Qualitative Study Protocol

The Experiences and Healthcare Needs of Families Living With Pediatric Brain Tumor: A Longitudinal Qualitative Study Protocol

Kate Young1, Evonne Miller2, Stuart Ekberg1,3, and Natalie Bradford1

Abstract
For most children and adolescents diagnosed with a brain tumor, whether malignant or not, there will be an irrevocably negative impact on their life and that of their family. In Australia, 5 year disease-free survival is approximately 76%, meaning young survivors will live for a long time with the negative consequences—including neurological and cognitive deficits, reduced school performance, psychological problems, and problems with peer social relationships—of the tumor and associated treatment. Little is known about the experiences and psychosocial healthcare needs of families living with brain tumor, particularly from the perspectives of children and adolescents. We will fill this knowledge gap with a multimethods approach for flexible data collection that addresses the diverse needs of children and families living with a life-threatening illness. Recruited through the largest state pediatric health service in Queensland, Australia, we will follow families from diagnosis to capture their experiences and healthcare needs as they navigate their child’s treatment and survivorship or death. Data collection methods include semi-structured interviews, virtual tours and Photovoice; all family members will be invited to participate. Reflective thematic analysis will be used to explore the lived experiences of families, and their community and health services needs and associated facilitators and barriers to receiving such care. Our analysis will consider multiple perspectives: the individual, dynamics within each family, and patterns observed across families. This research will inform the co-design of interventions with families to address the service gaps and healthcare needs identified by participants.

Keywords
methods in qualitative inquiry, photovoice, qualitative evaluation, arts based methods, critical theory

For most children and adolescents diagnosed with a brain tumor, whether malignant or not, there will be an irrevocably negative impact on their life and that of their family. Central nervous system (mainly brain) tumors account for the largest amount of cancer deaths for children in Australia (Cancer Council Queensland, 2019), the United States (American Cancer Society, 2018), and the United Kingdom (Cancer Research UK, 2019). In Australia, 5 year disease-free survival is approximately 76%, meaning young survivors will live for a long time with the negative consequences of the tumor and associated treatment (Cancer Council, 2019). New international evidence estimates that, compared to their healthy counterparts, survivors of childhood brain tumors are 2.6 times more likely to have negative cognitive and socioeconomic effects, even for those patients with the least severe tumors, receiving the least toxic treatment (Ris et al., 2019). Negative effects post-treatment include neurological and cognitive deficits, reduced educational and school performance, psychological problems, and problems with peer social relationships (Nicklin et al., 2019). These late effects of treatment threaten and undermine the ability of young survivors to transition independently to adulthood (Rey-Casserly & Diver, 2019), with current healthcare systems—designed to provide acute medical treatment and care—often neglecting the survivorship experience. Balancing...
the needs of an unwell child with the competing demands of family life is a tension for families that is poorly understood and not well supported by medical and community services (Long et al., 2011). Where a child does not survive, families carry the burden of a child’s death for the rest of their lives.

Many inter-disciplinary team members contribute to the care and management of children with brain tumor and their families. Fragmented and fractured care can occur, and the psychosocial, physical, vocational and spiritual needs of the child and family are not always met (Nicklin et al., 2019; Soanes et al., 2009). In our location in the state of Queensland, Australia, equitably addressing the needs of children and families is further complicated by the geography of a large state with dispersed population. Approximately 60% of children and adolescents with brain tumors live outside of metropolitan Brisbane (the capital of Queensland), where services can be limited (Anderson et al., 2020). To affect changes in the way services are delivered during treatment and in survivorship, health services and implementation research is required.

Little is known about the healthcare experiences and needs of families in Australia who have a child diagnosed with a brain tumor, particularly with regard to their psychosocial health and wellbeing. Further, few studies in this area have centered the voices and perspectives of children. This reflects a long history of medical and research professionals talking about children but rarely to them (Kirk, 2007; Söderbäck et al., 2011; Stafford, 2017). From a research perspective, this has been largely due to concerns around potentially exploiting children’s vulnerability and the reliability of data produced by children (Kirk, 2007). Children have a human right—supported by the 1989 United Nations Convention on the Rights of the Child (Office of the United Nations High Commissioner for Human Rights, 2020)—to be encouraged and enabled to make their views known on the issues that affect them, including within their healthcare (Söderbäck et al., 2011). Children are competent participants of research and, as with adults, their accounts are valid as representations of their evolving perspectives (Kirk, 2007).

Our research project will address the gap in research involving children in developing a comprehensive understanding of the diverse experiences and needs of children and adolescents with a brain tumor and their families in the state of Queensland, Australia. This information will be used to inform service models that will best support tailored and individualized interventions to improve families’ experiences and health outcomes. In recognition of the importance of consumer and community involvement (Consumers Health Forum of Australia, 2016), our research aims were developed through collaboration with families of children with brain cancer, who voiced concern that their needs were not well understood or documented. Specifically, we will investigate:

1. What are the lived experiences of children and adolescents and their families in living with brain tumor?
2. What are the community and health service needs of children and adolescents with brain tumor and their families?

a. What are the facilitators and barriers to accessing and receiving these elements of care?

Method

The development of this project was driven by families and clinicians at the Queensland Children’s Hospital requesting research that highlighted families’ experiences of brain tumor and to develop services that address the current gaps in care. The interview schedule and study design were reviewed through the consumer advocacy group, Brainchild (brainchild.org.au).

Overview

This is a longitudinal qualitative study. We will take a “multiple perspectives” approach to explore and understand both individual perspectives and experiences, and the family dynamics and experiences, of living with a pediatric brain tumor diagnosis (Harden et al., 2010; Van Parys et al., 2017). A multi-method (“mosaic”; Clark, 2017) approach will be used for flexible data collection that addresses the diverse needs of children and families living with a life threatening illness.

We have conceptualized this project through the framework of social constructionism, recognizing that knowledge is created through humans’ assumptions about the world, rather than there being a single and fixed reality that applies to all people (Lupton, 2012). Further, we acknowledge that people’s experiences of their bodies and the healthcare they receive occur within complex sociocultural structures and influences, and to inform healthcare that meets people’s diverse needs, we must acknowledge these factors (Lupton, 2012).

Our research is based on the fundamental philosophical position that children are full human beings with rights, rather than the possessions of adults (Office of the United Nations High Commissioner for Human Rights, 2020). We acknowledge children as experts in their own lives and as competent communicators and meaning-makers (Clark, 2017). Our approach is child-centered, while considering potential risks at a vulnerable time in their lives—in terms of both their dependence on adult support and also experiencing a life threatening illness—and potential diverse developmental and communicative needs (Gibbs et al., 2013).

Recruitment

Participants will be children and adolescents who are currently receiving care for a brain tumor (malignant or non-malignant) through the Queensland Children’s Hospital, and their families. We will recruit approximately 10 families with varying socio-demographic backgrounds and experiences of brain tumor; recruitment and data collection will occur for a period of 18 months between August 2020 and February 2022. Eligibility criteria are outlined in Table 1.

With support from the research team, clinical staff involved in the care of children newly diagnosed with brain cancer or
brain tumors will utilize knowledge of patients and families, and their circumstances and rapport with the service to determine their potential receptiveness to participation:

1. The neuro-oncology clinical nurse consultant (CNC) will notify the research team when a family who meets the inclusion criteria has entered the hospital care system.
2. If the research team assesses that they have the capacity to include the family in the research, the CNC will approach the family to tell them about the study and inquire if they would be interested to meet with the researcher to discuss further.
3. If interested, the CNC will notify the researcher who will then contact the family at their preferred time to discuss the study further and arrange an initial meeting by telephone or in person, as preferred by the family.

If, at any time or stage in the research, the CNC gauges that the family would experience distress from being contacted by the researcher, the CNC will notify the team to inform them of this and the researcher will temporarily withdraw contact until such time it is appropriate to continue.

Data Collection

Fluidity in data collection is needed to acknowledge children’s agency, and the fluctuating and challenging circumstances of families living with life threatening illness (Pyle, 2013). Children will be able to select from several different modes of data collection (interviews, tours, Photovoice) and families can opt to meet with the researcher in hospital or another location of their preference and by different modes, such as telephone or video call (Vogl, 2013). Table 2 outlines suggested timepoints and methods for data collection for each family member.

The following general procedural points will be adhered to for all episodes of data collection:

- The same researcher will conduct all interviews with participants and be the primary point of contact to facilitate building trust and comfort with participants, and to ensure communication and records are consistent.
- The interviewer-researcher will send a reminder text message to the participant or their carer the day prior to their interview to reconfirm. If the participant is no longer available, the interviewer-researcher will reschedule to a suitable time.
- Drawing will be offered to children, as appropriate, as a form of “icebreaking” activity and to enhance communication during the initial meeting and at data collection points (Hyslop et al., 2018; Kirk, 2007). Rather than being interpreted and having meanings projected onto it, the drawing is used as a framework for discussion and questions on the child’s experience, thoughts and beliefs.
- For in hospital appointments, the interviewer-researcher will accommodate any consultations or treatment as preferred by the family. If the interview is no longer feasible the interviewer-researcher will reschedule with the participant.
- The interviewer-researcher will ensure large blocks of time are allocated for each interview to allow for unrushed and respectful data collection in the context of often fluctuating circumstances, particularly when in the hospital setting.
- The researcher will make a detailed summary of each interview or meeting to be reviewed prior to subsequent...
measures to re-familiarize the interviewer-researcher, aiding appropriate exploration of previously identified sensitive topics (Harden et al., 2010).

Initial Meeting

An initial meeting will be conducted with the child and their primary care provider; additional family members will also be welcome. The aim of this meeting is for participants to become familiar with the interviewer-researcher and vice versa. This will include discussion of who the family members are, how each are/may be involved in the child’s care, and which, if any, data collection methods they may each want to be involved in. Initial written informed consent (and child assent) for the research project will be obtained at this meeting for the primary care giver and child. Verbal or written consent will be obtained from other members not in attendance prior to their initial data collection episode.

Semi-Structured Interviews

Prior to each interview, a schedule specific to the participant will be created from the question pool outlined in Online Supplementary File 1; additional iterative questions will be added based on matters raised in previous interviews. The interview schedule is informed by the research team’s systematic review of previous research that examined psychosocial care for brain tumor from perspectives of children and their families (Young et al., 2020). The schedule was also reviewed by the consumer advocacy group, Brainchild, and a parent representative. The participants’ interests and perspectives will, however, be prioritized with the interview schedule used as a guide. We anticipate that interviews will take about 30–60 minutes.

When interviewing children and adolescents, the interviewer-researcher will be flexible and open to a co-construction of the child’s perspective with the parent while keeping the child’s voice central (Hillier & Aurini, 2018). The interviewer-researcher will conclude each interview with the primary carer by mapping the health and community services accessed by the family from just prior to diagnosis to the current time point. To aid memory recall, this will be a continual exercise throughout the data collection period.

Creative research methods for children. We will offer children a range of methods to facilitate communication and participation (Clark, 2017). We do not offer such methods under the assumption that children are not capable of ordinary conversation like adults, but rather to meet their diverse needs and interests during a likely physically and emotionally challenging time in their lives. We remain conscious that while “special” research techniques for children, such as drawing and dramatic play, have been frequently used, there has been little critical examination of their use, particularly from the perspective of children and families (Kirk, 2007). All children and adolescents will be informed of their options and the final decision to use any data collection method will rest with them and their parent/caregiver.

Tours. Tours will be offered to children as a communication tool to discuss their experiences and care needs in their home and communities. The physical nature of showing another around a space fosters the sharing of children’s knowledge of their own environment and places them in the role of expert (Clark, 2017). Tours will likely take place toward the end of treatment or just after completion to capture retrospective knowledge of treatment needs and of those at the end of treatment when children may be returning to school. This will also further establish the relationship between the child and the interviewer-researcher (Clark, 2017; Stafford, 2017).

Children will be asked to take the researcher on a virtual tour of where they move within their home and local community within a typical week for them. They will be asked to focus on locations where they spend the most amount of time and/or that have the most amount of meaning (i.e., feel special) to them. Children will be asked to capture things about those places that make themselves and their bodies feel good (e.g., going to school again and seeing friends) and the things that don’t make them feel good (e.g., not feeling able to keep up with school work).

The choice of medium for the tour will be made by the child and their parent/caregiver, with consideration of their available resources. This may be a recorded video call with the researcher, a video recorded and sent to the researcher, and/or photographs, drawings or a map made by the child with the help of the parent/caregiver, as required. The tour is led completely by the child (Clark, 2017); the caregiver in attendance will be issued information about the ways in which they can facilitate their child’s expertise and independence (e.g., by directing the camera, mapping or drawing based on the child’s instructions and physical needs).

Once the child has begun to return to some of their usual activities post-treatment (e.g., schooling), a follow-up interview will be conducted where the child and researcher review the material together to discuss the meaning of it for the child. This review of material can foster metacognition (i.e., thinking about what they think), giving children the opportunity to observe changes in their perspectives and experiences over time (Clark, 2017). Importantly, in reviewing the content we do not aim to assess recall but to use it as a communication tool for children’s experiences of brain tumor outside of a hospital setting (Theobald, 2012).

Photovoice. Photovoice is participatory research method where photographs are used as a means of communication about phenomena from the perspective of those who experience it (Wang & Burris, 1997). Photovoice assists in capturing marginalized voices that are rarely heard and projects them into spaces of decision-making; it is particularly useful for research with children and people with socially stigmatized health conditions or status (Latz, 2017, p. 63; Wang & Burris, 1997, p. 182). While
the photographs provide visual data, the role of narration is essential to provide context and meaning (Miller, 2019).

Consistent with our overarching theoretical framework, our epistemological standpoint on the use of photos is that we view the photographs produced by participants as evidence of the social world from their perspective at the moment in time it was taken (Latz, 2017). The meaning and interpretation of the photograph will likely change at later timepoints, reflecting participants’ evolving life and illness narratives. We will follow Latz’s (2017) eight steps of Photovoice. These steps may be taken out of order or repeated to meet families’ needs; Photovoice is a flexible method, malleable to the complexities of our social world (Latz, 2017; Wang & Burris, 1997).

The purpose of this aspect of the project is to document and share the lived experience of brain tumor diagnosis including the impact on self and family, and associated health service and care needs. Adolescents diagnosed with a brain tumor are the primary candidates for this component of the study; however, all family members are welcome to participate. The initial meeting will include discussion of what their participation will entail and how the photographs will be used. Participants will be given general advice about how to frame a photo; however, technical advice will be kept to a minimum so as not to stifle participants’ creativity. The researcher will engage participants in discussions about ethics and power, to identify appropriate ways to approach someone if wanting to take a photo of them and whether they should take a photo of someone without their knowledge. This information will also be provided in a written format, and the interviewer-researcher can be contacted for clarification or support.

Participants will then be asked to respond to ten themes, outlined in Table 3, through photography. The interviewer-researcher will prompt each participant to complete one theme per month. However, the participant will be informed of the themes from the beginning of the project and can choose to complete them at any time. Participants will be asked to contribute one to five photographs per theme. Participants can choose to respond to these themes with any medium of their choosing (e.g., Playdoh, Lego, dressing up) and take a photo of their product. Participants can choose to upload their photos onto Padlet (padlet.com), a secure and private online bulletin board, or they can email them to the interviewer-researcher who will upload the photos for them. Overall, we are aiming to receive 10 photos from each family that are meaningful to the participant/s regarding their experience of brain tumor.

There will be two photo-elicitation interviews: one at about 5 months/themes and another at the completion of all 10 months/themes. Though focus groups are commonly used in Photovoice, the use of interviews can be warranted (Latz, 2017, p. 83); we selected the latter as we think it inappropriate to request families to convene for a group event when they are dispersed across a geographically large state and are going through an immensely challenging time. Participants will be asked to narrate the contents of their photographs to give meaning and context. The interviewer-researcher, in concert with the participants, will generate thematic strands within the narrations following Braun and Clarke’s reflexive thematic analysis (Braun & Clarke, 2006, 2019). (See “data analysis” section below for further detail.)

The photographs and findings of the entire project (i.e., including and beyond the Photovoice component) will be presented in a public exhibition, co-curated with all participants. This enables participants and their contributions to connect with those in the community who have the capacity to change policy and practice (e.g., clinicians, local government members); reaching decision-makers and enacting change is the ultimate aim of Photovoice. We anticipate that these photographs, as well as forming part of the research outcomes, may well also live on the walls of the hospital—creatively sharing with others the experiences of these participants, and serving as a visual prompt about the key factors that facilitate or hinder wellbeing during and after treatment.

### Table 3. Photovoice Themes and Elements.

| Theme       | Description                                                                 |
|-------------|-----------------------------------------------------------------------------|
| 1. About you | Photos about the participant and their life. For example, where they live or activities they like doing. |
| 2. Diagnosis | Photos that capture something about the participant’s experience of when they were first told that they had a brain tumor and the events that led to this moment. |
| 3. In hospital | Photos that capture things the participant (1) find helpful or good and (2) things that they find unhelpful or bad when they are in hospital receiving treatment. |
| 4. At home   | Photos that capture things that the participant (1) find helpful or good and (2) things that they find unhelpful or bad when the participant is at home. |
| 5. Family    | Photos that capture how the participant’s brain tumor is experienced by them and their family. |
| 6. Wild card! | Photos about anything the participant wishes to share with the interviewer-researcher about their experience of brain tumor. |
| 7. Friends   | Photos about how the participant’s friends (however the participant defines this) have played a role in their experience of brain tumor. |
| 8. Your body | Photos that capture aspects of how the participant’s brain tumor has affected the way they experience or feel about their body. |
| 9. School    | Photos about the participant’s experience of being away from and/or returning to school due to having a brain tumor. |
| 10. Your future | Photos that capture aspects of what the participant see for themselves in next year and beyond. |

Note. These themes can be adapted to the perspective of multiple family members, should they choose to participate in Photovoice.
Table 4. Proposed Levels of Analysis.

| Individuals          | Groupings                      |
|----------------------|--------------------------------|
| Within families      |                                |
| Diagnosed child      | Parents/carers × children      |
| Sibling/s            | Diagnosed child × sibling/s    |
| Mother/s             | Parent × parent                |
| Father/s             | Family as unit                 |
| Across families      |                                |
| Diagnosed child      |                                |
| Sibling/s            |                                |
| Mother/s             |                                |
| Father/s             |                                |

**Data Analysis**

Our analysis will consider multiple perspectives: the individual, dynamics within each family, and patterns observed across families (presented in Table 4). Within our analyses, we will consider that such perspectives or roles are not always separate and can be simultaneously reflected within family experiences (Harden et al., 2010). We will also address the possible influences on, and co-construction of, perspectives in having multiple people (e.g., child and parent, both parents) present at an interview or making creative outputs together (Hillier & Aurini, 2018; Van Parys et al., 2017).

To guide our analysis, we will use the principles and six steps of Braun and Clarke’s (2006, 2019) reflexive thematic analysis. We will take an inductive (data-driven) approach privileging participants’ perspectives rather than applying a pre-conceived analysis framework. Our analysis will conclude at the latent level, exploring underlying ideologies and systems that shape families’ experiences and the meaning they (individuals, families) make of these. We will frame the health and community services implications of our analysis within the Bronfenbrenner’s Ecological System Theory model (Bronfenbrenner, 1994).

“Data” for this project constitutes both interview transcripts and any visual stimuli presented by children and adolescents within the tour and Photovoice components, and any artwork created during interviews they wish to share with the research team. Individual interviews and visual stimuli will first be analyzed; follow up analyses will then be conducted to search for “overlaps” and “contrasts” between individual accounts—at both descriptive and interpretative levels—by the groupings in Table 4 (Van Parys et al., 2017).

The analysis will be led by the interviewer-researcher who is likely in the best place to make sense of the links between and across different perspectives (Van Parys et al., 2017). To enhance credibility, the research team will be asked to challenge the way in which the interviewer-researcher has constructed themes at various points in the analysis. Where appropriate, the analysis process will be discussed reflexively with participants—a process called “member reflections”—to allow participants to give feedback on the researchers’ analyses (Tracy & Hinrichs, 2017).

**Ethical Considerations**

This study has been approved by the Children’s Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC/19/QCHQ/53816).

Participants aged 18 years and older, who meet the legal and ethical tests of competence, will be given their own consent form (Spriggs, 2010). Parental consent will be required for all children and adolescents younger than 18 years. If, at the time of data collection, the child does not wish to assent, this will be respected, and data collection will be attempted at an appropriate time. Dissent will be recognized through both verbal (e.g., saying “no” or “I’m tired”) and behavioral (e.g., silence, constant looks toward door, crying) signs (Spriggs, 2010). Continuing consent will be obtained and documented prior to each data collection point to ensure that the participant wishes to continue with the study. All data will be de-identified prior to analysis; however, participants may choose to be referred to by their own first name or a self-selected pseudonym (Kaiser, 2009).

All contact regarding children’s participation will be made through the primary caregiver, unless otherwise requested. Adolescents may wish to be contacted directly in which case this will be facilitated with parental permission. If the child or adolescent would like to speak with the interviewer-researcher by themselves, and the parent/guardian consents to this, what the adolescent or child says to the researcher will remain confidential. If, however, the child discloses circumstances that put their lives in immediate danger (e.g., suicidal ideation or reports of family violence) the parent/carer, if appropriate, or assigned social worker will be notified immediately after the interview. The child will be informed of this possibility prior to agreeing to speak alone with the researcher.

Any stimuli that includes a person who is not participating in the project (e.g., a nurse or doctor in the background) will be de-identified, or not used in publications or exhibitions. Consent to publish or present any participant’s stimuli will be re-confirmed prior to doing so. Creative outputs uploaded to Padlet will be captured by a screenshot and photographs also individually downloaded after the participant’s final interview, if completing Photovoice. Participants will also be asked to choose how they would like to be identified as the photographer: their own first name or a self-selected pseudonym (Kaiser, 2009). Once the data has been securely stored, the interviewer-researcher will inquire with the participant if they would like to have their board permanently deleted or if they would like to remove permission for the interviewer-researcher to access the content.

**Rigor**

We assessed the rigor of our study through the “gold standard” (Liampuntong, 2013, p. 25) of Lincoln and Guba’s four criteria: credibility, transferability, dependability, and confirmability (Lincoln, 1985). Credibility is supported by purposive recruitment of families with diverse socioeconomic backgrounds and
with diverse experiences of pediatric brain tumor. Further, where appropriate, the analysis process will be discussed reflexively with participants (“member reflections”; Tracy, 2010) to construct a scholarly report that reflects their perspectives while also reflecting our (the researchers’) critical social theory approach; any differences between the perspectives of participants and researchers will be made transparent in associated reporting (Varpio et al., 2017). All research processes, including data analysis, will be (and have been) meticulously documented supporting “dependability.” Confirmability is supported by (1) the multidisciplinary research team (featuring academics with nursing, social science, public health, and design backgrounds) and (2) that we will ground all analyses in the data and present quotations within the context which they were made when reporting the findings. The diverse families and perspectives brought to the research will aid the findings “transferability” to most families in Queensland receiving care for pediatric brain tumor, and likely other Australian states with similar geographic disparity and services, and potentially other countries with similar healthcare systems (Morse, 1999).

Conclusion
This is the first longitudinal research project to capture families’ experiences of brain tumor in the state of Queensland, Australia. We have drawn upon diverse and creative research methods to meet the needs of children and adolescents and their families at a challenging time in their lives. This research will cumulate in the co-design of interventions with families to address the service gaps and healthcare needs identified by participants.

Acknowledgments
We would like to thank Christine Cashion and Brooke Spencer for their clinical expertise in assisting to develop the protocol for this research project. We also wish to thank the members of The Brainchild Foundation, Belinda Brunoli and Karen Prain, who reviewed the interview schedule and shared their experiences to inform the development of this study.

Declaration of Conflicting Interests
The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding
The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This project is funded by The Children’s Hospital Foundation as part of the state-wide, multi-institutional Centre for Child and Adolescent Brain Cancer (2019).

ORCID iD
Kate Young https://orcid.org/0000-0002-3539-3727

Supplemental Material
The supplemental material for this article is available online.

References
American Cancer Society. (2018). Cancer Statistics Centre: Childhood and adolescent cancer. https://cancerstatisticscenter.cancer.org/#/childhood-cancer
Anderson, K., Bradford, N., Edwards, R., Nicholson, J., Lockwood, L., & Clark, J. (2020, April 1). Addressing the barriers to optimal management of febrile neutropenia in children with cancer. European Journal of Oncology Nursing, 45, 101719. https://doi.org/https://doi.org/10.1016/j.ejon.2019.101719
Braun, V., & Clarke, V. (2006, January 1). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/https://doi.org/10.1191/1478088706qp063oa
Braun, V., & Clarke, V. (2019, August 8). Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health, 11(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806
Bronfenbrenner, U. (1994). Ecological models of human development. In M. Gauvin & M. Cole (eds) Readings on the development of children. (2nd ed., pp. 37–43). Freeman.
Cancer Council. (2019). Cancer council and childhood cancers. Cancer Council Australia. https://www.cancer.org.au/about-cancer/types-of-cancer/childhood-cancers/cancer-council-and-childhood-cancers.html
Cancer Council Queensland. (2019). A summary of childhood cancer statistics in Australia, 1983-2016. https://cancerqld.blob.core.windows.net/site/content/uploads/2020/01/20017_Childhood_Cancer_Report.pdf
Cancer Research UK. (2019). Children’s cancers mortality statistics. https://www.cancerresearchuk.org/health-professional/diagnosis/hp-covid-19-and-cancer-hub
Clark, A. (2017). Listening to young children: A guide to understanding and using the mosaic approach (Expanded 3rd ed.). Jessica Kingsley Publishers.
Consumers Health Forum of Australia. (2016). Statement on consumer and community involvement in health and medical research. www.nhmrc.gov.au/guidelines/publications/s01
Gibbs, L., MacDougall, C., & Harden, J. (2013, June 1). Development of an ethical methodology for post-bushfire research with children. Health Sociology Review, 22(2), 114–123. https://doi.org/10.5172/hesr.2013.22.2.114
Harden, J., Backett-Milburn, K., Hill, M., & MacLean, A. (2010, December 1). Oh, what a tangled web we weave: experiences of doing ‘multiple perspectives’ research in families. International Journal of Social Research Methodology, 13(5), 441–452. https://doi.org/10.1080/13645571003650979
Hillier, C., & Aurini, J. (2018). What role does the ‘parent-effect’ play in child centered research? The case of photo-interviews of children’s home reading practices. Qualitative Research, 18(4), 492–509. https://doi.org/10.1177/1468794117728410
Hyslop, S., Sung, L., Stein, E., Dupuis, L. L., Spiegler, B., Vettese, E., & Tomlinson, D. (2018, October 1). Identifying symptoms using the drawings of 4–7 year olds with cancer. European Journal of Oncology Nursing, 36, 56–61. https://doi.org/https://doi.org/10.1016/j.ejon.2018.08.004
Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative Health Research, 19*(11), 1632–1641. https://doi.org/10.1177/1049732309350879

Kirk, S. (2007, September 1). Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies*, 44(7), 1250–1260. https://doi.org/10.1016/j.ijnurstu.2006.08.015

Latz, A. O. (2017). Photovoice research in education and beyond: A practical guide from theory to exhibition. Routledge.

Liamputtong, P. (2013). *Qualitative research methods* (4th ed.). Oxford University Press.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications.

Long, K. A., Marsland, A. L. J. C. C., & Review, F. P. (2011). *Family adjustment to childhood cancer: A systematic review*. London: Routledge.

Lupton, D. (2012). *Medicine as culture: Illness, disease and the body*. Routledge.

Morse, J. M. (1999). Qualitative generalizability. *Qualitative Health Research, 9*(1), 5–6. https://doi.org/10.1177/10497329912912162

Nicklin, E., Velikova, G., Hulme, C., Rodriguez Lopez, R., Glaser, A., Kwok-Williams, M., & Boele, F. (2019). Long-term issues and supportive care needs of adolescent and young adult childhood brain tumour survivors and their caregivers: A systematic review. *Psychooncology, 28*(3), 477–487. https://doi.org/10.1002/pon.4989

Office of the United Nations High Commissioner for Human Rights. (2020). *Convention on the Rights of the Child United Nations*. https://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf

Pyle, A. (2013, 2013/11/01). Engaging young children in research through photo elicitation. *Early Child Development and Care, 183*(11), 1544–1558. https://doi.org/10.1080/03004430.2012.739444

Rey-Casserly, C., & Diver, T. (2019). Late effects of pediatric brain tumors. *Current Opinion in Pediatrics, 31*(6), 789–796. https://doi.org/10.1097/MOP.0000000000002837

Ris, M. D., Leisenring, W. M., Goodman, P., Di, C., Noll, J., Levy, W., Robison, L. L., & Armstrong, G. T. (2019). Neuropsychological and socioeconomic outcomes in adult survivors of pediatric low-grade glioma. *Cancer Medicine, 12*(5), 3050–3058.

Soanes, L., Hargrave, D., Smith, L., & Gibson, F. (2009, September 1). What are the experiences of the child with a brain tumour and their parents? *European Journal of Oncology Nursing, 13*(4), 255–261. https://doi.org/https://doi.org/10.1016/j.ejon.2009.03.009

Söderbäck, M., Coyne, I., & Harder, M. (2011). The importance of including both a child perspective and the child’s perspective within health care settings to provide truly child-centred care. *15*(2), 99–106. https://doi.org/10.1177/1367493510397624

Spriggs, M. (2010). Understanding consent in research involving children: The ethical issues. https://www.mcri.edu.au/research/projects/consent-research/educational-resources

Stafford, L. (2017). ‘What about my voice’: Emancipating the voices of children with disabilities through participant-centred methods. *Children’s Geographies, 15*(5), 600–613. https://doi.org/10.1080/14773285.2017.1295134

Theobald, M. (2012). Video-stimulated accounts: Young children accounting for interactional matters in front of peers. *Journal of Early Childhood Research, 10*(1), 32–50. https://doi.org/10.1177/1476718X11402445

Tracy, S. J. (2010). Qualitative quality: Eight “big-tent” criteria for excellent qualitative research. *Qualitative Inquiry, 16*(10), 837–851. https://doi.org/10.1177/1077800410383121

Tracy, S. J., & Hinrichs, M. (2017). Big tent criteria for qualitative quality. In *The international encyclopedia of communication research methods* (pp. 1–10). https://doi.org/10.1002/9781118901731.iecrm0016

Van Parys, H., Provoost, V., De Sutter, P., Pennings, G., & Buysse, A. (2017). Multi family member interview studies: A focus on data analysis. *Journal of Family Therapy, 39*(3), 386–401. https://doi.org/10.1177/0163480317698757

Varpio, L., Ajjawi, R., Monrouxe, L. V., O’Brien, B. C., & Rees, C. E. (2017). Shedding the cobra effect: Problematising thematic emergence, triangulation, saturation and member checking. *Medical Education, 51*(1), 40–50. https://doi.org/10.1111/medu.13124

Vogl, S. (2013). Telephone versus face-to-face interviews: Mode effect on semistructured interviews with children. *Sociological Methodology, 43*(1), 133–177. https://doi.org/10.1177/0038023715591264

Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369–387. https://doi.org/10.1177/109019819702400309

Young, K., Bowers, A., & Bradford, N. (2020). Psychosocial experiences and health service needs in child and adolescent brain tumour: A systematic review and synthesis of qualitative research. Manuscript in progress.