al., 2008). Inductively derived themes such as ‘treatment close to home’ and ‘understanding my cancer’ were reached through processes guided by Minichiello et al., (2008) of free association, making comparisons between data, codes and themes and research maps leading to six main themes. Codes and themes identified by the first author were discussed with co-authors until
agreement was reached. NVivo 12 qualitative software was used to store data and facilitate analysis.

Findings

Demographic characteristics

Ten young people, seven female and three males, living with cancer participated in the study. A further four, three male and one female, agreed to participate, later declining. Another potential participant did not meet eligibility criteria. At interview participants were aged 18-25 years (mean=20). Participant age at diagnosis varied from 22 months to 19 years, ranging in age from under 15 (n=6) to 15-25 (n=4). Locations at diagnosis were outer regional (n=8), and very remote (n=2) (ASGS-RA classifications) (AIHW, 2020). The average time from treatment completion was 6.9 years. Nine participants re-located to larger towns or cities for initial cancer treatment, ranging in time from three weeks to nine months. All participants undertook travel to major cancer centres for treatment, medical procedures and specialist appointments multiple times. Average distance from home to major treatment centre was 1704km, with distances ranging from 347km to 2390km.

Six themes were identified as important to young people in the study: place (treatment close to home), knowledge (being acknowledged and understanding my cancer), people (family, friends and health staff), support (coping strategies), lifestyle (surviving cancer and how it has shaped me) and peers (sharing my experience). These themes encompassed concerns participants shared, shaping their cancer experiences positively and negatively. The
theme of connection emerged as central. Young peoples’ connections with and within each theme are illustrated in Figure 1.

[Figure 1 near here]

**Connection with Place: Treatment Close to Home**

All young people in this study travelled away from home to larger towns or cities for diagnosis or treatment, describing associated health and psychological hardships. Re-location was often painful and uncomfortable. One participant described being flown by the Royal Flying Doctor Service from his hometown to the city for specialist cancer care as particularly challenging. Of the flight itself, he said: “It was a tiny little twin-prop plane. Bumpy as hell. It was quite a rainy night. It was dark, gloomy, rainy … quite fitting” (George).

Participants described uncertainties travelling away for treatment brought:

…they (health staff) told us we had to go down to [city] and they weren’t sure at the time how long that would be so, you know, I kind of found it hard leaving friends, not knowing how long that would be for. (Raymond)

Participants found travelling away hard with disruptions to school and work, experiencing distress due to separation from loved ones. They found it easier when treatment was transferred closer to home:

I think just the fact you can be in your own home in your own bed. I guess if you’re feeling unwell even with the flu, it’s nice to just be at
home in your own house with your own things. So, I think that to me
was the biggest relief. (Gracie)

All participants noted differences between their experiences and those they observed of young people living in cities. They thought young people living in cities could go home at the end of treatment days, stayed connected with loved ones, school and friends, were more familiar and connected with staff at specialist cancer centres and with the cities:

Somebody down there would know [city] – they’d probably know
doctors there. They’d know the people doing the (treatment) … some of
the nurses, I’m pretty sure, rotate throughout where you have chemo so
they would know the nurses and that, too. (Layla)

Differences young people described highlight why connection with place mattered. Treatment closer to home meant physical proximity with loved ones, familiar environments, familiar visitors in hospital and connections with school, work and community. Travelling away interrupted those connections. “Mia” explained: “So I didn’t really know much about [city] other than the hospital. It wasn’t home.”

Connection with Knowledge: Being Acknowledged and Understanding my Cancer

Acknowledgement by health staff and inclusion in their care plans were important for participants. Some described staff talking to their parents rather than them:

We also like to know what’s happening. My family’s not experiencing it,

it’s me that’s experiencing it … just because the person being diagnosed

is young … doesn’t mean they’re completely unaware of what’s
happening, because they do want to know … knowledge is a powerful thing. (Mia)

Participants favoured being spoken to directly. “Raymond” explained: “I wanted to be in the loop, you know, so I knew what was happening next, and what I needed to be prepared for and everything”. “George” experienced not only being unacknowledged when asking questions, but also his mother being unacknowledged by a nurse. He explained his frustration at this behaviour: “It’s, ‘No, that’s my Mum. If I don’t get to know, then at a minimum, she gets to … Why am I not allowed to know? You’re bloody doing this to me’”.

Knowing about and understanding their cancer was important to participants. At diagnosis, clearest memories included information provided by health staff and family. Five participants feared their illness might be fatal: “I didn’t really show that I was absolutely terrified, because obviously watching TV, cancer is often portrayed as fatal” (George). “Gracie” remembered considering she may not survive her cancer: “you’re faced with your mortality at a very young age”. “Mia” also linked cancer with fatality: “I just remember connecting cancer with death. And just wondering, like: ‘Is this gonna happen to me?’”. Perceptions of inaccurate diagnostic information led some participants to search the internet, which added to their fears: “I didn’t wanna die … all I saw was cancer and all the images that pop up and I just, just thought I would die, ‘cos you know – this young child looking at all that” (Andrea).

Although uncommon, two participants in remote locations discussed length of time between their first presentation to a health service with cancer symptoms and diagnosis. One remote participant said:

I feel like because we were so remote and probably because [remote staff]
didn’t have the knowledge, that was probably why it took so long for them
to figure it out … if we were in more of a, like, less remote location, I feel like we
probably could have caught onto it a little bit earlier. (Sharon)
The other remote participant commented: “… in the [regional or city] hospitals, if [a staff
member] goes away, someone else comes to pick up, you know, where they left off…”
(Andrea).

Participants found treatment difficult, describing mixed reactions including boredom and
fear. Treatment rendered many participants with lowered immunity unable to socialise and
experiencing the harsh side-effects of chemotherapy such as broken bones. Other negative
impacts included pain. “George” stated although health staff said he had curable cancer,
treatment was still painful: “You’re telling me ‘The cancer is weak’, but the chemo isn’t. Just
because you can get rid of it doesn’t mean it hurts any less”.

Finishing treatment brought mixed feelings. Whilst glad treatment was finished,
participants were unsure of their futures, reporting unforeseen treatment after-effects. These
included cognitive delays, short-term memory loss, hearing loss and potential infertility. One
participant liked joking about having had cancer, whilst another exercised caution with
dietary intake and: “not doing anything too dangerous” (Raymond). Two participants stated
they currently experienced anxiety when separated from their parents due to their cancer
experience. Reported mental health after-effects included anxiety, a “late mental break”
(Andrea), “post-traumatic stress” (Brianna) and an ongoing fear of needles.

**Connection with People: Family, Friends and Health Staff**
All participants missed loved ones whilst away. “Gracie” said of living away: “…you’re more isolated from your family and friends.” Keeping connections through communication was important: “I ended up having Facebook … Mum set it up so I could message friends” (Brianna). Some participants felt friendships suffered through having cancer: “…nobody sort of really came around as much” (Layla). “George” described how his cancer experience revealed who his friends were, noting: “The real ones, who actually messaged me and continued chatting with me, are the ones that I still chat to today …”. Not surprisingly, young people who were older at diagnosis had a stronger emphasis on social relationships than those who were younger at diagnosis.

Having good connections with health staff was important to participants. One participant remembered the psychologist in the city he went to like this: “[the psychologist] sort of became one of my friends in the hospital because he … had the same sense of humour as me” (George). Four participants spoke of the connection they had with a particular health staff member in paediatric oncology. “Mia” explained the importance of this connection: “Cos she just remembers you. She remembers what you like and all these other things. Which – yeah, it’s really good. There was a connection between the two of us … a therapeutic relationship, I would say”.

Connection with Support: Coping Strategies

Participants identified strategies they used to develop autonomy and manage hardships, noting where help came from. Coping strategies included generating their own solutions to
challenges. For example, finding ways of managing stressful situations: “watching the needle go in made it easier than eyes closed” (Layla) and connecting with others who have cancer:

I think you make friends quite quickly when you can share experiences …

not everyone has had that experience [cancer] … there was someone I met at Canteen – he’s so like me … (Brianna)

Other ways of coping included staying connected with loved ones back home and using humour:

I liked messing with my siblings about it … you know … to make fun out of it, ‘cos they’re not sure what’s going to happen, they’re always getting a bit scared, so you’d go ‘oh, oh, oh no’ [grabs his chest and makes a sound like he cannot breathe with dramatic, scared look on his face, then laughter]. (Raymond)

Help for participants came from family, friends, psychiatrists, psychologists, schools, nurses, social workers and their community. “Andrea”, although in the health system, got psychological help through her school: “The school started noticing my mental health going down … through the school I got support – not through health”. One participant’s family had fund-raising support from their local community: “Financially it was tough. Our local town fundraised which was so lovely” (Sian’s mother). The physical presence of family, due to publicly subsidised travel and accommodation, for all participants whilst away having treatment was important: “It was really good, actually. It means I had someone there in an unknown situation. Like, had someone familiar with me, which was really good … it was huge, I guess” (Mia).

Connection with Lifestyle: Surviving Cancer – How it has Shaped Me
Participants reflected on ways having cancer shaped their lives. Physical changes included wearing hearing aids, cognitive delays and potential infertility. Psychological changes including anxiety, depression and fear of needles. “Brett” spoke of being more cautious: “…before it was a pretty normal kids’ life – doing what kids do, and the changes are I just stayed at home … being cautious about everything”. Positive personal attributes resulting from their cancer experiences included tolerating pain better, being braver, more health-conscious and understanding of others. Realisation of how many others have cancer occurred: “Once you get into that world of knowing about it, you realise how many people have it and how many people around you end up having it as well” (Brianna). Participants spoke of spiritual and philosophical learnings: “I couldn’t be a normal teenager, but I can be a normal adult” (Andrea). Long-term effects on relationships were described both positively; “…it made my family closer” (Mia), and negatively; “…friends sort of distanced themselves a little bit …” (Layla). Losing friends who died from their cancer was one of the hardest effects of all: “…not long after that he passed away, after having leukaemia for the third time … That really was hard, doing that – saying goodbye to people” (Brianna).

Connection with Peers: Sharing my Experience

Nine participants suggested ways to improve young people’s experiences of living with cancer. Connecting with knowledge to understand their cancer was recommended by listening to health staff, researching and asking questions:

… writing down my questions that I wanted him to answer because you’d forget them otherwise. He’d be like: “You got any questions?” and you’d be like: “Not really.” But then, you’d get home and you’d be like: “Oh I wanted to ask him that”, write it down, take it with you. (Layla)
Maintaining connections with loved ones was suggested: “…surround yourself with your family as much as you can” (Sharon). Connecting with other young people experiencing cancer for support was recommended: “Being with other people who are going through the same experience as you and know what you’re going through …” (Mia).

Connecting with support, including social work support, was suggested; “…talking to someone is the key … your mental health is the key to getting through” (Andrea). Social worker availability was important to participants for regular welfare checks: “… just being a little bit more readily available … just to check in a bit more often … I think I met maybe one [social worker] in the whole time …” (Gracie). Social work access was more readily available for other participants: “… trying to stay in touch as much as possible - you guys do that quite well … you connect with parents as well, which is good” (Raymond). As participants put it; “…they’ve [social workers] all been nice and very quick to getting stuff that you need done, but … I wish there were more … so it wasn’t so: ‘Ahh, damn they’re busy’, or: ‘Ahh, damn it’s their day off’” (George). Social workers offering psychosocial support was seen as important: “… support [young people] and let them know that there’s a lot of people there for them” (Brianna). “Gracie” suggested: “…give them more access to support systems of someone who can answer their questions if they have any”. Offering support and arranging referrals were key social work roles for participants.

**Discussion and Conclusion**

The aim of this study was to explore experiences of young people living with cancer in regional and remote Queensland and therefore contribute to the evidence base for oncology social work practice. These aims were achieved. For young people in this study, maintaining
connections with place, knowledge, people, support, lifestyle and peers were important. Participants described more positive experiences where connections were strong, such as; receiving treatment closer to home, understanding their diagnosis, being acknowledged by health staff, having a good connection with at least one key health professional and having adequate coping strategies.

In this study travelling away for treatment was hard for young people living with cancer. Study participants wanted to connect with place and the strongest valued connection was with home. All participants desired treatment as close to home as possible. Travelling away for treatment brought physical and psychological hardships caused by separation from home, loved ones, school and community. In contrast Marris et al.’s (2011) review of the literature on the experiences of teenage and young adult patients concluded that young people were prepared to travel away for specialist cancer care if age-appropriate care near home was not available and that treatment close to home was a low priority. Marris et al. (2011) cited UK studies where geographical distances are far less than those experienced by regional and remote Australians. The participants in this study reported travelling up to 2390kms to access specialist cancer care.

Connection was a central concept in this study linking young people from regional and remote areas with what mattered to them. Examining impacts of geographical distances between home and specialist cancer care highlights that for participants, travelling long distances disrupted connections developmentally critical to young people living with cancer. Participants valued strong connections with place, knowledge, people, support, lifestyle and peers. Other studies have found similar domains to be important for young people living with cancer. For example, Schreiner et al., (2020) found that physical, mental and emotional
health and enjoying meaningful, age-appropriate activities with the people who matter to them was important to young people living with cancer. Holland et al. (2021) found that young people needed access to psychological and emotional support, support to cope with relationships and carer support, education support, integrated care with schools, work, finances and relationships and peer support. What our study highlights are the challenges treatment away from home brings, which are likely to increase the more remote young people are. Travelling long distances for cancer treatment, medical appointments and follow-up brought significant hardships and disruptions to young people’s lives resulting in negative impacts on connections with what mattered to them. This was especially the case for participants aged 15-25 at diagnosis, who were impacted more broadly across a range of relationships.

Young people in this study wanted to be acknowledged, recognised as the centre of their care and spoken to directly by health staff. When communication needs regarding information and options are met, psychosocial problems are reduced for young people living with cancer (Jager et al., 2017). A 2018 scoping review found that patient-centred communication is a developing area of research in the adolescent and young adult cancer population, and much less attention is given to improving that communication (Gorman et al., 2018). Not all young people have good health literacy, especially the skills to communicate about complex health information (Sansom-Daly et al., 2016). Despite age at diagnosis, young people in this study valued honest communication with themselves and their family. Participants valued individual connection that acknowledged their unique circumstances and informed health staff who understood the challenges they face as regional and remote patients, expecting social workers to be proactive in making connections with them.
Social workers in metropolitan and nonmetropolitan areas can play a key role in ensuring young people from regional and remote areas are connected with what matters to them, including ensuring health staff understand their needs as they traverse their cancer experience. Maintaining connections is a way of anchoring young people at diagnosis, during and after treatment. Recognising connections can inform social work psychosocial assessments, whether conducted in metropolitan or nonmetropolitan areas, and assist social workers to respond appropriately to information shared by young people. With study participants noting the importance of having a connection with health staff, this study indicates a social work response requires communicating directly and regularly with young people from nonmetropolitan areas, providing help to stay connected with home, loved ones, knowledge, support, lifestyle and peers, and educating health professionals on these unique needs to improve their cancer experience. Increasing availability of social workers can mitigate many psychosocial factors that impact negatively on those living with cancer (Pockett et al., 2020).

These findings need to be considered in the context of study limitations. Study participants identified as non-Indigenous and are therefore not reflective of increased health vulnerability of Indigenous Australians (AIHW, 2020). The lack of any Indigenous participants is an important gap to be addressed in future research. The study was conducted at a single site; however, the geographical and service context has been described to enable assessment of transferability of findings elsewhere. The sample size of young people living with cancer at the study site was small. However, it included a cross section of experiences for all young participants who needed to travel away for significant portions of their cancer care resulting in physical and psychosocial hardship. Further, the sample size was appropriate according to guidelines on information power in qualitative interviews given the narrow study aim, small
sampling frame and quality of the in-depth interview dialogues (Malterud et al., 2015). To protect confidentiality, we have not reported participant age and diagnosis.

We undertook social work research (Pockett et al., 2015) on experiences of young people living with cancer in regional and remote Queensland. Disruptions to young people’s connections with home, loved ones, school and community were significant at a developmentally critical time, exacerbated by vast Queensland distances and necessary travel away for cancer treatment. Social workers can improve care for nonmetropolitan young people living with cancer by moving from crisis-driven, although sometimes unavoidable, to preventive interventions seeking to maintain connections important to young people through direct, regular communication and appropriate age-specific interventions. The six spheres of connection emergent in this study are recommended interventional discussion starters. Further in-depth qualitative social work research with a greater diversity of participants, including social workers, from nonmetropolitan areas across Australia is recommended.

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References


Canteen. (2011). *Adolescent and Young Adult Oncology Psychosocial Care Manual*. Canteen Australia.


Palmer, S., & Thomas, D. (2008). *A practice framework for working with 15-25 year-old cancer patients treated within the adult health sector.* onTrac@PeterMac: Victorian Adolescent & Young Adult Cancer Service, Melbourne


https://doi.org/10.1080/00981389.2015.1046577


https://doi.org/10.1089/jayo.2015.0059

Sariman, J. A., Harris, N. M., Harvey, D., & Sansom-Daly, U. M. (2020). Experiences of young people living with cancer in nonmetropolitan areas: A review of the literature. *Journal of Adolescent and Young Adult Oncology, 9*(2), 133-144.

https://doi.org/10.1089/jayao.2019.0053


https://doi.org/10.1080/0312407X.2018.1481341

Paediatric Psychosocial Oncology: Textbook for Multidisciplinary Care. Springer International Publishing.
Figure 1. Spheres of connection important to study participants.