

"I haven't even taken them to the doctors, because I have that fear of what to expect": a qualitative description study exploring perceptions and experiences of early childhood healthcare among ethnically diverse caregivers in Aotearoa New Zealand



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Summary

Background Equity underpins Aotearoa New Zealand's publicly funded healthcare system; however, ethnic inequality persists. This qualitative study explored the perceptions and experiences of ethnically diverse parents accessing health services for their children.

Methods A qualitative description methodology informed interviews and focus groups that were conducted with caregivers of preschool aged children who identified as being of Māori, Pacific, Asian and/or European ethnicity (n = 145). Data were analysed following a reflexive thematic analytic approach.

Findings Five themes were constructed. *Hierarchies of knowledge and trust* Caregivers relied on multiple sources of health information and particularly trusted providers or other caregivers who had children. *Relational versus transactional health encounters* Caregivers were often disappointed that health providers did not build trusting relationships to support positive experiences. *Bad mother vibe* Mothers often felt judged by providers when accessing care and felt pressure to conform. *The 'slow burn' of waiting* Caregivers were often frustrated by how slow and fragmented the health system was, which was particularly distressing if their child was unwell or required referral. *Navigating complexity* Caregivers had to be proactive and assertive to ensure their child received care amidst the numerous barriers they faced, including discrimination and bias. While many commonalities were shared by ethnicity, unique to Indigenous Māori caregivers were the ongoing colonial traumas that impacted their ability to trust the healthcare system.

Interpretation A non-judgemental, competent, and culturally sensitive approach by healthcare professionals and services may help foster trusting relationships and positive health encounters. Strategies to improve trust, ease of access and navigation are needed to mitigate existing complexity, fragmentation, and counter-intuitive nature of the NZ healthcare system. Caregivers require more autonomy over decisions about their child's care and availability of services that reflect their cultural values. Policies are required to alleviate the indirect costs of accessing healthcare, prioritising of whānau/family-centred care, and addressing pervasive racism and bias within the system.

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Research in context

Evidence before this study

Despite equity unpinning health systems, disparities in the uptake of child health services by ethnicity continues to be an important health issue globally and in Aotearoa New Zealand. While empirical quantitative evidence presents persistent ethnic disparities in accessing child health services, there has been limited qualitative research among ethnically diverse caregivers that dives into the complex factors influencing their health seeking behaviours for their children.

Added value of this study

This study reports the findings from a large qualitative descriptive study that explored the perceptions and experiences of 145 caregivers accessing health services for their children. Caregivers represented Indigenous Māori (n = 83), Pacific (n = 19), Asian (n = 24), and/or European (n = 19) ethnicities. The study found many commonalities across caregivers from the four ethnic groups regarding

sources of trusted health information, preference for relational health encounters, feeling judged by healthcare professionals, frustrations with the slow and fragmented health system, and having to be assertive to access care for their children amidst numerous barriers. Unique to Māori caregivers were challenges that reflected ongoing colonial trauma and systemic racism within the health system.

Implications of all the available evidence

To support culturally-appropriate and equitable health services, policies are needed to alleviate the indirect costs of accessing child health services and address the various ways in which systemic racism acts as a barrier to care. Healthcare professionals must continue to develop trusting relationships to foster positive health encounters. System-level changes to address the complexity of navigating the health system and offer more choice and inclusivity are needed to enable timely and appropriate care for children.

Introduction

Every parent wants healthcare that is accessible, easy to navigate and culturally safe for their children—yet for many, this is not the reality. Access to primary health is a basic right, and is the gateway for expectant families, new-borns, and children to healthcare throughout the lifespan.¹ Primary care can include a broad range of health services including promotive, preventive, curative, and rehabilitative services, palliative care, health education, maternal and child health care, and immunisation.² Addressing the primary healthcare needs of children and their families requires a broad array of social determinants that empowers communities to optimise their wellbeing.³ This is foregrounded by evidence that countries with a robust national primary care system have improved access to care, deliver better and more equitable health outcomes, and are more efficient.^{4–7} However, access to primary care is not universally accessible and appropriate. Some populations, specifically Indigenous^{8,9} and ethnic minorities¹⁰ face substantial barriers to accessing (optimal) care, which can contribute to health disparities.

In Aotearoa New Zealand (NZ), a universal, tax-funded national health service was established in the late 1930s, including general practitioner and hospital services, prescription medicines, and no-fault accident coverage.¹¹ Equitable access to health services, particularly for children, underpins policies and programmes in NZ. For instance, doctor visits for children are free until their 14th birthday, all routine vaccines on the National Immunisation Schedule are free for children, and dental care is free until a child's 18th birthday.^{12–14} However, despite a long-term commitment to equity,

there is extensive inequity by ethnicity across a range of indicators.¹⁵ More specifically, Indigenous Māori and Pacific children face considerable barriers to accessing general practitioners (GPs) than European children.¹⁶ A quantitative analysis using the Growing Up in New Zealand (GUINZ) longitudinal study cohort (n = 5947) reported that facing a barrier to seeing a GP was more common in Māori compared to non-Māori (8.3% vs. 3.5%) children, with a similar pattern noted for Pacific compared to non-Pacific (7.0% vs. 4.1%) children.¹⁶ Māori and Pacific children consistently have the lowest immunisation rates across immunisation milestone ages.^{17–19} Currently, only 68.9% of Māori children and 81.2% of Pacific children are fully immunised at 24-months of age (January–March 2023) compared to 86.3% for NZ European children.¹⁸ Moreover, Māori and Pacific children were reported to have the lower likelihood of seeking dental care when compared to NZ European children.²⁰ In both the short and long term, underutilisation of healthcare services may contribute to poor health outcomes for children over their life-course.¹⁶

While these “zero-fees” policies attempt to reduce the direct costs associated with accessing childhood health services, other barriers remain largely unaddressed by these policies. More specifically, there remain barriers related to indirect costs, such as transportation and parents taking time off work, racism and bias within the health system, and other barriers, such as appointment availability.¹⁶ Some descriptive evidence is available on the household and individual characteristics associated with inequitable uptake of healthcare services.^{15,16,21} For instance, among Māori mothers, not

being able to get an appointment time was an important barrier to seeing a GP in the last 12 months at age 24-months, while not having transport was a barrier for Pacific families.¹⁶ A quantitative analyses using the GUINZ study cohort of the uptake of early childhood services showed time-variant differences in the association between ethnicity and child immunisation indicators.^{20,22} For example, socio-economic deprivation was a significant factor for families not having timely immunisations in the first year of the child's life, but not at the 15-months and 4-year old immunisation events.²⁰ This suggests that there are socio-economic drivers in the first year of life affect timely access to healthcare. Another significant finding was that when families experienced ethnic discrimination, this was associated with reduced satisfaction levels, and childhood immunisations.^{20,22} This is consistent with other substantive research that finds that racism and ethnic discrimination are determinants of inequitable immunisation coverage and healthcare access for children and their whānau (family).^{23–25}

Although empirical quantitative evidence reveals persistent ethnic disparities in accessing health services, there has been limited qualitative research among parents that delves into the complex factors that influence access to primary care health services for their children. Moreover, to inform improvements to health policies, there is a need to understand both the barriers and enablers with respect to accessing childhood health services for ethnically diverse families. Thus, the aim of the presented qualitative study is to explore the 'why' behind empirical evidence of inequitable access to childhood health services among ethnically diverse caregivers. While some research has been done within specific ethnic groups, this research extends our knowledge by exploring commonalities and differences across ethnic groups in order to inform recommendations to improve healthcare access.

Methods

Qualitative description methodology

This study is part of a larger multi-method research programme examining factors that influence access and experiences of early childhood healthcare services across ethnic groups in NZ. The complementary quantitative analyses that examined the relative contribution of a range of factors, including mobility, socio-economic status, mother and child characteristics, household characteristics and social aspects, on ethnic differences in the uptake of childhood healthcare services across the life-course has been previously published.²⁰ Drawing from an interpretivist paradigm, underpinned by ontological relativism and epistemological constructionism,²⁶ we conducted a qualitative description study. This methodology places emphasis on comprehensively describing healthcare phenomena and thus was

appropriate to explore caregivers' perceptions and experiences of accessing healthcare for their children.^{27,28} Within this methodology, each ethnic group utilised culturally informed methods to engage with caregivers in an appropriate manner. For instance, a kaupapa Māori researcher recruited and engaged with Māori participants utilising kaupapa Māori research principles²⁹ and a Pacific researcher utilising Talanoa principles.^{30,31}

Study site and participants

We aimed to understand the perceptions and experiences of mothers, fathers, and legal guardians (herein inclusively referred to as caregivers) of preschool aged children, who identified as being of Māori, Pacific, Asian and/or European ethnicity. Ethnicity can be defined as "the ethnic groups that people identify with or feel they belong to" which is a "measure of cultural affiliation ... not a measure of race, ancestry, nationality, or citizenship."³² The measure is self-selected and multiple ethnic groups can be selected. We aimed for broad representation that included caregivers born in NZ and those who migrated. As the 'Asian' ethnic group comprises various different groups, we focused on those who identified as Chinese or Indian as these are the largest two ethnic groups residing in Tāmaki Makaurau (Auckland) and NZ.^{33,34}

Given the heterogeneity within each ethnic group, our recruitment efforts aimed to obtain a diverse range of perspectives. Purposive sampling and snowball sampling techniques were adopted, which had the advantages of efficiently accessing a range of participants who met the eligibility criteria, including those that are 'hard-to-reach'.³⁵ Recruitment avenues were through our collective professional and community networks, and included posting flyers in venues and on social media platforms. Geographically, participants were recruited from across the Te Tai Tokerau (Northland) and Tāmaki Makaurau (Auckland) regions to capture rural and urban perspectives.

Data collection

Considering this research was exploratory and constructionist in nature, semi-structured interviews and focus groups were conducted. The question guide included open-ended questions and prompts to encourage kōrero (discussion) about caregivers' decision-making process to access health services for their children, their experiences, and suggestions for improvement. To ensure the questions were appropriate, the guide was vetted through the Advisory Committee of the wider project, which included members representing central agencies (Ministry of Health, Oranga Tamariki–Ministry for Children), District Health Boards (now under Te Whatu Ora Health New Zealand as part of the recent health reforms), and Primary Health Organisations (with a particular focus on

Māori and Pacific communities) involved in the delivery of early childhood health services (GP, immunisation, and dental). The guide was subsequently piloted with participants from each ethnic group to ensure the questions were culturally appropriate and modified to improve clarity and flow. Participants also completed a brief form to collect basic demographic information.

Data collection occurred at a convenient time and location for participants between January and August 2021. Participants could choose whether to partake in an interview or focus group depending on their preference and availability. Moreover, data collection was conducted either in-person or virtually (via Zoom) according to the participants' preference and COVID-19 restrictions. In-person data collection was held in convenient community venues (e.g., Church Hall, community buildings, whare (house), and library) and participants were offered kai (food) and koha (contribution) as a token of our appreciation of their time. Each interview lasted approximately an hour while focus groups lasted from one and half to three hours.

Ethical approval was granted by Auckland University of Technology's ethics committee (20/160). To support creating a safe and welcoming environment for participants to share their stories, interviewers were primarily selected to be linguistically- and culturally-matched in that they identified as being of the same broad ethnic category and were fluent in English in addition to other language(s) that participants would be familiar with, including Te Reo Māori, Samoan, Tongan, Hindi and Mandarin. More specifically, SB (Ngāpuhi, Ngāti Hau) and TC (Ngāpuhi) are Māori, TL is Samoan and Tongan, ET is Samoan and Cook Islands Māori, NC, AB and DS identify as Indian, and HQ as Han Chinese. On-site childcare was provided to allow caregivers to better participate in the kōrero (discussion).

Data analysis and trustworthiness

All sessions were audio recorded with participants' permission and transcribed verbatim. Data were analysed using the six phases of reflexive thematic analysis.^{36–39} Data were coded manually and using QSR NVivo® computer software (QSR International Pty Ltd., Doncaster, Victoria, Australia). This process was used to iteratively code and construct candidate themes and sub-themes within each ethnic group (dataset) from the respective cultural perspective that privileged its world-views and social meanings, and then across all ethnic groups (data corpus) as a research team. We present the themes across the data corpus, and separate pieces that present findings from each ethnic group have been published⁴⁰ or are underway.

An experiential orientation to data analysis was undertaken that prioritised participants' perspectives and understandings.³⁷ Each researcher began the familiarisation phase with their respective datasets. Transcripts were re-read multiple times and familiarisation notes

were made for each data item and for the dataset. Systematic inductive coding was conducted involving both semantic and latent aspects of the data, including any field notes taken during data collection. The process of generating initial themes involved a combination of clustering and promoting codes to construct thematic maps.⁴¹ Throughout the coding and initial theme generation process within each dataset, we met regularly as a research team to share insights and discuss nuances and common ideas. Collectively, we developed prototype themes and sub-themes across the data corpus, which were reviewed against coded data extracts and datasets. We then worked as a team to refine the themes and iteratively draft the findings.

The concept of trustworthiness was used an avenue to demonstrate the study's rigour.⁴² We have included a detailed description of the study context, including justification for philosophical, methodological, and analytical decisions made, to assist with transferability, dependability, and confirmability.⁴² As reflexivity is paramount in qualitative research, we regularly engaged in self-reflexivity activities, such as journaling about how our background and values influenced the decisions we made. In addition, our team members represented extensive qualitative experience and cultural diversity; meeting regularly as a team was used as opportunities to engage in conversations to enhance our reflections about our positionality.⁴³

Role of the funding source

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Results

In total, 145 caregivers representing Māori (n = 83), Pacific (n = 19), Asian (n = 24) and/or European (n = 19) ethnicities participated ([Supplementary Table S1](#)). Māori participants were oversampled as part of an extension project to understand their whakaaro (thoughts and opinions) and lived experiences regarding childhood immunisations.⁴⁰ Of the included caregivers, half were between 30 and 39 years old, and almost all were female. About one third (35%) were born overseas, and had lived in NZ for 12 years on average. Five themes were constructed based on caregivers' understandings and perspectives of GP, childhood vaccination, and oral health access; similarities and differences across ethnicity within these themes are discussed.

Hierarchies of knowledge and trust

Caregivers discussed multiple sources of health information that they accessed for their children and trusted to varying degrees. While many caregivers, particularly

those identifying as Indian, Chinese, and European, noted that GPs were a trusted source of information and advice, caregivers knew their children the best. Parents wanted healthcare professionals (HCPs) to trust and respect their instincts and the vital information they held about their child's concerns; however, they were often made to feel that medical knowledge was superior to their experiential knowledge as a parent.

"You're trying to talk to them [health care professional] so that they can understand what's going on, but it's like 'yeah, yeah, yeah' ... you don't even listen ... 'we are the nurse, we know what we're doing. You don't know anything' because that's how I feel when they do that."

(Pacific caregiver)

When seeking advice about their children, there were hierarchies about who they first consulted. Caregivers often talked to their networks of family and friends who were parents in the first instance, demonstrating the influence of the informal 'parent network'. The lived experiences of family and other parents were seen as trusted sources of information from which to guide their health seeking decisions and behaviour. Some caregivers also noted how they trusted and respected HCPs who were also parents themselves as their advice was very pragmatic.

"They [parent network] provide you more information sometimes than the midwife. Like experienced moms, moms who already have kids who have been through that stage."

(Indian caregiver)

"I'll ask my family first then, if they tell me to take her to the doctor then I take her ..."

(Pacific caregiver)

"The medical system are a last resort."

(Māori caregiver)

Caregivers from Asian, Pacific, and Māori backgrounds discussed how they sought treatment and advice from traditional healers and medicine unless their child was in a critical condition. This reflected their cultural health perceptions and practices that influenced their utilisation of primary health for their children in NZ, with health services seen as more of a last resort.

"The GP [in New Zealand] likes to give you Panadol, no matter which illness ... it is a pain killer. I don't think it's good for kids to have them. Moreover, there are very limited medicine options here, I prefer the traditional Chinese medicine"

(Chinese caregiver)

"I will ... rub my child with the traditional Samoan oil if it makes them better first before I consider taking them to the GP."

(Pacific caregiver)

"In my generation we were always judged... in that moment of crisis and need, you shut your mouth."

(Māori caregiver)

Several Māori caregivers described a strong mistrust of HCPs, with inter-generational experiences of racism and discrimination in healthcare influencing how they engaged with HCPs and what information they trusted. Traditional knowledge and practices (Mātauranga Māori and rongoā Māori) provided comfort and reassurance enabling them to be active participants in their children's care. However, Māori caregivers were often reluctant to use these, unless they were openly encouraged by HCPs. Previous experiences where they had been criticised or made to feel ashamed for including traditional Māori practices alongside Western medicine were shared.

"They [Māmā] have permission to be open about it. Don't tell anyone that we're doing karakia. My Nan lost her job for doing rongoā."

(Māori caregiver)

Some Māori caregivers have learned to resist the criticisms and racism experienced by HCPs by exerting their rangatiratanga or self-determination and right to decide what treatment would be most appropriate for their child. This may be perceived by HCPs as being vaccine hesitant, resistant, or aggressive, but on the contrary, these Māori caregivers saw their advocacy, protectiveness, and questioning as part of their role as kaitiaki (protectors) for their children.

"I wouldn't let them operate until he [healthcare professional] signed, he would operate as if he was operating on his own child. I brought the whole operating team into her room, and we did karakia."

(Māori caregiver)

Relational versus transactional health encounters

Caregivers' discussions about accessing health care for their children reflected the transactional nature of health appointments. In some cases, parents felt that they were being rushed during appointments without an opportunity to have their questions answered and simply being given pamphlets to read. Parents often left their doctor's office feeling hurried, unwelcomed, dismissed, and unheard with a lack of empathy for their situation (i.e., being anxious and worried about their sick child). These stories highlighted how parents saw health encounters as an opportunity for authentic whaka-whanaungatanga (building relationships) with HCPs, but were disappointed when this did not happen in reality. Parents also spoke of instances of racism during health encounters in which they were treated differently based on their ethnicity.

"As a Pacific Islander, I sometimes feel that I am not treated the same as the other patients. Maybe it is just me ..."

(Pacific caregiver)

"... the doctor is very inpatient when he saw me as Chinese ..."

(Chinese caregiver)

While speaking the same language and being of the same cultural background was seen as an avenue to make parents feel more at ease, this was not necessarily a requirement to facilitate positive health encounters. Instead, participants who expressed satisfaction with the health care for their children positively commented that it was the HCP's overall demeanour, focusing on how their kind and inviting nature and their competence and ability to clearly communicate made them feel safe and comfortable. Parents went on to comment about the importance of the whole health care setting (e.g., GP office) being welcoming, starting with the receptionist. Moreover, a few participants highlighted how the holistic approach of the practice they visited created a safe and comfortable environment as the staff were very caring and supported the family with accessing other services.

"I just want the receptionist to be more welcoming ... because we go there all worried and very anxious because my child is sick ..."

(Pacific caregiver)

"The certain nurses that I have, they talk to me, not at me or down to me. They're touching our kids, but they need to be precious about this, so I've had positive experiences."

(Māori caregiver)

"My healthcare centre at (Māori health provider) is very good. They're very helpful with what they have helped me with, like housing and other things. I am satisfied with their service."

(Pacific caregiver)

"I know the ladies [nurses]. Makes it easier for me to give my babies over because I know them now and trust them to care."

(Māori caregiver)

Building connections and having continuity of care with midwives was vital as they provided support during a mother's pregnancy journey and during the first few weeks of motherhood. This support was particularly important for first time mothers who appreciated guidance during each stage of pregnancy, childbirth, and postpartum.

"I would have lost my youngest son, if it wasn't for her [midwife], she was there for me 24/7"

(Pacific caregiver)

When the six weeks of postpartum midwifery support came to an end, a European mother summarised it as "Oh no, I'm alone now ...". The bridging of care between midwifery, primary care and well-child providers was often absent. The importance of having trusting relationships instead of transactional encounters was particularly important to support mothers through their postpartum journey, especially with regards to their mental health. It was evident that mothers felt neglected by the health system once they delivered as the focus shifted to the health of their newborn. Mothers shared stories about how there was no ongoing support or resources for their mental health and wellbeing postpartum; they wanted to receive this support, but instead their needs were overlooked by midwives and Plunket nurses.

"It's like we just have to go through this checklist ... 'sorry I have to ask these questions'. She [nurse] just wants me to say 'no' to everything. So, I felt kind of uncomfortable saying 'well yeah, I am kind of experiencing that [mental health issue]' and her being like 'oh you're probably not'."

(European caregiver)

"I think I just buried it [postpartum depression] eventually, there was no coping strategy as such. Me and my husband were just dragging it along."

(Indian caregiver).

Bad mother vibe

Mothers shared their various struggles with motherhood, displaying feelings of being overwhelmed and under immense pressure; this was especially evident among first-time mothers. Mothers talked about the various commitments that they juggled daily and how this impacted their ability to seek timely medical care for their children. They relayed feelings of guilt and shame when they could not always prioritise their child's health.

"There's always a delay in taking the child to see the doctors or seek help for when she's sick. Because I prioritise the work that I need to do first, before my child ... I should prioritise my babies before anything else ... it's very hard when you're a full-time worker, and also having a baby ..."

(Pacific caregiver)

Although some felt that they were 'failing as a mother', they felt that they had to conceal these feelings to appear as if they 'have it all together' and not disappoint their HCPs. Mothers spoke about the judgement they often faced from HCPs and they feared being labelled as a 'bad mother'. Mothers felt pressure to care for their children in the exact manner that was recommended by their HCPs rather than trusting their instincts and deciding what was best for their child and whānau. One European mother

summarised the feeling as “Do it the Plunket way or no way.”

“My second [child], because she was premature and the lactation lady was quite pushy towards baby must breast-feed. And that was really hard because the baby wouldn’t latch, and it was like ... if she had made it feel okay for me to decide or not to, then that would have made me feel a little bit better in my decision to eventually change to formula. So that was a bit of a downfall with that. And then she called me to follow-up a few weeks after she helped me and then I told her [that I changed to formula and] I felt like I was disappointing her.”

(European caregiver)

“I haven’t even taken them to the doctors, because I have that fear of what to expect about dealing with my kids’ immunisation ... it makes me feel unease and also uncomfortable, and turns off my kids health.”

(Pacific caregiver)

“Plunket ... they’re not great. I have had bad experiences. When I had my first baby they were supposed to come and see me, but they said come in and see them. Then they said I look highly likely to harm my baby because I looked tired. I didn’t see Plunket for about a year.”

(Māori caregiver)

Some mothers also shared stories of how HCPs made assumptions based on their ethnicity that reflected racist stereotypes and made them feel judged.

“I encountered a doctor who has strong bias for Chinese parents. Before I say anything, he started his accusation for Chinese by complaining ‘you Chinese like to feed your kids medicine’.”

(Chinese caregiver)

Māori caregivers spoke about the history of colonisation and generational trauma of long-standing policies that policed Māori whānau and their ability to care for their pēpi (infant) and tamariki (children). They talked about the mistrust of health providers, particularly when feeling pressure to follow their advice. They also described how vulnerable they felt when non-Māori HCPs came into their homes “because you get judged, they might take [the] baby.”

“It’s part of being colonised – you do it [get immunised] or else.”

(Māori caregiver)

“It makes a difference to have Māori nurses, they understand us. They do not talk down to you or make you feel uncomfortable or judge you. They’re sweet to sit on the floor. It is like having whānau in your home.”

(Māori caregiver)

The ‘slow burn’ of waiting

Parents of all ethnic groups talked about how the health system operated extremely slow with long wait times to access all health services for their children, including primary care, specialist appointments and emergency services. Paradoxically, caregivers commented that after waiting a long time for a health appointment, the consultation time was very short.

“... sometimes I feel like going to the emergency is a waste of time, especially around night-time, you’ve spent whole night over there.”

(Indian caregiver)

The long wait times had implications on caregivers’ work and family commitments and importantly, was emotionally distressing as they wanted their children to be treated as quickly as possible to alleviate their discomfort. Long wait times also impacted parents’ health-seeking behaviours, as some went to the emergency department or decided not to access care at all. Parents also expressed difficulties with consulting a specialist as it was a very time consuming and complicated process to initially be referred by a GP, which only prolonged the wait time to then see a specialist. Caregivers were grateful for the free healthcare services provided to their children; however, some caregivers were so worried that they expressed a willingness to pay for faster access to health services for their children, rather than waiting. This raised concerning equity implications for caregivers who do not have the financial means to pay for faster care.

“It’s the time frame of waiting that really, really discouraged them often they’d come home and they’d go ‘oh, we have to wait for two hours.’ They just decided not to take the kids there for check-up.”

(Pacific caregiver)

“I think the hospitals can consider to charge some fees. We are willing to pay as long as we can see the doctors quickly when the kids are sick, instead of waiting for a few days.”

(Chinese caregiver)

Due to the slow healthcare system and long wait times, the mothers were acutely aware of how overwhelmed HCPs were, especially their midwives and Plunket nurses and Māori HCPs. As a result, in some instances, they purposely did not disclose information for not wanting to burden their HCPs.

“My Plunket nurse was my go to. So, I would text her or call her, but again you know the amount of stress those people go through, so you don’t always feel comfortable going, you know she’s always available for me, so you would only text her or call her if you really, really need to.”

(Indian caregiver)

Some caregivers also highlighted how limited their options were for health care. For instance, when choosing their midwife, their choices were limited by the time of year (summer being the hardest time) and by geographic location (less midwives available in rural regions). Therefore, pregnant people surmised that they should be grateful for at least having some access to care, as HCPs would perceive them as being ungrateful or demanding if they asked for more appropriate care.

Navigating complexity

Caregivers found the health system difficult to navigate when accessing care for their children. Receptionists were often seen as administrative ‘gatekeepers’ for booking GP appointments thereby presenting a barrier to accessing care. Filling out extensive paperwork to access care depending on migrants’ visa status presented another barrier; this was especially stressful for parents when seeking emergency care for their children. Migrant parents revealed that as non-residents, their children were not entitled to free medical services, thereby presenting additional financial barriers to accessing care.

“She [daughter] was not covered on Plunket for one year because we were on work visas, and they don’t cover you. You’re not covered by health, basically. None of us were covered for that one year. But once we got our PR [permanent residency] in the second year, we were all covered”

(Indian caregiver)

Caregivers of all ethnic groups, particularly those with migrant backgrounds, expressed a lack of awareness and understanding of the healthcare services available during pregnancy. Many pregnant people come from countries where midwives are not as common, so it was very overwhelming to proactively navigate the process of finding a midwife.

“I did not know how to do it ... the concept of a midwife was brand new to me. I did not know how to find one, so I just searched for midwives online, and then called a few or emailed a few, and found one that had availability.”

(European caregiver)

Caregivers experienced numerous barriers to accessing care, including transportation costs (e.g., parking and petrol) and language barriers. In particular, Asian migrant caregivers talked about their concerns as they were not able to understand medical terminology. To overcome the language barrier and enable them to discuss their concerns more freely, Asian migrant caregivers preferred to approach a GP who spoke the same language and they also suggested that interpreting services would be helpful.

“Due to the language barrier, I have a sense of insecurity ... I would be concerned that what if I cannot understand the doctor.”

(Chinese caregiver)

“... the vaccination list was quite confusing because she had a vaccination card which was in Marathi. And here we got new card which was in English, and we were just quite confused about matching their names. So it was quite difficult for us.”

(Indian caregiver)

Caregivers talked about how assertive they had to be to ensure their child received care amidst the barriers they faced to accessing care and the complex system they had to navigate. Mothers shared stories of how asking clarifying questions to HCPs would result in them being perceived as obstructive and difficult. But, mothers saw themselves as kaitiaki (protectors) and fierce advocates for their children, they talked about how they had to be proactive, vocal, and persistent to receive proper care for their children.

“The people are important. I went through three previous people before I had someone I could relate to. They are coming into my space.”

(Māori caregiver)

For instance, many caregivers were dissatisfied with the dental service as most had to proactively call to book appointments. Unfortunately, due to how hard it was to get a dental appointment and the limited advice provided during the appointment, many caregivers saw little value in dental services even though it was free.

“Oh, gosh. Dental clinic, right. I have to follow them up for... It was like ‘Can you see my son? Can you see my son? Is it time to see my son?’ Literally, I went in there with my son who was... Oh, god, what was it? He would have been one or over one. They didn’t even look in his mouth. They just gave me a couple pamphlets, and said a couple of things, and then sent me on my way basically.”

(European caregiver)

In contrast, caregivers talked about how they received vaccination reminders which prompted them to book immunisation appointments, and they were generally satisfied with immunisation services. However, it was still important that caregivers were not pressured with their decision to vaccinate their children.

“If you get your kids immunised, they make you feel like very special. They say, well done. Like you get a certificate. The opposite is not getting a certificate, so where’s the balance? They try to force you to do it.”

(Māori caregiver)

Discussion

This study sought to explore the perceptions and experiences of early childhood health services among an ethnically diverse group of caregivers. While there were many shared concerns amongst caregivers of various ethnicities about how services did not always meet their needs, some factors disproportionately affected non-European caregivers, thereby perpetuating inequities. Caregivers reported some positive experiences when accessing healthcare for their children and appreciated that there were no direct costs. Financial cost plays an important role in accessing healthcare services thereby supporting policies for low or zero cost primary care services.⁴⁴ However, our study demonstrated that in practice these “zero-fees” policies were not enough to support child health and development across the lifespan. Caregivers in our study, particularly those of non-European ethnicities, mentioned multiple barriers to timely access of healthcare services, including transportation costs, paying out-of-pocket if their child was not entitled to publicly funded services (depending on their visa), geographical proximity to and availability of services, and opportunity costs to access care (e.g., taking time off work). Our study also found the notable influence of ethnic discrimination, mistrust, and judgement, particularly for non-European caregivers. Racism and ethnic bias towards non-European ethnic caregivers continue to privilege Western healthcare practices and ideals in early childhood healthcare.^{25,45–47} Similarly, previous research notes how marginalised groups experience multiple financial, cultural, and geographical barriers at different points of the pathway of accessing care.^{16,48,49} Moreover, ethnic differences influence the extent to which barriers related to stigma, logistics, and socio-economic status affect parents accessing health and mental health services for their children.⁵⁰

Caregivers across all ethnic groups highlighted how disengaging practices of HCPs presented a substantial barrier to accessing care for their children. Health interactions were often described as transactional and lacked regard for the wellbeing of the whānau. Similar to other studies, caregivers in our study looked to HCPs for advice and reassurance about the health of their young children.^{20,51,52} However, caregivers across all ethnic groups often felt that their expertise and experience as parents were undermined by HCPs and that they were being judged, thereby delegitimising their parenting choices. Unfortunately, caregivers felt pressured to conform to HCPs’ recommended practices and felt they were seen as obstructive when they asked clarifying questions about their child’s health.⁴⁰ Caregivers shared stories about how they would subsequently delay or avoid seeking care for their children. Literature reports that promoting a partnership approach that combines the specialised knowledge of HCPs and the personal/experiential knowledge of

parents is desirable.⁵² Parents should not be viewed as passive recipients of healthcare services, but instead should be supported to increase their autonomy and decision-making to ensure positive outcomes for their child.⁵³

Caregivers stressed the importance of HCPs being kind and competent to foster meaningful relationships. Previous research also found that HCPs’ medical knowledge and skills was central to support positive cross-cultural health encounters.⁵⁴ Trusting provider–patient relationships were particularly vital for mothers to share their mental health struggles and get required support as post-partum women who are most likely in need of mental health care are also those least likely to honestly disclose their symptoms.⁵⁵ Some non-European caregivers described instances of racism and stereotyping by HCPs when accessing care for their children, which can negatively influence their future health-seeking behaviours. Similarly, previous NZ research noted that caregiver experiences of racism were associated with poorer child healthcare utilisation.²³ While some caregivers preferred HCPs who were culturally ‘matched’, others relayed that HCPs did not necessarily have to be of the same ethnic or cultural background to provide culturally-appropriate care. Literature has also noted that parents value HCPs ability to respect caregiver’s different norms and values rather than expecting HCPs to be familiar with all cultures, traditions, and beliefs.⁵⁴

Unique to Indigenous Māori caregivers, were additional fears that children would be removed by child protective services if they did not conform to Western ideals of parenting. This resulted in either avoidance of care, resistance, or keeping quiet. The colonial traumas that impact whānau Māori paint a disturbing picture of child health services in NZ with strong currents of racism in child health. Inequities in health services and outcomes among tamariki Māori has been widely reported in literature and attributed to the historical and ongoing impacts of colonisation, socioeconomic disparities, and racist policies.^{56–60} In our study, Māori caregivers reported how they were discouraged or made to feel embarrassed for using rongoā Maori in mainstream health care settings. To address this, HCPs need to be aware of how the many ways racism operates within the health system and reflect upon the effect that their unconscious bias can have on the care they provide.¹⁶ Indigenous organisations have increasingly sought more self-determination over primary health care services since the 1960s as mainstream services often excluded Indigenous communities and did not adequately meet their needs leading to poor health outcomes.^{61–63} For example, in NZ, health reforms in the early 1990s led to the development of nationally and locally Māori-led services to improve the access and quality of services for Māori whānau, but these have been progressively under-funded and undermined.^{63,64} A

scoping review identified eight characteristics underpinning Indigenous primary health care service delivery models, including accessible health services, community participation, continuous quality improvement, culturally appropriate and skilled workforce, flexible approach to care, holistic health care, and self-determination and empowerment.⁶⁵ Many of these characteristics were echoed by caregivers in this study suggesting that mainstream services would benefit from incorporating the values, principles, and components of Indigenous primary health care services.

Caregivers talked about the complex, bureaucratic, and disconnected nature of childhood healthcare service delivery. It was evident from all caregivers that the health system could be difficult to navigate, non-intuitive and did not always meet their needs. Caregivers reflected upon how proactive and assertive they had to be to access care for their children. Health experiences and system navigation was particularly challenging for migrants as their expectations of services in NZ were influenced by how the health services were delivered in their home country.⁶⁶ For instance, many migrant mothers were not familiar with the role of midwives and found the process of finding one to be overwhelming. Specifically among migrant caregivers, their health practices, access barriers, and unsatisfactory experiences echo previous research.⁶⁶ Improving knowledge and navigation support by streamlining enrolment, referral, and appointment systems, and providing migrants with an orientation of the health system could help mitigate existing complexity and fragmentation.

Implications for policy and practice

Understanding the reasons for ethnic disparities in health care is vital to inform effective policies and programmes to improve health equity. Despite some differences noted, caregivers overwhelmingly shared commonalities in their experiences that underpin suggested improvements. First, in tandem with “zero-fee” policies and other strategies to reduce direct financial barriers, additional strategies are needed to alleviate the indirect costs of accessing early childhood health services, particularly among marginalised communities.¹⁶ Some strategies to minimise the indirect costs could include subsidising transportation costs (e.g., petrol vouchers), offering outreach services (where HCPs visit patients’ homes), and adjusting operation hours to accommodate the schedules of working parents (e.g., longer weekday hours, opening on weekends). Second, HCPs need to continue developing trusting relationships with parents and delivering culturally safe care to foster positive and transparent health encounters. Some interventions to improve cultural safety of healthcare systems include hiring culturally diverse HCPs and cultural competency training for HCPs.^{67,68} Moreover, as there are multiple pathways that racism can act as a

barrier to accessing healthcare and the quality of services, policies are needed to address racism to reduce health inequities.^{23,69} Third, post-partum care needs to better address the support that new mothers require and take a more whānau-centred approach. Mothers reported that postnatal checks primarily focused on their infant and only superficially addressed their (mental) health and wellbeing needs. Fourth, system-level changes are required so that health services are less complex, offer more choices, and are more inclusive. These systematic changes will support parents’ ability to navigate the health system and access timely and appropriate care for their children. The system should be less fragmented and bridge care between various antenatal and postnatal services so whānau do not “fall through the cracks”. Also, the system should automatically enrol parents and their newborns at general practices to avoid instances of “casual patients”¹⁹ and offer welcoming orientation sessions. With the current health system reforms in NZ, there is also an opportunity to deliver child health services in localities, in a manner where parents have more autonomy to self-determine decisions about their child’s care that align with their values and cultural practices.

Strengths and limitations

The study has many strengths, as it included ethnically diverse caregivers from different socio-economic backgrounds, with an overrepresentation of Māori caregivers. Furthermore, in-depth information was ascertained directly from caregivers engaging with healthcare services, and delved deeper into the experiences of seeking healthcare that have been previously highlighted in quantitative studies. While this study provided useful insights regarding the barriers and enablers to accessing healthcare for children in NZ, being a qualitative study, the results are not generalisable on a statistical basis and cannot address all the health concerns that caregivers may have. However, we have provided rich, detailed descriptions of our methodology, methods, study context, and findings to enable readers to assess if some findings may be transferable (case-to-case generalisation) to other health system contexts.⁷⁰ The use of snowball sampling may have led to oversampling those with a similar viewpoint. Indeed, despite our efforts to recruit ‘hard-to-reach’ caregivers, almost all the caregivers in this study reported that their children were enrolled with a GP office and the majority of children were fully vaccinated thereby implying a level of engagement with the health system. Future studies would benefit from gaining insights from caregivers whose children are not enrolled and/or are engaging with the healthcare system for their children.

Conclusion

Ethnically diverse caregivers reported some common barriers to accessing health services for their children,

which negatively affected their engagement even when direct financial costs have been minimised. Healthcare professionals need to develop trusting, culturally safe relationships and build rapport using a non-judgmental approach to foster open discussions and positive health encounters. Caregivers expressed the need for healthcare professionals to change the narrative from caregivers being passive receivers, to active participants to self-determine their child's care.

Contributors

NC, ET, and TC conceptualised the study and applied for funding. AB, SB, TL, HQ, and DS conducted data collection and analysis with input from NC, ET, and TC. NC, AB and TC co-wrote the manuscript draft with input from all authors. All authors read and approved the final manuscript.

Data sharing statement

The datasets generated and analysed during the current study are not publicly available due to privacy and ethical reasons. The collected data is of a sensitive and personal nature, and was collected from participants on the basis that strict confidentiality would be maintained. Data can be available from the corresponding author on reasonable request and will require completion of relevant confidentiality agreements.

Ethics approval and consent to participate

Ethical approval was obtained from the Auckland University of Technology Ethics Committee (19/4). All methods were carried out in accordance with relevant guidelines and regulations. All participants provided informed written consent before participation in the study.

Consent for publication

Not applicable.

Declaration of interests

TC declares philanthropic funding for her Professorial Chair position from Cure Kids New Zealand. All other authors have no conflicts of interest to declare.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.lanwpc.2023.100882>.

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