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A qualitative study of specialist multidisciplinary clinician perspectives on barriers/facilitators to care for children with brain cancer and their families: "*We're a little bit different to our adult counterparts*"

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Abstract

Objectives. Children with brain cancer and their families have complex care needs throughout diagnosis, active treatment, long-term survivorship, and the palliative phase of illness. This study aimed to explore the perspectives of Australian specialist clinicians on barriers and facilitators to health care for children with brain cancer and their families.

Methods. A qualitative approach was taken using semi-structured interviews. Eligible participants were clinicians of any discipline providing care to children with brain cancer and their families in Australia. Interviews were conducted by telephone and asked about perceived strengths and weaknesses in health care and available resources for this population. Qualitative content analysis used a directed approach with inductive refinement.

Results. Eleven clinicians participated, 5 of whom were medical, 3 nursing, and 3 allied health. The overarching theme was that the rarity and diversity of brain tumors in children confers challenges to care that lead to variation in practice. Participants reported having to adapt care from guidelines and patient/family resources designed for adults with brain cancer and children with other cancers, and rely on clinical and research networks. Specialist comprehensive cancer care was generally perceived to offer the best model for accommodating the unique needs of each child/family, but barriers to access were highlighted for children in remote Australia, and long-term follow-up was perceived to be inadequate regardless of where children lived.

Significance of results. Until further brain cancer-specific paediatric guidelines become available, our findings highlight the need for communities of practice to share resources and reduce unwarranted variation.

Conclusion. Future research should focus on developing and evaluating guidelines and other resources specific to children with brain cancer, as well as informing suitable models for long-term follow-up care for survivors.

Introduction

Pediatric brain cancer is an umbrella term for various types of brain and spinal cord tumors, such as medulloblastomas and gliomas, which develop during childhood. Brain cancer is the most common cause of childhood cancer deaths (Udaka and Packer 2018).

Children with brain cancer and their families have complex care needs during the active treatment, long-term survival, and the palliative phases of illness (Fischer et al. 2016). Internationally, many qualitative studies have canvassed the perspectives of children with brain cancer and their families regarding their experiences of illness and health care. Themes identified by 2 recent meta-syntheses of such studies highlighted a wish to carry on life as normally as possible despite uncertain prognosis and the lasting impact that life-threatening illness can have on the life views of children and families, as well as a lack of support with regard to schooling, with negative impacts on academic and social development (Young et al. 2021){Young, 2022 #6746}. In contrast, little is known about health professionals' ("clinicians"') views regarding the

health-care needs of children with brain cancer and their families, or the strengths and weaknesses of available services.

Australia ranks among the top countries in the world for 5-year survival rates for children with brain cancer (Allemani et al. 2018). However, its health system faces challenges from the country's socio-demography – a small population of 25.4 million people spread unevenly across a large area of 7.6 million square kilometers (Australian Bureau of Statistics 2021). Only 116 children aged 0 to 14 years were diagnosed with brain or other central nervous system cancer in 2018 (Australian Institute of Health and Welfare 2022).

The current study aimed to explore the perspectives of Australian specialist clinicians on barriers and facilitators to health care for children with brain cancer and their families.

Methods

A qualitative descriptive study was situated within a larger mixed-methods study. A qualitative approach was used to enable an in-depth exploration of clinician perspectives.

Reporting has been guided by the Consolidated criteria for Reporting Qualitative research (COREQ; Tong et al. 2007).

Sample

People were eligible for inclusion in the current analysis if they were Australian clinicians of any discipline providing care to children living with primary brain cancer and/or their families.

Sixteen Australian organizations were approached directly via email requesting that an invitation to participate in the project be distributed to their members (Box 1).

Data collection

Data were collected via semi-structured telephone interviews that were conducted by 3 experienced female qualitative researchers, 2 with backgrounds in health services research and 1 in oncology and palliative care nursing. The average duration of interviews was 40 minutes, which ranged from 25 to 55 minutes. Permission to record telephone interviews was obtained from interviewees. Reflecting objectives of the larger study, open-ended interview questions pertained to perceptions of strengths and weaknesses of care for children with brain cancer and resources for clinicians, patients, and families. Professional characteristics were also collected during interviews. Notes were taken as needed to contextualize verbal data. Audio recordings were professionally transcribed. Neither transcripts nor analysis were returned to participants for comment and/or correction.

Analysis

A directed approach to qualitative content analysis (Hsieh and Shannon 2005) began by extracting all data relevant to children into an MS Excel spreadsheet. Transcripts were coded into predetermined categories of strengths/weaknesses and resource use in brain cancer care in Australia. Within each category, data were further refined into themes via an inductive process that facilitated nuanced descriptions of identified weaknesses, strengths, and resources. Coding was undertaken by a female medical student (MG) in regular discussion with a male social scientist (TL). Both were experienced qualitative researchers, but neither had experience in the care of people with brain cancer, nor did they conduct the interviews or have existing relationships with participants. The analysts engaged in regular peer debriefing together and then with the larger team to facilitate analytic triangulation and credibility.

Results

Sample characteristics

Interviews were conducted between November 2019 and February 2020. A total of 233 stakeholders were approached for the larger study, of whom 94 participated. Of the remaining 139, 28 declined and 110 did not provide any response. Interviews with 11 participants included information relevant to pediatrics. These participants included 5 physicians (3 neuro-oncologists, 1 pediatric oncologist, and 1 palliative care physician), 3 registered nurses specializing in neuro or pediatric oncology, and 3 allied health professionals (occupational therapist, physiotherapist, and speech/language pathologist). Nine worked exclusively with children, while the remaining 2 also saw adolescents and young adults. Participants devoted a median 40% of their clinical roles to brain cancer versus other cancer types (interquartile range: 17%–67%). All except 2 had 10 or more years of experience in their roles. Nine participants worked predominantly in Queensland (8 of whom worked in its capital, Brisbane), and 2 in Sydney.

Themes

The overarching theme was that the rarity and diversity of brain tumors in children conferred challenges to care that led to variation in practice. Participants reported having to adapt care from guidelines and patient/family resources designed for adults with brain cancer and children with other cancers, and rely on clinical and research networks. Specialist comprehensive cancer care was generally perceived to offer the best model for accommodating the unique needs of each child/family, but barriers to access were highlighted for children in remote Australia, and long-term follow-up was perceived to be inadequate regardless of where children lived. Subthemes are presented as follows.

Low prevalence leads to variation in practice

Participants blamed the relative rarity of brain cancer in children for a perceived dearth in related research evidence, clinical practice guidelines, patient resources, and specialist skills.

> Guidelines do not always align with clinical practice …[because] there are no guidelines for children [with brain cancer]. (BCA_010, nurse)

This problem was perceived to be worsened by the diversity of specific brain cancer types affecting children versus adults.

> I don't think we use any brain tumour guidelines per se. Only because paediatric brain tumours are different to adult brain tumours. So, in adults, they have a more narrow range of tumours that occur. And primarily glioblastoma with a few others, whereas we have a multitude of different types of tumours. (BCA_058 Paediatric oncologist)

The number of different childhood brain cancers and their relatively low prevalence were said to make it difficult for new clinicians to acquire the capabilities required to manage children's and families' complex care needs.

A medical participant pointed out that pediatric neuro-oncology lacked a central point of reference for up-to-date treatment information, in contrast to clinicians working in adult cancer care.

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> … incorporation of more paediatric things into a platform by [the Cancer Institute New South Wales' online point-of-care resource] 'eviQ' would make it much more accessible for people working in the paediatric brain tumour field, I think, because at the moment we're really not using a platform like that. (BCA_080, pediatric oncologist)

The prolific development of new emerging treatments was perceived to exacerbate the difficulties clinicians faced with keeping up to date with the evidence.

> I find when a new child starts a new MAC [mitochondrial apoptosis-induced channel] inhibitor, I've got to madly race around trying to find information to give to the families because I don't know anything about it myself. (BCA_016, neuro-oncology clinical nurse consultant)

Participants from all disciplines noted that the lack of a single evidence-based standard for treatment led to variation in practice between centers.

> Often, you'll find that, in [children's hospital in Sydney], most of us may go to a certain treatment protocol for medulloblastoma, because that's what we've had as an open trial here. But then, if you're presented with medulloblastoma in Perth, you would get yet another but – from what we know - equally efficacious, but just a different approach with similar drugs given a different way. So, there is definitely variability. But variability depends on whether it's between a couple of protocols, which is most diseases, or when it comes to rarer things, there's huge variability in what people do as their practice. And some of it is more evidence based, meaning like some people would do the deeper dive every time for each patient, whereas others just by virtue of experience may go to a protocol that they've used before. So, I think you'll see a huge variability in how we go about it. (BCA_080, pediatric hematologist/oncologist)

Care needs to be adapted from resources designed for other patient populations

Across disciplines, participants highlighted that a scarcity of resources specifically designed for children with brain cancer forced them to use others designed for adults with brain cancer, or pediatric cancer care more generally. This required clinicians to be cognizant of important differences between populations that would lead them to evaluate the applicability of each specific recommendation, rather than follow guidelines as a whole.

> I have pulled things from the adult framework, but often it's just not applicable because it's varied radiation needs and there's young kids who can't receive radiation. So, it's often not a field where you can just pull from your adult colleague's guidelines or resources, because again there's things that are a risk for an adult. For example, there's a much more risk of stroke if you do anything in the brain for an adult. So, they're not risks that are easily translatable to children. So, it is a challenging space to get resources in. (BCA_080)

While acknowledging that disease- and population-specific resources would be optimal for guiding practice, participants also highlighted that some resources could be relevant to an individual patient's needs regardless of diagnosis. This was especially true where practice was focused on managing symptoms or other problems rather than anti-cancer treatment.

> The clinical need of what many of these families have is not actually related to their diagnosis, it's just related to what are the problems that we need to work through here? And that's sort of how it is, it's certainly from the palliative care side of things, and that's probably why we don't really have a lot that's sort of specifically brain cancer or cancer. (BCA_091, pediatric palliative care specialist).

As in the case of guidelines for clinicians, participants reported that brain cancer-specific information resources for children and their families were relatively few ("compared with other cancers…there could be more available," (BCA_032, RN)). Australian brain cancer-specific resources for pediatrics that *were* used included those from organizations called Redkite and the Brainchild Foundation (BCA_032, RN case manager). While some participants reported finding international resources useful, 1 neuro-oncology clinical nurse consultant noted a risk that overseas pediatric cancer treatment information could lack applicability to the Australian context (BCA_016, neuro-oncology clinical nurse consultant).

In contrast, most participants spoke of there being an abundance of pediatric patient and family resources for cancer in general. Certain of the more generic pediatric cancer resources for children/families received commendation, including those relating to school from various government and non-government organizational websites, such as the *Monkey in My chair* school initiative ((Love Chloe Foundation 2022); BCA_012, neuro-oncology clinical nurse consultant). However, participants worried that families might have to work through a lot of irrelevant information to find content suited to their needs or – worse still – be unable to tell what was more or less relevant from the plethora of more general resources available online.

> And I wonder sometimes whether or not it's much better to have some more general education about how can anyone look at the breadth of things that you might find if you do a Google search for something, in order to weed out the stuff that might just send you down a rabbit hole of confusion. (BCA_091, pediatric palliative care physician).

> Plenty of [resources are] out there but need to be carefully curated for the individual case. (BCA_031, occupational therapist)

Participants reported undertaking this task on occasion to tailor information to a given family's individual needs. However, this was considered too time consuming to be realistic on a routine basis.

> And it's very frequent that families say to me, do you have a handout or something. And then often I'll then put something like that together, so I know they're getting accurate information. But I just feel that that's not a sustainable practice for us to have to put together a handout for each family.

Specialist comprehensive cancer care is the best model, but access is limited

Several participants emphasized the uniqueness of each child's needs and requirement to tailor care accordingly, "almost as opposed to the patient needing to work around you and your centre" (BCA_080, pediatric oncologist).

The diverse range of patient/family needs often required input from a large array of disciplines from medicine, nursing and allied health. Careful timing was also needed according to each child's cancer trajectory, often into long-term follow-up. Participants who worked in comprehensive cancer centers were the only ones to report that services were available commensurate to need.

> We're lucky enough to have four of our six solid tumour consultants actually work within the neuro-oncology field … because, again, we're a single service, we actually have ready access to our rehab team and our neuropsychology team, so we can easily hook into those support services. For the kids who are on treatment, we've got quite a comprehensive allied health team. So, all the kids on treatment will need social workers, OTs, physios, speech therapists, dieticians. (BCA_016, nursing)

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However, participants highlighted that children living in more remote regions of Australia lacked access to comprehensive care of this kind, including those from Aboriginal and Torres Strait Islander communities.

> I have got one boy who lives in the bush. Actually, he lives in the Northern Territory, I think, but the closest hospital to him is Mount Isa [Queensland town, 200km from the NT border]. And he is a little Indigenous boy, and getting him down here is such a major exercise. So, theoretically he is meant to have scans at least twice a year, but those scans are, like - you might get one in February and then another one in December. (BCA_058, pediatric oncologist)

Where children and their families from remote Australia *were* able to access comprehensive cancer care, this was reported to require lengthy periods away from home, to the detriment of social support.

> The downside would be that we are a huge state in Queensland, and we have families coming from, you know, anywhere from the Torres Strait down to the top of New South Wales, and sometimes the Northern Territory, so that does mean that families are required to be away from home for extensive periods of time, and the impact of that, even though the clinical outcomes are good from this model of care, what are the social and mental health outcomes as a result. (BCA_038, speech pathologist)

Even for children with access to comprehensive care, participants highlighted gaps in allied health services post-treatment, especially into long-term survivorship, despite a belief that such support was critical for optimizing children's physical, cognitive, and psychological functioning over their lifetime.

> I think we need more in the community that families can access when they've finished treatment, because our on-treatment therapists can't keep everybody, you know, you can't possibly keep every kid you ever met in your service, you haven't got the facilities or the capability for that. So, I think we are missing some community services for kids once they've finished treatment.… More things that families can — a resource where they can access to find, is there a physio in my area who knows specifically about post-brain injury type rehab? I think we know that our kids – we are having more kids survive their childhood brain tumours, but they're not going on to have particularly full grown-up lives. A lot of them won't get a proper job, they won't be able to drive, they won't be able to reach the potential they could have reached if they haven't been treated and that's a future gap. (BCA_016, Neuro-oncology clinical nurse consultant).

> [There is a] lack of neuro cognitive input for long term effects, lack of therapeutic intervention, when people finish treatment - there is a gap in long term follow up. (BCA_31, occupational therapist)

The lifelong nature of impacts from brain cancer on children were emphasized by the speech pathologist (BCA_038), who felt that families are not always adequately prepared for the side-effects and disabilities that arise from brain cancers and their associated treatment.

> I think [we need to be] monitoring for, and providing more information to families about what to expect as their child gets older, because a lot of families are stuck in the mindset of 'my child has cancer but if we cure the cancer everything will be fine' but, as you know, with brain tumours there's a lot of different side effects. Some of those can be short-term but many of them can be long-term, and they can be quite debilitating in nature. (BCA_038, speech pathologist)

The pediatric palliative care physician felt that psychosocial supports outside of hospital were especially lacking for families.

> I think from the point of view of how tricky that is for families, I think in many respects is that perhaps the psychosocial support for families is a very great need. And that can be hard, particularly if the patients aren't actually in the hospital a lot, it's how you can actually provide a lot of that outside of the hospital. Because certainly, it's probably a tricky one for private providers. But, then, the public provider processes are probably not adequately funded to be able to give as much of that support as perhaps what might really be needed. (BCA_091, pediatric palliative care physician)

Clinical and research networks are invaluable

Where barriers to access for more remote children *were* overcome, this was achieved by means of a centrally coordinated and supported network of clinicians who provided care near the person's home. Telehealth was identified as especially important in enabling care of this kind.

> I think we have an exceptional network of clinicians … all children begin their treatment in a tertiary centre for their diagnosis and beginning of treatment … Where possible they receive certain aspects of their treatment closer to home, but it's very much managed centrally, and as a result, we are one of the only areas in Australia that doesn't have a discrepancy between outcomes for the Indigenous population versus non-Indigenous. (BCA_038, speech pathologist)

Given the lack of guidelines for pediatric brain cancer highlighted above, access to clinical trials networks was also identified as important, with COGNO (Cooperative Trials Group for Neuro-Oncology) and ANZCHOG (Australian and New Zealand Children's Hematology/Oncology Group) cited as 2 national examples. These networks were considered important not only for enrolling patients in new trials but also for finding out about the latest treatments that might be effective for a given patient.

> So, I think in paediatrics we're a little bit different to our adult counterparts in terms of how we use resources, especially in the brain tumour space. We're often trying to enrol patients in open clinical trials, and they will either be through an Australian consortium like ANZCHOG, or the other big resource we use is the [US] Children's Oncology Group protocols, the COG protocols, which are both open and previously closed trials that we use as standard of care for a number of diseases.… And then, for trials that are emerging and opening and recruiting, we are now part of many or a couple of international consortiums that are opening trials here. So, we use their resources as well.… We're always trying to do new and exciting things.… There's a great [clinical trial] platform for checking whether tumours have particular molecular changes that might have a drug that can target it. (BCA_080, pediatric oncologist)

> If, for example, a patient is not eligible for a study for whatever the reason might be, we will often follow those protocols [just the same]. (BCA_058 pediatric oncologist)

Finally, 2 participants identified neuro-oncology journals and networking via conferences to be especially important in the care of children with brain cancer because of the potential these offered to keep up to date with new treatments, clinician and patient education resources.

Discussion

This study explored the perspectives of Australian multidisciplinary clinicians regarding the strengths and weaknesses of health care for children with brain cancer and their families. Participants emphasized the need to make up for an absence of guidelines and patient/family resources designed for children with brain cancer by adapting those for other populations, and relying on clinical and research networks. A lack of standard best practice was said to have

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led to widespread variation in care between different providers. Specialist comprehensive cancer care was generally perceived to offer the best model, but access was said to be limited for children in remote Australia, and long-term follow-up was deemed inadequate regardless of where children lived.

Five qualitative studies have explored the perspectives of Australian children with brain cancer and/or families regarding their care needs (Cheung et al. 2014; Jackson et al. 2009, 2007, 2003){Young, 2023 #7024}, 2 of which focused exclusively on a single quaternary hospital in 1 Australian State (Jackson et al. 2007, 2003). Findings from these studies are consistent with our results that children and families sometimes receive inadequate information and experience a reduction in support following the initial treatment phase. They also suggest that parents' emotional needs are sometimes overlooked in favor of those of their children. In accordance with the finding that unmet needs may increase over time, a survey study at the Queensland Children's Hospital in Brisbane found that quality of life was worse for parents 6 months after diagnosis compared to those with children more recently diagnosed {Young, 2023 #7025}.

A recent systematic environmental scan identified 119 online self-management resources for adults with brain cancer although, even for this age-group, there was little guidance available on rehabilitation, managing behavioral changes, survivorship and living with uncertainty, recurrence, or transitioning to palliative care (Schaefer et al. 2021). Developing information for children is challenged by the "moveable feast" posed by the ongoing development of literacy and health literacy throughout the childhood years. However, displaying information in pictorial format can lead to improvements in knowledge/understanding, especially where children (or indeed adults) have lower health literacy (Schubbe et al. 2020). This is important because children have been found more likely to use internet health information where they come from a family with lower health literacy (Park and Kwon 2018).

Health-care barriers to long-term follow-up for childhood cancer survivors have been recognized internationally, including: an interrupted transition from pediatric to adult health services; under-resourced health services; changing patient-clinician relationships; a lack of experience with long-term effects on the part of general practitioners; and inadequate communication with survivors about the need to monitor for long-term effects (Howard et al. 2018). Findings from our study suggest that the most important barriers for long-term survivorship care of Australian children with brain cancer may be a lack of allied health support for activities of daily living and psychosocial wellbeing. Fortunately, services to support cancer survivors are increasing in number across Australia, including those that provide advice and training for shared and primary care led models of care, which may be more cost-effective than specialist-led care (Chan et al. 2023). Our study highlighted telehealth as an important asset for enabling integrated care for children with brain cancer at a time when reimbursements for this mode of care had been recently extended as a public health measure in response to the COVID-19 pandemic. More recently, however, the Australian government has restricted eligibility for telehealth reimbursement in response to relaxed public health measures (MBS Online 2022). While telehealth offers limited capacity for some aspects of cancer survivorship care, there are also substantial benefits both to survivors and the health-care system which should continue to be leveraged into the future (Jefford et al. 2022). Our study also highlighted the role that telehealth can play in enabling children with brain cancer and other rare cancer groups to access new treatments offered within clinical trials, even when they live outside a metropolitan area. National efforts to improve implementation of tele-trials were underway in Australia before the COVID-19 pandemic (Clinical Oncological Soceity of Australia 2016), and have gathered pace since.

Our study has several limitations. While our study was designed to fill a gap in qualitative research on the perspectives of clinicians, we omitted the views of other stakeholders such as service managers and policy-makers. Even among clinicians, our sample was small ($n = 11$), limited in geographic spread to metropolitan settings (10/11) in 2 states, and focused on specialist rather than primary care providers, which may have led to an over-emphasis on the value of comprehensive care rather than innovative community models such as the "pop-up model," which has been found to be an effective way of leveraging local capacity for pediatric palliative care in more remote parts of Australia (White et al. 2005). Moreover, our sampling was likely subject to a volunteer effect, leading to perspectives that were informed and considered but unlikely to be representative of clinicians more generally.

Finally, our study identified a number of directions for future research. A prevalent message across interviews was that children's needs change over time as well as differ between individuals, but more research is needed to document this in a consistent and rich enough way to inform the potential for stratified personalized pathways that have proven effectiveness in survivorship care for other cancer populations (MBS Online 2022). A longitudinal qualitative study underway in Queensland, Australia, is among the first worldwide to offer insights of this kind (Young et al. 2020), and there is scope for quantitative research to add further value if coordinated through the national research collaboratives highlighted by participants in order to attain a representative sample. Also, both our study and qualitative research carried out with children and families provide insights into the information needs of both clinicians and consumers that could be addressed by future studies to develop and evaluate new resources.

Clinicians interviewed in the current study perceived there to be a dearth of guidelines and patient/family resources designed for children with brain cancer, which they addressed by adapting those designed for other populations, and relying on clinical and research networks. Future research should focus on developing and evaluating guidelines and resources specific to children with brain cancer, as well as informing suitable models for long-term follow-up care for survivors.

Box 1. Australian organizations approached to invite participation

- Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG)
- BrainChild
- Brain Tumour Alliance Australia (BTAA)
- Cancer Clinical Academic Group (Cancer CAG)
- Canteen
- Clinical Oncology Society of Australia (COSA)
- Cooperative Trials Group for Neuro-Oncology (COGNO)
- Medical Oncology Society of Australia (MOSA)
- Nepean Cancer Centre
- Neuro-oncology Nurses Network
- New South Wales Neuro-oncology Group
- Northern Territory Palliative Care
- Primary Care Collaborative Cancer Clinical Trials Group (PC4)
- Royal Australian College of General Practitioners (RACGP)
- The Kids' Cancer Project
- Youth Cancer Services Community of Practice (YCS)

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