Narrative review

Current gaps in knowledge and future research directions for Aboriginal and Torres Strait Islander children with cancer

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Summary

- Paediatric cancer is the leading cause of disease-related death in Australian children. Limited research focuses on cancer in Aboriginal and Torres Strait Islander children.
- Although there appears to be a lower incidence of cancer overall in Aboriginal and Torres Strait Islander children compared with non-Indigenous children, a high proportion of Aboriginal and Torres Strait Islander children are diagnosed with acute myeloid leukaemia.
- Five-year overall survival is lower for many cancer types in Aboriginal and Torres Strait Islander children.
- There is a need for Indigenous-specific research focused on molecular and genetic profiles, pharmacogenomics and survivorship, both within Australia and globally.
- Future research in this space should be co-designed and led by Aboriginal and Torres Strait Islander communities; alongside clinicians, researchers and services to ensure that the priorities of Aboriginal and Torres Strait Islander people are met.

Childhood cancer is a leading cause of death in Australian children.[1] The incidence rate of cancer is about 174 cases per million children each year, with registry data reporting around 770 new cases diagnosed in children aged 0 to 14 years each year in Australia.[2] There have been many advances in childhood cancer diagnostics and treatment over the last 30 years, leading to improved survival rates for Australian children aged 0–14 years, with 5-year overall survival now over 86%.[3] However, many survivors are left with significant and permanent disabilities from the toxic effects of therapy, which significantly reduce their quality of life.[4] Consequently, research priorities have shifted towards reducing long term complications in high-survival cancers, and introducing novel treatments such as targeted therapies and immunotherapies in cancers refractory to current treatments. However, research specific to cancer in Aboriginal and Torres Strait Islander children is limited and remains a significant knowledge gap.

In this narrative review, our team of Aboriginal scientists, researchers and medical students, alongside non-Indigenous paediatric oncologists and researchers, review what is currently known about cancer in Aboriginal and Torres Strait Islander children. We outline future areas of research necessary for improving outcomes, with a prioritisation of Aboriginal perspectives and worldviews. Additional context is also provided from relevant articles examining cancer in Aboriginal and Torres Strait Islander adults, and Indigenous children globally. Using databases including PubMed and Google Scholar, we conducted a literature search and collated publications up to November 2024. Search terms used included “Aboriginal”, “Indigenous” or “First Nations”, and “childhood cancer” or “paediatric cancer”. Studies reporting on children aged 0–18 years were included. There were no exclusions on article type, and specialist publications were also included. A statement addressing the CONSolIdated critERia for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement[5] has been included (Supporting Information).

Cancer in Aboriginal and Torres Strait Islander people

Most cancer research in Aboriginal and Torres Strait Islander people has studied cancers prevalent in adults, including cancers of the lung, liver, head and neck, and cervix.[6] Compared with non-Indigenous adults, cancer mortality is higher in Aboriginal and Torres Strait Islander adults, with a range of underlying contributing factors including advanced stage at diagnosis, barriers to treatment access, and higher rates of comorbidities.[7-9] Reduced access to clinical trials for Aboriginal and Torres Strait Islander people has also been documented, which may in turn affect mortality rates.[10] Barriers affecting access to clinical trials include systemic racism in the health service, and biases of health practitioners relating to perceived adherence to trial protocols.[10] Further barriers to equitable clinical trial access include exclusion on the basis of comorbidities commonly affecting Aboriginal and Torres Strait Islander people, alongside barriers faced by those living in regional and remote areas.[10] In a paediatric cancer setting, where enrolment in a clinical trial is considered standard of care, barriers to clinical trial access could have a disproportionate effect on outcomes.[11]

Cancer in Aboriginal and Torres Strait Islander children

There is a paucity of research that focuses on cancer in Aboriginal and Torres Strait Islander children. Much of the research reports on childhood cancer incidence across populations. The first report of differing incidence of cancer in Aboriginal children was published in 2000, based on data from 1968 to 1998.[12] A high proportion (18%) of children with de novo acute myeloid leukaemia (AML) from the Women’s and Children’s Hospital in South Australia were identified to be Aboriginal. Consistent with this finding, a more recent report from SA and the Northern Territory, which examined diagnoses made between 1997 and 2018, also found an increased proportion of Aboriginal children with AML compared with non-Indigenous children.[13,14] Although this over-representation was not seen in Western Australian children,[13] it was observed in the population-based Australian Childhood Cancer Registry, which analysed data

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across Australia in children aged 0–14 years.[15] However, it is unknown why there appears to be an increased incidence of AML in Aboriginal children, and this should be prioritised as an area for future research. Notably, there appeared to be a trend towards younger age at diagnosis[14] and lower 5-year overall survival for Aboriginal children with AML;[13] however, statistical analysis was limited due to small patient numbers. There are no studies that have reported on whether there are molecular or genetic differences associated with outcome disparities in Aboriginal and Torres Strait Islander children with cancer. This is largely due to the relatively small number of patients with each molecular subtype presenting at each treatment centre, making identification of patterns and robust statistical analysis difficult. Despite such limitations, this highlights the need to understand the role of ethnicity on disease-specific cancer genomics and treatment outcomes.

For cancers other than leukaemia, published incidence data are primarily from the Australian Childhood Cancer Registry. Childhood cancer incidence, mortality and survival in Aboriginal and Torres Strait Islander children across Australia were reported in two articles by Valery and colleagues in 2013.[16,17] For cases diagnosed between 1997 and 2007, cancer incidence for Aboriginal and Torres Strait Islander children was 99 cases per million children, which was significantly lower than in non-Indigenous children.[17] When categorised by cancer type, this reduced incidence was apparent in central nervous system (CNS) tumours, neuroblastoma, renal tumours, malignant bone tumours, and "other" tumour types. A similarly reduced incidence of cancer is also seen in the Aboriginal and Torres Strait Islander adolescent and young adult (AYA) population.[18] Another recent study examined childhood cancer incidence in patients from the NT, which has a high proportion of Aboriginal and Torres Strait Islander children.[19] This study found that cancer incidence in Aboriginal and Torres Strait Islander children has not changed significantly over time and was slightly lower than for non-Indigenous children.[19] However, difficulties in identifying patients as Indigenous within health data, and cancer data specifically, remains a significant limitation[20] and has resulted in a historical underestimation of age-standardised incidence rates.[21,22] Within Australia, the accuracy of Indigenous identification in statistics varies widely between health jurisdictions.[22] Although most health care providers use the Standard Indigenous Question for determining Indigenous status, recording of data is not always complete, nor accurate.[22] For this reason, many registries use algorithms to help increase the accuracy of their data, including those studies by the Australian Childhood Cancer Registry, which uses a multistage median approach.[23]

Survival of childhood cancer in Aboriginal and Torres Strait Islander populations has also been reported. Australian Childhood Cancer Registry data show that 5-year overall survival for Aboriginal and Torres Strait Islander children between 1997 and 2007 was significantly lower than for non-Indigenous counterparts.[16] This disparity remained even after adjustment for remoteness of residence, socio-economic status, cancer type and year of diagnosis.[16] When more contemporary data up to 2016 were included, cancer incidence remained significantly lower among Aboriginal and Torres Strait Islander children; however, incidence rates increased to 124 cases per million children, representing a more rapid increase than in non-Indigenous children,[15] which may reflect increased accuracy of identification of patients as Indigenous. This study also showed that the gap in survival outcomes narrowed between Aboriginal and Torres Strait Islander and non-Indigenous children, and that the reduced survival seen in Aboriginal and Torres Strait Islander children with solid tumours diagnosed between 1997 and 2007[16] was not found to be significant between 2007 and 2016.[15] Data from NT patients have also shown that 5-year overall survival was notably lower at 38% for Indigenous children, than at 79% for non-Indigenous children.[19] Although survival rates in this cohort have improved over time, there remains a significant gap in outcomes for Aboriginal and Torres Strait Islander children in the NT, and further research examining the effects of remote residence and socio-economic status on survival is warranted. Five-year survival is also reported to be lower among the Aboriginal and Torres Strait Islander AYA population, compared with their non-Indigenous counterparts.[18] Together, these data suggest that many factors contribute to the disparities in outcomes for Aboriginal and Torres Strait Islander children, and that further investigation into treatments received, treatment-associated morbidity, and molecular subtypes should be considered.

Few studies have focused on treatment-related short and long term side effects, and quality of life for Aboriginal and Torres Strait Islander children. For example, although paediatric oncologists in Australia often anecdotally report that Indigenous children suffer more treatment-related severe short and long term side effects, this has not been widely studied in the literature. Rotte and colleagues found some evidence of longer durations of hospital admission in Aboriginal patients, with increased rates of complications during treatment, although these differences were not statistically significant, potentially due to small patient numbers.[14] Another recent study found that Aboriginal and Torres Strait Islander childhood cancer survivors had higher rates of hospitalisation than non-Indigenous survivors.[24] Children who survive cancer require a lifetime of surveillance and follow-up, with many suffering from late effects induced by their cancer treatment.[25] However, there is a paucity of research regarding long term complications in Aboriginal and Torres Strait Islander children. Indeed, a significant proportion of Aboriginal and Torres Strait Islander children reside in remote geographical locations where survivorship services are often not available, accessible or culturally appropriate,[26] placing further burden on children and their families long after remission is achieved.

There is currently a limited understanding nationally of barriers to accessing equitable and culturally safe care for Aboriginal and Torres Strait Islander families facing a childhood cancer diagnosis. Two recent studies undertaken at the Women's and Children's Hospital in SA examined perspectives of culturally safe care in paediatric oncology. Interviews conducted with Aboriginal families and health care workers identified individual, systemic and cultural barriers to care. These included delayed diagnosis, accessibility of hospitals and specialist clinics, affordability and communication difficulties.[27] Recommendations for improvements to services were also discussed, and a particular area identified related to communication, with interpreter availability, visual education materials and telehealth access suggested.[27] A second study on cultural safety in palliative care identified a lack of cultural awareness and training for health care workers treating Aboriginal children with cancer.[28] More than 60% of respondents were not satisfied with the care they provided to Aboriginal children and their families, with barriers including poor understanding of cultural and spiritual beliefs surrounding death and grieving, and difficulty in supporting families to return to Country with an appropriate level of medical care.[28] These studies, while limited by representing a single centre, highlight the need for further research and resources directed towards improving the experience of Aboriginal and

Torres Strait Islander children and their families in paediatric oncology.

In summary, Australia has robust population-based data on incidence, mortality and survival from the Australian Childhood Cancer Registry. However, issues remain with the accuracy of identification of Aboriginal and Torres Strait Islander children within the data, despite using data combined from multiple sources.[15,22] Improvements in the direct reporting from each of the nine paediatric cancer centres in Australia will assist in increasing the accuracy of the data. For studies such as the analysis of early treatment-related toxicity, late effects, molecular classification and genomics, clinicians and researchers will need to engage and collaborate on a national scale to create datasets with sufficient patient numbers for meaningful analysis.

Cancer in Indigenous children worldwide

Outside of Australia, childhood cancer in other Indigenous populations is similarly under-researched. Although incidence rates by ethnicity are relatively well documented,[29] challenges remain in the accurate reporting of Indigenous status in medical records, along with accurate estimates of Indigenous population denominators around the world. Conversely, reporting of mortality and survival vary dramatically between countries, with most data available from population-based registries in high income countries.[30]

Cancer in Indigenous children around the world has been comprehensively examined by Valery and colleagues in 2014.[31] The key findings from this systematic review were that childhood cancer in Indigenous children is relatively rare, with incidence varying greatly between different Indigenous populations. Overall, cancer incidence was generally lower in Indigenous than non-Indigenous children from the same region. Data concerning survival and mortality were not well reported for Indigenous children, with limited studies available.[31] In general, although similar mortality rates were reported for Indigenous and non-Indigenous children, 5-year overall survival was often lower in Indigenous children, particularly for leukaemia, solid tumours and neuroblastoma. In many instances, small case numbers resulted in survival differences that were not statistically significant. This highlights one of the major challenges facing research in this area: studying a small proportion of patients in an already rare disease. In the ten years since this 2014 review, subsequent studies reporting on cancer incidence and survival in Indigenous children have largely confirmed these disparities.[32-40]

Survivorship research in racial and ethnic minorities has been identified as a pressing research priority globally.[41] Even in large studies, Indigenous patients are sometimes excluded from subgroup analyses as small patient numbers make statistical data analysis difficult.[42] Similar to the Australian context, few studies have focused on treatment-induced morbidity and long term quality of life, and those that have paint conflicting pictures. Looking at treatment-induced side effects, a study of First Nations children in Manitoba, Canada, found no difference in number or length of admissions for treatment-related complications.[32] However, a study of children in Washington found a higher risk of hospitalisation in Native American children, with particularly disproportionate admissions for infection, haematology, mental health and digestive-related conditions.[43]

In summary, the context of paediatric oncology research in relation to Indigenous children worldwide is very similar to Australia. Most countries have limited research, which has primarily focused on incidence and survival. Worldwide there is a paucity of data on molecular phenotypes, pharmacogenomics and survivorship in Indigenous children with cancer. This knowledge gap should therefore be a priority for future investigation.

Recommendations for future research

Achieving equity in cancer outcomes for Aboriginal and Torres Strait Islander people is a key strategic objective of the Australian Cancer Plan,[44] including both survival and quality of life outcomes. To date, most research on paediatric cancer in Indigenous children has described incidence, survival and mortality, largely from population-based registries. However, the field of paediatric oncology research is rapidly evolving with improvements in our understanding of the genetic underpinnings of disease. With improvements in childhood cancer survival rates in Australia, there is expanding focus not just on survival, but quality of survivorship. As such, research for Aboriginal and Torres Strait Islander children affected by cancer needs to move far beyond the basic measures, and it is time to ensure parity in the progress of research in Aboriginal and Torres Strait Islander children.

Characterisation of the biological basis of paediatric cancers has improved diagnosis, prognosis and treatment. This research primarily uses patient-derived samples to establish xenograft and cell line models. However, there are important considerations for biobanks and preclinical research using samples from Aboriginal and Torres Strait Islander people that are yet to be addressed in Australia. The ability to identify patient samples as being from Aboriginal and Torres Strait Islander peoples is critical as some language groups consider blood and other tissue samples as important parts of a person's spirit, and provisions for return to Country of these samples are important to many.[45] In this context, New Zealand has comprehensive guidelines for culturally informed biobanking with Māori samples,[46,47] along with guidelines for genomic research.[48] It is recommended that similar guidelines are also established nationally in Australia.

There are many important considerations for cancer genomics research in Aboriginal and Torres Strait Islander children. In the paediatric oncology context, this is exemplified by the ZERO Childhood Cancer clinical trial (NCT05504772), which aims to provide genomic testing for all children in Australia diagnosed with cancer, including Aboriginal and Torres Strait Islander patients. The genomic data generated have the potential to aid our understanding of cancer biology, pharmacogenomics, and Indigenous genomics more generally. Within Australia, clinicians and researchers will need to engage and collaborate on a national scale to create datasets with sufficient patient numbers for meaningful analysis. Worldwide, it has been recognised that Indigenous leadership in the genomics space is a necessity for equitable and beneficial precision medicine research in Indigenous peoples,[49-51] including for cancer research.[52,53]

Globally, significant effort focuses on improving outcomes for paediatric cancer in Indigenous children. In the USA, the Pacific Pediatric Neuro-Oncology Consortium (PNOC) and the Children's Brain Tumor Network (CBTN) have established a diversity, equity and inclusion working group that aims to improve equitable access to care and diversity within the neuro-oncology research community.[54] Within Australia, this will require a new generation of Aboriginal and Torres Strait Islander clinical and research capability and leadership. There is currently a wave of emerging Aboriginal and Torres Strait Islander cancer researchers, with strengths in epidemiology, genomics and cancer biology. Important to the success of any effort in childhood cancer research will be the development of clinical capability alongside research, by identifying, training and mentoring Aboriginal and Torres Strait Islander paediatric oncologists, clinical nurse specialists, medical students and allied health professionals. Any future research in this space should be co-designed and led by Aboriginal and Torres Strait Islander communities; alongside clinicians, researchers and services,[55,56] and following the key principles and best practices of co-design in Indigenous health.[57] This will help meet the priorities of Aboriginal and Torres Strait Islander people. This will be critical to ensure that any global advances for Indigenous children with cancer are also reflected in the Australian context.

Conclusion

Paediatric cancer is the leading cause of disease-related death in Australian children; however, there is limited research on cancer in Aboriginal and Torres Strait Islander children. Although cancer incidence is lower in Aboriginal and Torres Strait Islander children, the 5-year overall survival remains inferior. These patterns are also reflective of paediatric cancer in Indigenous children worldwide, necessitating further research, both in Australia and internationally, to improve cancer outcomes for Indigenous children. Any future research in this space should be co-designed with Aboriginal and Torres Strait Islander communities with their priorities in mind, and should ideally be led by Aboriginal and Torres Strait Islander researchers.

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Supporting Information

Additional Supporting Information is included with the online version of this article.