Access to and Health Outcomes of Pediatric Solid Organ Transplantation for Indigenous Children in 4 Settler-colonial Countries: A Scoping Review

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Abstract. Solid organ transplantation (SOT) is considered the optimal treatment for children with end-stage organ failure; however, increased efforts are needed to understand the gap surrounding equitable access to and health outcomes of SOT for Indigenous children. This scoping review summarizes the literature on the characteristics of access to and health outcomes of pediatric SOT among Indigenous children in the settler-colonial states of Canada, Aotearoa New Zealand, Australia, and the United States. A search was performed on MEDLINE, EMBASE, PsycINFO, and CINAHL for studies matching preestablished eligibility criteria from inception to November 2021. A preliminary gray literature search was also conducted. Twenty-four studies published between 1996 and 2021 were included. Studies addressed Indigenous pediatric populations within the United States (n = 7), Canada (n = 6), Aotearoa New Zealand (n = 5), Australia (n = 5), and Aotearoa New Zealand and Australia combined (n = 1). Findings showed that Indigenous children experienced longer time on dialysis, lower rates of preemptive and living donor kidney transplantation, and disparities in patient and graft outcomes after kidney transplantation. There were mixed findings about access to liver transplantation for Indigenous children and comparable findings for graft and patient outcomes after liver transplantation. Social determinants of health, such as geographic remoteness, lack of living donors, and traditional spiritual beliefs, may affect SOT access and outcomes for Indigenous children. Evidence gaps emphasize the need for action-based initiatives within SOT that prioritize research with and for Indigenous pediatric populations. Future research should include community-engaged methodologies, situated within local community contexts, to inform culturally safe care for Indigenous children.

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INTRODUCTION

Indigenous peoples are the original inhabitants of present-day Canada, Aotearoa New Zealand, Australia, and the United States,[1] and are diverse groups with cultures, traditions, and knowledge systems that are foundational to the health of Indigenous children.[2] Yet, settler-colonial relations persist in these former European colonies, including land dispossession, state paternalism, loss of culture, racism, and violence, which are documented to impact the health and well-being of Indigenous children, families, and communities.[3-5] Indigenous children have reported disproportionately higher rates of kidney, liver, cardiovascular, and respiratory diseases compared with non-Indigenous children[2,6-8] that may progress to organ failure. Solid organ transplantation (SOT) is the optimal treatment for children with end-stage organ failure[9] and is associated with markedly improved clinical and patient-reported outcomes.[10,11] However, SOT is a complicated process, from an initial referral to a transplant center for evaluation to a strict regimen of immunosuppressant drug therapy and life-long medical follow-up, amid risks of severe complications posttransplant.[9,12] The barriers for patients and families proceeding through these stages are multifaceted and ethno-racial disparities exist in access to and health outcomes of pediatric SOT.[13]

Recent studies have suggested that Indigenous pediatric patients have lower rates of access to kidney transplantation (KTx)[14] and worse long-term graft outcomes than non-Indigenous patients[15]; however, research in this field is limited. Increased efforts are needed to understand and address the gap surrounding equitable access to and health outcomes of SOT between Indigenous and non-Indigenous children. Indigenous-focused and Indigenous-led data collection, through meaningful community-engaged partnerships, is the first step to understanding how to support Indigenous child health in pediatric SOT.

In recognizing this need, this scoping review addresses the question: What are the characteristics of access to care and health outcomes of pediatric SOT among Indigenous children in the settler-colonial states of Canada, Aotearoa New Zealand, Australia, and the United States? This exploratory review aims to summarize the current body of knowledge within pediatric SOT to identify evidence gaps and inform future research priorities to optimize the health and well-being of Indigenous children.

MATERIALS AND METHODS

This review was conducted following Arksey and O'Malley's framework.[16,17] In addition, a Patient Advisory Committee composed of First Nations and Métis SOT patient and family partners was established.[18] Patient Advisory Committee members engaged in research processes, including codeveloping the search strategy and providing feedback on results and interpretation. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews was referred to for study reporting.[19]

Identifying the Research Question

The Participants, Concept, and Context framework was used for research question development.[17] These elements are identified as follows: (a) Participants: Indigenous children; (b) Concept: characteristics of access to care and health outcomes of pediatric SOT; and (c) Context: Canada, Aotearoa New Zealand, Australia, and the United States. Access to care was defined as the ability to use timely and available healthcare services to achieve the best health outcomes,[20] including being placed on the SOT waitlist, time to SOT, and access to living or deceased transplantation.

Setting Inclusion Criteria

Articles were included if the study (1) was English language and peer-reviewed; (2) was a primary study; (3) participants were <19 y old; (4) described access to or health outcomes of SOT (ie, heart, kidney, liver, lung, pancreas, and multiorgan); and (5) participants included Indigenous peoples in Canada, Aotearoa New Zealand, Australia, or the United States. Articles that included a participant population different from the population described above were included if the results were disaggregated within the article. Publication year was not a parameter for inclusion because this is the first known review on this topic.

Identifying Relevant Studies

Search Strategy

A comprehensive search of articles was performed on MEDLINE, EMBASE, PsycINFO, and CINAHL from inception to November 17, 2021. The search strategy was developed collaboratively among the research team, Patient Advisory Committee, and a medical librarian to identify a combination of most relevant search terms (**Appendix 1, SDC,** http://links.lww.com/TP/D65).[21]

Article Selection

Two independent reviewers (J.L. and I.S.) screened the title and abstracts and examined the full text of potentially relevant articles to determine eligibility. Discrepancies were reviewed and resolved, and if necessary, a third reviewer (S.J.A.) collaborated. The Kappa value for full-text review was scored at 0.77. Title, abstract, and full-text article screening were conducted on Covidence software.[22]

Extracting Data

A data extraction sheet was created and piloted by extracting data from 3 articles independently and comparing for alignment. Data extraction was then continued independently by the reviewers (J.L., I.S.) for the remaining articles, followed by a comparison for reliability and consistency. Data extracted from each article included as follows: (1) study characteristics, (2) participant characteristics, and (3) summary of results (eg, access to SOT, health outcomes, social determinants of health [SDOH]).

Summarizing and Reporting Results

Results were summarized and co-interpreted with the Patient Advisory Committee, who shared their lived experiences and feedback that provided patient and family perspectives on the included articles, aggregated results, research gaps, and clinical interpretations of the larger research team.

Gray Literature Search

A preliminary gray literature search was performed using Google Advanced Search to scope for published gray literature addressing SDOH affecting pediatric SOT among Indigenous children in Canada, Aotearoa New Zealand, Australia, and the United States. Searches were conducted with various word combinations of the same search terms as the peer-reviewed literature, using advanced search features for domain types (eg, .org and .gov) and search boxes (eg, 'all these words' and 'any of these words'). Four searches were completed for website landing pages, and the author (J.L.) reviewed the first 60 results of each search for relevance. Because of the lack of relevant gray literature found, this search was not continued past these preliminary steps.

RESULTS

Study Characteristics

The original search yielded 3530 articles, of which 1117 articles were removed as duplicates. A total of 2413 articles were screened for eligibility at the title and abstract level, and 569 articles were reviewed at the full-text screening level. See Figure 1 for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews diagram.[19]

Twenty-four articles were retained for analysis and included Indigenous populations within the United States[23-29] (n = 7), Canada[15,30-34] (n = 6), Aotearoa New Zealand[35-39] (n = 5), Australia[6,14,40-42] (n = 5), and Aotearoa New Zealand and Australia combined[43] (n = 1). Article publication years ranged from 1996 to 2021, with 6 articles (25%) published within the last 5 y. Most articles used a retrospective cohort design (n = 21); 2 used a multiple case study design and 1 used a case study design. Several articles gathered participant data from the same databases: Australia and New Zealand Dialysis and Transplant Registry (n = 5), US Renal Data System (n = 3), and United Network for Organ Sharing (n = 2). A summary of the included articles is outlined in Table 1.

Participant Characteristics

Articles included kidney (n = 13), liver (n = 10), and heart (n = 1) organ groups. No articles included participants across multiple organ groups or addressed lung or pancreas organ groups. Studies composed of 43 767 pediatric patients overall, consisting of Native Americans, including American Indians and Alaska Natives (n = 1980), Aboriginal and Torres Strait Islander peoples, hereafter respectfully referred to as First Nation Australians (n = 288), First Nations, Métis, and Inuit peoples (n = 200), and Māori peoples (n = 140).

Access to Pediatric SOT
Kidney

Ten articles reported on access to pediatric KTx among Indigenous children in Canada[15,33] (n = 2), Aotearoa New Zealand[38,39] (n = 2), Australia[6,40] (n = 2), Aotearoa New Zealand and Australia combined[43] (n = 1), and the United States[23-25] (n = 3). Overall, articles showed that Indigenous children with kidney failure spent longer time on dialysis, were less likely to receive a preemptive transplant—the preferred kidney replacement therapy modality, and were less likely to receive a
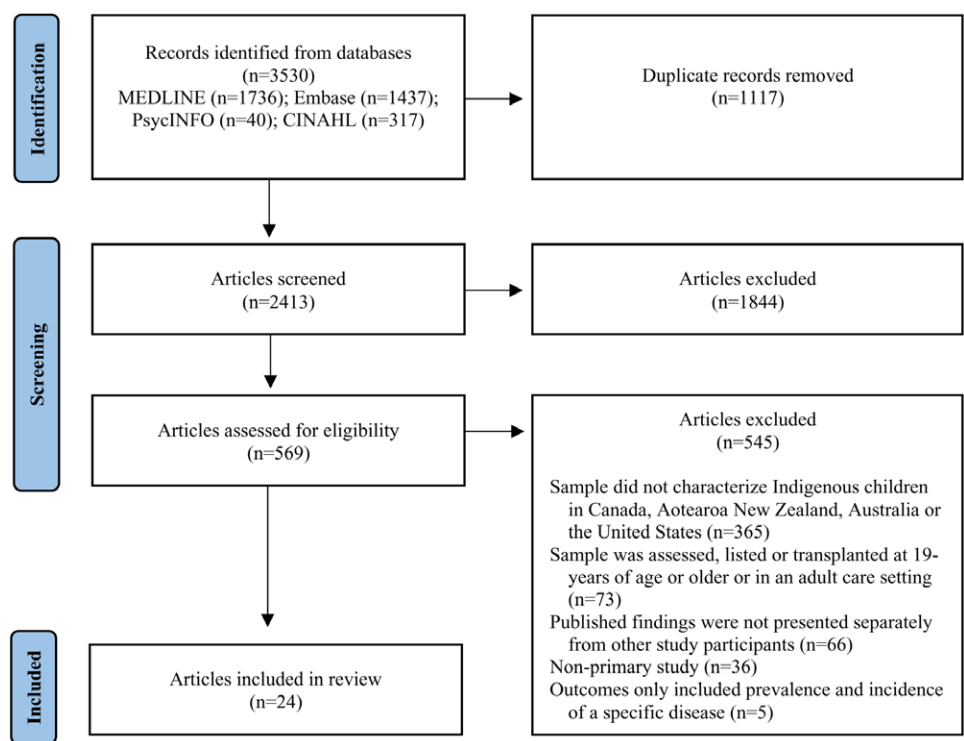

FIGURE 1. PRISMA-ScR: Flow of information through different phases of the scoping review. PRISMA-ScR, Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews.

TABLE 1.

Overview of included articles

Author, year; country	Organ	Objectives	Design and data source	Sample and characteristics
Chaturvedi et al,[6] 2021; Australia	Kidney	Described trends in incidence, prevalence, cause, and modality selection of KRT for First Nation Australian children and young adults in Australia	Retrospective cohort study using ANZDATA, between 1963 and 2017	First Nation Australian (n = 178) Other (n = 3451)
Ferris et al,[24] 2006; United States	Kidney	Characterized the survival and outcomes of patients starting ESRD therapy and assessed specific outcomes in different ethnic groups	Retrospective cohort study using USRDS, between 1978 and 2002	Native American (n = 208) White (n = 11 329) Black (n = 4639) Asian (n = 587) Other (n = 272)
Grace et al,[40] 2014; Australia	Kidney	Investigated racial disparities in uptake of KTx for pediatric patients in Australia and investigated clinical factors likely to influence KTx	Retrospective cohort study using ANZDATA, between 1990 and 2011	First Nation Australian (n = 35) Caucasian (n = 655) Other (n = 133)
Grace et al,[39] 2014; Aotearoa New Zealand	Kidney	Investigated racial disparities in access and outcomes to KTx for pediatric patients treated for ESRD in New Zealand	Retrospective cohort study using ANZDATA, between 1990 and 2012	Māori (n = 48) European (n = 125) Asian (n = 12) Pacific (n = 30)
Hiraki et al,[23] 2011; United States	Kidney	Identified predictors of waitlisting for KTx, KTx, and mortality among children with ESRD	Retrospective cohort study using USRDS, between 1995 and 2006	American Indian (n = 14) White (n = 219) African American (n = 287) Asian (n = 46) Hispanic (n = 142) Non-Hispanic (n = 441)
Le Page et al,[41] 2021; Australia	Kidney	Described the incidence of new-onset vascular disease and vascular death in children receiving KRT and identified risk factors	Retrospective cohort study using ANZDATA, between 1991 and 2017	First Nation Australian (n = 47) Caucasian (n = 915) Other (n = 306)
Matsuda-Abedini et al,[15] 2009; Canada	Kidney	Determined the short- and long-term outcomes of KTx among Aboriginal and non-Aboriginal children	Retrospective cohort study using British Columbia Children's Hospital Transplant Program database, between 1985 and 2005	Aboriginal (n = 24) Non-Aboriginal (n = 135)
McDonald and Russ,[43] 2003; Australia and Aotearoa New Zealand	Kidney	Reported the incidence and outcomes of Indigenous peoples who began KRT in Australia or New Zealand	Retrospective cohort study using ANZDATA, between 1991 and 2000	First Nation Australian (n = 11) Māori (n = 10) Non-Indigenous (n = 253) Pacific Islander (n = 10)
Narva et al,[25] 1996; United States	Kidney	Investigated reported Arizona and New Mexico resident cases to understand more about Native American and White ESRD patients	Retrospective cohort study using ESRD Network No. 15; follow-up period not reported	Native American in Arizona (n = 1039) Native American in New Mexico (n = 533) White in Arizona (n = 5448) White in New Mexico (n = 1811)
Samuel et al,[33] 2011; Canada	Kidney	Evaluated differences in dialysis modality, time on dialysis, rates of KTx, and patient and graft survival between Aboriginal and non-Aboriginal children	Retrospective cohort study using the Canadian Pediatric End-stage Renal Disease database, between1992 and 2007	Aboriginal (n = 104) White (n = 521) Other (n = 218)
Samuel et al,[34] 2011; Canada	Kidney	Estimated age-specific graft failure rates among KTx recipients and determined the influence of the adaptation period after adult care transfer on graft failure risk	Retrospective cohort study using the Canadian Organ Replacement Register, between 1992 and 2007	Aboriginal (n = 35) White (n = 256) Black (n = 9) Other (n = 113)
Verghese et al,[28] 2020; United States	Kidney	Assessed rehospitalization rates within 1 y of KTx for recipients, risk factors associated with early and late rehospitalization, and the impact of rehospitalizations on patient and graft survival	Retrospective cohort study using USRDS, between 2006 and 2016	American Indian (n = 14) Caucasian (n = 153) African American (n = 13) Asian (n = 15) Unknown (n = 2)

TABLE 1. (Continued)

Author, year; country	Organ	Objectives	Design and data source	Sample and characteristics
Weststrate et al,[38] 2021; Aotearoa New Zealand	Kidney	Determined the rates of preemptive KTx in the New Zealand pediatric chronic kidney disease population and sought potential barriers to preemptive KTx	Retrospective cohort study using the New Zealand National Paediatric Nephrology KF clinical database, between 2005 and 2017	Māori (n = 21) European (n = 34) Asian (n = 7) Pacific Islander (n = 13)
Arnon et al,[26] 2013; United States	Liver	Investigated government insurance and outcomes after first LTx for children with biliary atresia	Retrospective cohort study using UNOS Standard Transplant Analysis and Research files, between 2003 and 2011	American Indian or Alaskan Native, Native Hawaiian, Pacific Islander (n = 73) White (n = 758) Black (n = 302) Hispanic (n = 335) Asian (n = 111)
Chinnaratha et al,[14] 2014; Australia	Liver	Compared overall and graft survival after LTx between First Nation Australian and non-Indigenous patients, assessed the factors influencing survival, and examined the proportion of First Nation Australian patients undergoing LTx	Retrospective cohort study using Australian and New Zealand LTx registry, between 1985 and 2012	First Nation Australian (n = 14) Non-Indigenous (n = 622)
Drouin et al,[30] 2000; Canada	Liver	Described the features of Aboriginal patients with North American Indian cirrhosis	Retrospective cohort study using clinical records from 1981	Northern Ojibway or Cree descent (n = 30)
Evans et al,[36] 2018; Aotearoa New Zealand	Liver	Determined the incidence and outcome of biliary atresia with specific reference to whether these differed between ethnic groups	Retrospective cohort study using surgical records, databases and coding data, between 2002 and 2014	Māori (n = 45) Pacific Islander (n = 11) Asian (n = 9) European (n = 25)
Hanna et al,[42] 2000; Australia	Liver	Described 3 cases of fulminant hepatitis A in Indigenous children in north Queensland	Multiple case study; data source not reported	First Nation Australian (n = 3)
Hsu et al,[27] 2015; United States	Liver	Described trends in the use of exceptions among the pediatric liver waitlist population	Retrospective cohort study using UNOS Organ Procurement and Transplant Network database, between 2002 and 2013	American Indian/Alaskan Native (n = 28) Native Hawaiian/Pacific Islander (n = 16) White (n = 1911) Black (n = 663) Hispanic (n = 814) Asian (n = 206) Multiracial (n = 90)
Phillips et al,[31] 1996; Canada	Liver	Reported on 6 Native Canadian children with severe chronic cholestatic liver disease	Multiple case study using clinical records; follow-up period not reported	Native Canadian of Cree, Ojibwa-Cree, or unspecified descent (n = 6)
Shapiro,[32] 2005; Canada	Liver	Discussed whether parents should consent to having their child undergo LTx if considered medically necessary	Case study; data source not reported	First Nations (n = 1)
Smith et al,[35] 2002; Aotearoa New Zealand	Liver	Determined numbers and indications for LTx at present, current outcomes and estimated the likely demand for the service in the future	Retrospective cohort study using medical records, the Queensland LTx Unit database or the New Zealand LTx Trust, between 1990 and 2000	Māori (n = 6) Pacific Islander (n = 4) Other (n = 7)
Wilde et al,[37] 2007; Aotearoa New Zealand	Liver	Reported the first 5 y of pediatric LTx undertaken by the New Zealand LTx Unit	Retrospective cohort study; data source not reported	Māori (n = 10) European (n = 14) Pacific (n = 3) Asian (n = 1)
Kleinmahon et al,[29] 2019; United States	Heart	Identified risk factors for rejection with severe hemodynamic compromise and predictors of graft failure	Retrospective cohort study using data collected from the Pediatric Heart Transplant Study, between 2005 and 2015	American Indian/Alaskan Native/Pacific Islander (n = 55) African American (n = 622) Asian (n = 120) White (n = 2211) Other (n = 251)

ANZDATA, Australia and New Zealand Dialysis and Transplant Registry; ESRD, end-stage renal disease; KRT, kidney replacement therapy; KTx, kidney transplantation; LTx, liver transplantation; UNOS, United Network for Organ Sharing; USRDS, US Renal Data System.

TABLE 2.

Access to pediatric kidney transplantation

Variable	Source, year	Country	Relevant results
Kidney replacement therapy			
Disparities identified	McDonald and Russ,[43] 2023	Aotearoa New Zealand and Australia	Proportion of First Nation Australian patients <15 y old at start of KRT was lower compared with non-Indigenous patients ($P < 0.05$)
	Ferris et al,[24] 2006	United States	Native American patients were more likely to be hemodialysis-dependant than White patients but fared better than Black patients
Disparities not identified	Samuel et al,[33] 2011	Canada	No difference in median age at start of KRT among Aboriginal, White, and patients of other ethnicities; hemodialysis was the initial modality for 48% of Aboriginal patients, 43% of White patients, and 63% of patients of other ethnicities ($P < 0.001$)
	Grace et al,[39] 2014	Aotearoa New Zealand	No difference in patient age at start of KRT among Māori, European, Asian, and Pacific Islander patients
	Weststrate et al,[38] 2021	Aotearoa New Zealand	No difference in early vs late referral to KRT among Māori, European, Asian, and Pacific Islander patients
Time to KTx			
Disparities identified	Grace et al,[40] 2014	Australia	Median time from KRT to deceased donor KTx was 4.3 y for First Nation Australian patients, 3.3 y for Caucasian patients, and 3.4 y for patients of other ethnicities; First Nation Australian patients were more likely to be referred late for a KTx than Caucasian patients and patients of other ethnicities ($P < 0.001$)
	Chaturvedi et al,[6] 2021	Australia	First Nation Australian patients spent over double the time on dialysis before receiving a KTx compared with patients of other ethnicities ($P < 0.001$)
	Samuel et al,[33] 2011	Canada	Time from start of dialysis to first KTx was longer for Aboriginal than non-Aboriginal patients ($P < 0.001$)
	Hiraki et al,[23] 2011	United States	American Indian patients had a trend of lower age- and sex-adjusted odds ratio of waitlisting for KTx compared with White patients
Disparities not identified	Grace et al,[39] 2014	Aotearoa New Zealand	No differences in time to first KTx listing among Māori, European, Asian, and Pacific Islander patients on dialysis
	Grace et al,[40] 2014	Australia	Median time from KRT to deceased donor KTx was 4.3 y for Indigenous patients, 3.3 y for Caucasian patients, and 3.4 y for patients of other ethnicities
	Matsuda-Abedini et al,[15] 2009	Canada	No differences in waitlisting to KTx among Aboriginal and non-Aboriginal patients
Preemptive KTx			
Disparities identified	Matsuda-Abedini et al,[15] 2009	Canada	No Aboriginal patients received a preemptive Tx compared with 22% of non-Aboriginal patients
	Samuel et al,[33] 2011	Canada	Aboriginal patients were less likely to receive a preemptive KTx than White patients ($P < 0.001$)
	Weststrate et al,[38] 2021	Aotearoa New Zealand	No Māori patients received a (living or deceased) preemptive KTx; Māori patients were more likely to be "missed opportunities" for preemptive KTx ($P = 0.0009$)
	Grace et al,[39] 2014	Aotearoa New Zealand	Māori patients did not receive any (living or deceased) preemptive KTx compared with 30% of European patients ($P < 0.009$)
	Grace et al,[40] 2014	Australia	No First Nation Australian patients received a (living or deceased) preemptive KTx compared with 19% of Caucasian patients ($P < 0.001$)
	Chaturvedi et al,[6] 2021	Australia	Preemptive KTx was performed at a lower rate among First Nation Australian patients than patients of other ethnicities; a total of 6 First Nation Australian patients received a preemptive KTx
Living vs deceased KTx			
Disparities identified	Grace et al,[39] 2014	Aotearoa New Zealand	Māori patients had the highest mortality on KRT ($P = 0.008$) and were more likely to be dead without a KTx ($P < 0.001$); Māori patients were less likely to receive a living donor KTx but more likely to receive a deceased donor KTx than European patients ($P < 0.001$); there were proportionally fewer KTx of any type among Māori patients
	Weststrate et al,[38] 2021	Aotearoa New Zealand	There was a lower proportion of living donor KTx for Māori patients (71%) than Asian (100%) and European patients (88%); among 7 Māori patients who did not receive a KTx, 5 did not have a suitable living donor present for donor evaluation
	Chaturvedi et al,[6] 2021	Australia	A higher percentage of First Nation Australian patients did not receive a KTx ($P < 0.001$) and transitioned to adult care on dialysis ($P < 0.001$); living donor KTx was performed at a lower rate among First Nation Australian patients than patients of other ethnicities (11% vs 36%; $P < 0.001$)

TABLE 2. (Continued)

Variable	Source, year	Country	Relevant results
	Grace et al,[40] 2014	Australia	First Nation Australian patients were less likely to receive a living donor KTx but had higher rates of deceased donor KTx than Caucasian patients ($P < 0.001$); First Nation Australian patients had proportionally fewer KTxs of any type
	Samuel et al,[33] 2011	Canada	Aboriginal patients were less likely to receive a KTx from any source (HR = 0.54), a living donor (HR = 0.36), and a deceased donor (HR = 0.62) compared with White patients
	Narva et al,[25] 1996	United States	Age-specific KTx rate was lower for Native American than White American patients in Arizona and New Mexico, although the significance was not tested
	Ferris et al,[24] 2006	United States	Native American patients were less likely to receive a KTx compared with White patients (72% vs 82%; $P = 0.0001$) but more likely than Black patients
	Hiraki et al,[23] 2011	United States	American Indian patients had a trend of lower age- and sex-adjusted odds ratio of receiving a KTx compared with White patients
Disparities not identified	Matsuda-Abedini et al,[15] 2009	Canada	No difference in living donor KTx among Aboriginal and non-Aboriginal patients

HR, hazard ratio; KRT, kidney replacement therapy; KTx, kidney transplantation; Tx, transplantation.

KTx from any source (living or deceased), especially a living donor KTx. Table 2 summarizes findings related to access to KTx.

Liver

Nine articles reported on access to pediatric liver transplantation (LTx) among Indigenous children with liver disease in Canada[30-32] (n = 3), Aotearoa New Zealand[35-37] (n = 3), Australia[14,42] (n = 2), and the United States[27] (n = 1). Overall, articles showed mixed findings with respect to disparities in referral for LTx, time to LTx, and access to LTx among Indigenous and non-Indigenous children. Table 3 summarizes findings related to access to LTx.

Health Outcomes Following Pediatric SOT

Kidney

Eight articles reported on outcomes of pediatric KTx among Indigenous children in Canada[15,33,34] (n = 3), Aotearoa New Zealand[39] (n = 1), Australia[41] (n = 1), and the United States[23,24,28] (n = 3). Overall, articles showed disparities in long-term KTx graft outcomes and patient survival for Indigenous children compared with non-Indigenous children. Table 4 summarizes KTx graft and patient outcomes.

Liver

Six articles reported on outcomes of pediatric LTx among Indigenous children in Canada[30] (n = 1), Aotearoa New Zealand[35-37] (n = 3), Australia[14] (n = 1), and the United States[26] (n = 1). Overall, articles showed that LTx graft outcomes and patient survival were comparable between Indigenous and non-Indigenous children. Table 5 summarizes LTx graft and patient outcomes.

Heart

One article reported on outcomes of pediatric heart transplantation from an international registry including Indigenous children from the United States.[29] Analysis did not find an association between American Indian and Alaskan Native ethnicity with rejection with severe hemodynamic compromise after pediatric heart transplantation.[29]

SDOH Affecting Pediatric SOT

Seven articles reported on SDOH affecting pediatric SOT for Indigenous patients. According to Samuel et al,[33] a greater proportion of Indigenous children with kidney failure in Canada lived >300 km away from the nearest pediatric kidney center ($P < 0.001$) and were in the lowest income quintile ($P < 0.001$). Similarly, Chaturvedi et al[6] reported that First Nation Australian patients with kidney failure in Australia were more likely to reside in remote locations ($P < 0.001$). Another Australian study found that the remoteness of family residence was the only predictor of death and retransplantation among pediatric LTx recipients ($P = 0.03$), with a trend of increased death and retransplantation among First Nation Australian patients from remote areas.[14]

A lack of suitable donors and traditional beliefs were also highlighted to affect access to pediatric SOT. Weststrate et al[38] and Hanna et al[42] noted that the availability of a suitable donor organ may be a critical issue for Māori and First Nation Australian patients who were not transplanted in Aotearoa New Zealand and Australia. Another study suggested that disparities in graft outcomes for Māori KTx patients may be because of a lack of living donors and well-matched deceased kidney donors.[39] In 1 article, traditional spiritual beliefs was reported to impact the acceptance of SOT as a life-saving therapy.[32]

DISCUSSION

This is the first scoping review to synthesize the literature on the characteristics of access to and health outcomes of pediatric SOT for Indigenous children in Canada, Aotearoa New Zealand, Australia, and the United States. Twenty-four articles met inclusion criteria, and there was a paucity of relevant gray literature. This review identified that Indigenous children with kidney failure experience longer time on dialysis, lower rates of preemptive and living donor KTx, and disparities in long-term graft and patient outcomes. There were mixed findings about

TABLE 3.

Access to pediatric liver transplantation

Variable	Source, year	Country	Relevant results
Referral for LTx			
Case studies	Hanna et al,[42] 2000	Australia	Reported cases of fulminant hepatitis A in First Nation Australian patients; a total of 3 patients were transferred to a specialist and 2 patients were referred and listed for urgent LTx; however, all cases died before a donor organ was found; availability of a suitable donor organ may be a critical issue
	Shapiro,[32] 2005	Canada	Reported on a First Nations family's reasons for foregoing LTx for their child; the parents were informed that LTx was the only available life-saving therapy but their traditional spiritual beliefs precluded introducing another person's organ into their child, and they had concerns about the long-term effects of the immunosuppressive drugs; LTx was declined to allow the child to live their natural life
Time to LTx			
Disparities identified	Hsu et al,[27] 2015	United States	Exception requests to MELD/PELD scores can be made among waitlisted candidates to expedite LTx; American Indian and Alaska Native patients represented 1% of all pediatric LTx exception requests and only 18% of patients received exception requested compared with 29%–37% of non-Indigenous patients
Disparities not identified	Chinnaratha et al,[14] 2014	Australia	No difference in waitlisting for LTx and waitlist mortality among First Nation Australian and non-Indigenous patients; a greater proportion of First Nation Australian patients were too sick to receive an LTx, although the significance was not tested
Access to LTx			
Disparities identified	Smith et al,[35] 2002	Aotearoa New Zealand	Māori children were overrepresented in the pediatric LTx population as a higher proportion of Māori patients received LTx than would be expected from their proportion in the pediatric population (59% vs 29%; $P < 0.01$)
	Wilde et al,[37] 2007	Aotearoa New Zealand	Māori patients were overrepresented among pediatric LTx recipients, primarily because of the high incidence of extrahepatic biliary atresia in the pediatric Māori population
	Evans et al,[36] 2018	Aotearoa New Zealand	Of 90 children born with biliary atresia, 56% of Māori patients were transplanted at a median age of 1.92 y compared with 72% of European patients at 1.01 y ($P < 0.02$); Māori patients had better "transplant-free survival" than European patients ($P < 0.04$) despite later age at Kasai portoenterostomy, possibly because of a unique form of biliary atresia with later presentation and more favorable outcomes
	Chinnaratha et al,[14] 2014	Australia	First Nation Australian patients were older at age of LTx than non-Indigenous patients ($P = 0.048$), despite similar cause; approximately 2.2% of First Nation Australian patients received a LTx compared with 4.7% of non-Indigenous children in the general population, suggesting that First Nation Australian children are underrepresented in the Australian pediatric LTx population
Disparities not identified	Hsu et al,[27] 2015	United States	No difference in rates of LTx across racial groups that included American Indian and Alaska Native patients
Case studies	Phillips et al,[31] 1996	Canada	Reported cases of severe chronic cholestatic liver disease among First Nations patients; all 6 patients were referred for LTx; a total of 5 patients underwent LTx, whereas 1 was assessed for LTx during the study period
	Drouin et al,[30] 2000	Canada	Reported cases of North American Indian cirrhosis among First Nations children; a total of 9 patients underwent LTx and 4 could not for various reasons; of the 21 patients who did not undergo LTx, 9 were alive at the time of the study and 12 passed away because of liver failure, accidents, or sepsis

LTx, liver transplantation; MELD, Model for End-stage Liver Disease; PELD, Pediatric End-stage Liver Disease.

access to pediatric LTx and comparable findings for LTx graft and patient outcomes among Indigenous children. In 1 article addressing pediatric heart transplantation, there was no information about access and limited evidence about outcomes among Indigenous patients.

Although this review focused on Indigenous pediatric patients, it is notable that findings align with current research examining health disparities in access to and outcomes of SOT for Indigenous adult populations. In their review addressing Indigenous adults, Yeates et al[44] reported that Indigenous patients in Australia, Canada, Aotearoa New Zealand, and the United States faced significantly longer wait times for KTx and lower rates of KTx compared with Caucasian patients. The authors cited potential barriers as delayed referral for KTx evaluation and from

referral to KTx waitlist,[44] which is also reflected in the current findings showing low rates of preemptive KTx among Indigenous children.[33,38-40] Zhang et al[45] reported that the incidence of rejection, graft, and patient survival between adult First Nations and non-First Nations populations undergoing LTx were similar; however, they cited the reasons as unclear. The absence of disparities in access to and outcomes of pediatric LTx among Indigenous children in the current review is also unexplained, but notable.

It is apparent that additional research is needed to investigate the scope in topic that illuminates access to and outcomes of pediatric KTx and LTx among Indigenous patients. Namely, considerations of historical, contextual, and sociocultural determinants are essential if we are to provide an informed discussion on the biomedical outcomes of

TABLE 4.

Health outcomes after pediatric kidney transplantation

Variable	Source, year	Country	Relevant results
Graft outcomes			
Disparities identified	Grace et al,[39] 2014	Aotearoa New Zealand	Māori patients were more likely to experience delayed graft function among all primary KTx ($P < 0.05$), all primary deceased KTx ($P < 0.05$), but not living donor KTx compared with European patients; the 5-y death-censored graft survival was 61% for Māori patients and 88% for European patients; Māori patients reported lower rates of retransplantation compared with European patients (14% vs 36%), potentially because of noncompliance
	Matsuda-Abedini et al,[15] 2009	Canada	The estimated glomerular filtration rate at 2- and 5-y and long-term graft survival were worse for Aboriginal compared with non-Aboriginal patients ($P < 0.005$); Aboriginal patients also had increased rate of late rejections ($P = 0.03$)
	Samuel et al,[34] 2011	Canada	Aboriginal patients had a higher risk of graft failure at the 3-y adaptation interval during the transition period to adult care compared with White patients (HR = 3.26)
	Verghese et al,[28] 2020	United States	American Indian patients had a trend of higher rates of early rehospitalization compared with Caucasian patients (57% vs 39%)
Disparities not identified	Matsuda-Abedini et al,[15] 2009	Canada	No difference in early graft outcomes, number of acute rejection episodes, and estimated glomerular filtration rate at 1-y among Aboriginal and non-Aboriginal patients
	Samuel et al,[33] 2011	Canada	No difference in median time from first KTx to graft failure and overall unadjusted kidney graft failure at 5 and 10 y among Aboriginal, Black, White, and patients of other ethnicities
	Verghese et al,[28] 2020	United States	No difference in rates of late rehospitalization after KTx among American Indian, Caucasian, African American, and Asian patients
Patient outcomes			
Disparities identified	Grace et al,[39] 2014	Aotearoa New Zealand	Among children who started KRT, including those with and without a KTx, Māori patients had a higher adjusted mortality rate than European patients (HR = 4.26)
	Le Page et al,[41] 2021	Australia	For patients followed into adulthood receiving KRT, including those with and without a KTx, Indigenous ethnicity was associated with vascular disease (HR = 3.60), vascular mortality (HR = 4.51), and composite vascular outcome (HR = 3.62)
	Matsuda-Abedini et al,[15] 2009	Canada	There were 5.7% deaths in the study population, comprising 12.5% of Aboriginal patients and 4.4% of non-Aboriginal patients
	Ferris et al,[24] 2006	United States	Native American patients had lower 10-y KTx survival rates compared with White and Asian patients ($P = 0.0001$) but higher than Black patients
	Hiraki et al,[23] 2011	United States	American Indian patients had a trend of higher overall mortality compared with White patients
Disparities not identified	Le Page et al,[41] 2021	Australia	No difference in childhood vascular disease, vascular mortality, and composite vascular outcome among First Nation Australian and non-Indigenous patients receiving KRT, including KTx
	Samuel et al,[33] 2011	Canada	No differences in 5- and 10-y patient survival rates across Indigenous, Black, White, and patients of other ethnicities

HR, hazard ratio; KRT, kidney replacement therapy; KTx, kidney transplantation.

SOT for Indigenous pediatric populations. Findings from this review suggest determinants of Indigenous health,[46,47] similar to findings within the adult population,[48] that may affect pediatric SOT access and outcomes, including the lack of living organ donors, traditional spiritual beliefs surrounding SOT, and the geographic remoteness of patients and families. Specifically, the lack of specialized medical support in remote communities is a known barrier to accessing healthcare for Indigenous peoples.[49] Indigenous patients living in remote communities must often relocate to an urban center to await and undergo SOT, leaving behind their cultural support systems while incurring additional financial stressors,[48] both potentially affecting their SOT experience and subsequent outcomes. Furthermore, in the adult literature, Indigenous patients have reported that pursuing preemptive or living donor KTx is complicated by a reluctance to accept an organ from a family or community member,[50] concerns that the

donor may experience negative health outcomes,[51] and a need to integrate cultural practices within the SOT experience to honor the donor (eg, smudges, healing circles).[52] These are areas to further explore within the Indigenous pediatric population.

There is value in acknowledging the marked absence of meaningful discussion within the included articles of the impacts of settler colonialism, generational trauma, institutional racism, and cultural bias as critical barriers to accessing and receiving appropriate healthcare for Indigenous populations, including access to and health outcomes of pediatric SOT for Indigenous children.[3-5] Of interest, Gerrald and McDonald[53] assessed the multiple steps to receiving a KTx and identified several systemic biases for adult First Nation Australian patients, including culturally biased healthcare practices, that contributed to the lower rates of KTx within this population.[54] Their findings draw attention to the lack of access to traditional ceremony within

TABLE 5.

Health outcomes after pediatric liver transplantation

Variable	Source, year	Countries	Relevant results
Graft outcomes			
Disparities not identified	Wilde et al,[37] 2007	Aotearoa New Zealand	Graft survival was 97% in the sample, of whom 36% were Māori, during the 5-y study period
	Chinnaratha et al,[14] 2014	Australia	No difference in cumulative 5- and 10-y graft survival between First Nation Australian and non-First Nation Australian patients (72.4% and 63.4%)
	Arnon et al,[26] 2013	United States	No difference in 1- and 5-y liver graft survival among American Indian or Alaskan Native, White, Black, Hispanic, and Asian patients
Patient outcomes			
Disparities identified	Chinnaratha et al,[14] 2014	Australia	The remoteness of the family residence was the only predictor of death and re-Tx ($P = 0.03$), with a trend toward increased death and re-Tx rates in First Nation Australian patients from remote areas ($P = 0.08$)
Disparities not identified	Smith et al,[35] 2002	Aotearoa New Zealand	All 17 patients in the sample, including 6 Māori children, were participating in a full-time school program
	Wilde et al,[37] 2007	Aotearoa New Zealand	All 28 patients in the sample, including 10 Māori children, were living at home and those who were of school age attended school
	Evans et al,[36] 2018	Aotearoa New Zealand	Comparatively, 11% of Māori patients died, 8% of European patients died, 44% of Asian patients died, and 9% of Pacific Islander patients died
	Chinnaratha et al,[14] 2014	Australia	No differences in overall survival rate between First Nation Australian and non-Indigenous patients
Case studies	Drouin et al,[30] 2000	Canada	Of the 9 First Nations LTx recipients, 7 were alive at the time of the study with no reoccurrence of disease, whereas 2 patients did not survive LTx

LTx, liver transplantation; Tx, transplantation.

Western-based clinical care and the need for patient education and healthcare provider training that incorporates considerations of Indigenous worldviews and value systems.[55] We discern that a similar need in pediatric care is present, and future research is warranted to prioritize exploration and understanding of the impacts of systemic biases within pediatric SOT care for Indigenous patients and families.

Although this scoping review identified useful, albeit limited, evidence about the characteristics of access to and health outcomes of pediatric SOT among Indigenous children, published findings and gray literature illustrate substantial gaps in evidence with regards to organ groups (eg, heart, lung, pancreas, multiorgan), holistic patient-reported outcomes (eg, quality of life, strengths-based outcomes), and research approaches (eg, community-based and participatory research methodologies). Challenges in identifying and (mis)reporting Indigenous patients within healthcare and health research,[56] including because of stigma or historic lack of safety, may contribute to this population's erasure in research,[1] especially within studies that only use population health database registries. Of the included articles, only one explicitly reported working with Indigenous partners (eg, the Australia and New Zealand Dialysis and Transplant Registry Aboriginal and Torres Strait Islander Health Working Group[41]). Community-based and participatory approaches with Indigenous stakeholders, including community leaders, are necessary for research concerning Indigenous peoples and may support local Indigenous self-determination, nurture strengths-based interpretations inclusive of Indigenous worldviews, and research co-ownership.[57-59]

Furthermore, qualitative methodologies, including ethnography and narrative inquiry, may be valuable within future work that aims to elucidate social and historical determinants of care, such as the impact of colonialism, trauma, racism, and cultural bias on SOT experiences for Indigenous children. Their value lies in an understanding that Indigenous knowledge is often shared through unique representations of life experiences, such as storytelling, ceremonies, and artistic expression.[60]

This research demonstrates that exploring the experiences of Indigenous people globally can offer a shared narrative. Alternatively, it emphasizes a need to recognize the significant diversity within Indigenous communities and groups, including the distinct cultural, spiritual, historical, and political contexts that shape Indigenous health and well-being beyond geography.[1] Although this scoping review included Indigenous children across 4 settler-colonial countries, Indigenous peoples and communities are not homogenous, and researchers and healthcare providers must be attuned to how an individual or community identifies, offering respect for the diversity of history and culture within communities.[56] Research, care, and interventions need to reflect the distinct cultural values and specific needs of the local patient and community population and be community-engaged to offer impact on health outcomes for Indigenous children. As an exploratory approach, this scoping review used a global perspective as a necessary starting point to increase our understanding of the breadth of barriers and outcomes for Indigenous children accessing pediatric SOT within culturally-based lived experiences. Future research could build on this work by situating research questions within local community-led contexts to capture the depth of characteristics, experiences, and outcomes necessary to improve Indigenous health equity for children accessing SOT.

Limitations

It is possible that relevant articles were missed for review because of limited terminology that captures the broad range of community names within Indigenous

populations.[1,21] Furthermore, we did not exclude articles based on publication date, yet we acknowledge that data published 20 y past or more may have limited relevance given changes in contemporary contexts among Indigenous groups (eg, population demographics, disease incidence, clinical practices, and policies). Other research design approaches, such as an environmental scan, may have allowed us to be more culturally responsive to the contextual realities and perspectives of pediatric SOT underlying the lived experience of Indigenous communities through interviews with key stakeholders.[61,62]

CONCLUSIONS

This scoping review identified disparities and mixed findings concerning access to and health outcomes of pediatric SOT among Indigenous children in the settler-colonial states of Canada, Aotearoa New Zealand, Australia, and the United States. There was an absence of meaningful discussion within the included articles of historical and sociocultural determinants, including the impacts of settler colonialism, generational trauma, cultural bias, and institutional racism, that may enact as barriers to access and health outcomes of pediatric SOT for Indigenous children. Identifying substantial evidence gaps in the current review emphasizes the timeliness of action-based conversations and funding opportunities that prioritize research with and for Indigenous populations. Research initiatives that place value on community-engaged and participatory methodologies, situated within local community-led contexts, have the potential to inform culturally safe and strengths-based care for Indigenous children in need of SOT.

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