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Balancing personal and social identities for the care of priority populations in a paediatric hospital setting: a qualitative study

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Abstract

Background The Providing Enhanced Access to Child Health Services (PEACH) initiative at the Sydney Children's Hospitals Network (SCHN) aims to reduce inequity in healthcare access and outcomes for priority population children and young people (including Aboriginal and/or Torres Strait Islander, culturally and linguistically diverse, from refugee or asylum seeker backgrounds, living in out-of-home care or recipients of the National Disability Insurance Scheme). Central to PEACH is active children and caregivers engagement through co-design, recognising the importance of understanding their experiences to facilitate enhanced healthcare provision. This qualitative study explored the experiences of priority population children and caregivers at SCHN before the implementation of PEACH initiatives, with the aim of identifying strengths, limitations, and recommendations for enhancing healthcare services tailored to priority population needs.

Methods Guided by an experience-based co-design methodology, 28 qualitative semi-structured interviews were carried out with a total of 38 participants from priority population group(s) who had accessed care at SCHN. The data were analysed via inductive thematic analysis.

Results The findings are presented through the lens of the concept of identity, delineated into personal and social identity. Personal identity is related to person before problem and demography, while social identity is linked to cultural responsiveness. Participants emphasised both the significance of social identities in health service design, and the importance of an individualised approach that recognises and respects their unique personal identities within the broader social context.

Conclusions This research advocates for a person-centred approach to healthcare delivery that recognises and responds to the dynamic interconnected relationship between personal and social identities.

Keywords Priority populations, Equity, Identity, Paediatrics, Person-centred care

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Background

Within Australia, children and young people (CYP) from priority populations, including Aboriginal and/or Torres Strait Islander (hereafter referred to as Indigenous), culturally and linguistically diverse (CALD), refugee or asylum seeker backgrounds, living in out-of-home care (OOHC), or with disability, face inequities in healthcare access and health outcomes [1–10]. Compared to those in non-priority populations, they have an increased risk of potentially preventable hospitalisations, chronic conditions, ward admission, readmission, and extended hospital and emergency department (ED) length of stay. Belonging to more than one priority population increases the risk of adverse health outcomes [11].

Research consistently demonstrates that the social determinants of health have a profound influence on health inequities—unfair and avoidable differences in health status—especially among priority populations such as low-income groups, racial and ethnic minorities, Indigenous peoples, and other marginalized communities [12–14]. It is important to note that underlying causes of inequalities in the population may manifest in particular ways in the hospital setting. However, health services have struggled to adequately integrate the social determinants of health into their care practices [15].

United Nations and local Medical College Position statements and recommendations emphasise the importance of implementing initiatives focused on reducing inequities in child health [16–18]; however, systematic approaches to addressing disparities in healthcare access and outcomes remain limited, particularly for priority populations [19]. Within Australian child and youth health policies, there is a strong focus on strategies to address health inequities for children in the general population, such as inequities associated with chronic conditions. However, there are fewer recommendations tailored specifically to meet the needs of children from priority population groups [18]. There remains an ongoing need to redirect focus from describing inequity to actively taking steps to address and combat it [19, 20].

The Sydney Children's Hospitals Network (SCHN), Australia's largest paediatric health care service, has developed a strategic focus around providing equitable healthcare to all CYP aged 0–18, particularly those who are at increased risk of adverse health outcomes [21]. To understand and improve health outcomes for CYP from priority populations, the Providing Enhanced Access to Child Health Services (PEACH) initiative, an organisation-wide quality improvement project, has been established within SCHN. The PEACH initiative aims to identify patients from priority populations and enable processes focused on ensuring earlier, supported, and integrated access to services [22].

A key component of PEACH is engagement of children and young people through co-design. In the field of health, consumers are people who use, have used, or are potential users of health services [23]. Understanding consumers' experiences, particularly through qualitative methods, is vital for improving the quality and effectiveness of healthcare delivery [24, 25]. Actively engaging consumers enables a deeper understanding of the multifaceted challenges and opportunities within healthcare systems. This approach fosters empowerment and ownership among consumers and amplifies their voices in shaping policies and practices, ensuring that interventions and improvements are grounded in the real-world needs and preferences of those directly impacted [23, 26–28]. Ultimately, a collaborative approach enhances the relevance and applicability of findings. This contributes to the development of person-centred, culturally responsive, and inclusive healthcare environments, and leads to improved patient satisfaction, adherence to treatment plans, and overall health outcomes [29, 30].

This qualitative study aimed to explore the experiences of priority population children and their caregivers at SCHN prior to the implementation of PEACH initiatives. By gathering insights from both caregivers, children, and young people, this study sought to understand the strengths and limitations of the current healthcare service provided by SCHN and to identify recommendations for improvement, as perceived by those from priority population backgrounds.

Methods

Study design

This qualitative study was conducted as part of the broader mixed-methods PEACH study [31]. Guided by experience-based co-design methodology, qualitative interviews served as a means of gathering data as a part of the 'gather' and 'understand' stages of a more extensive co-design research process [32]. This will inform the subsequent PEACH co-design process with children, caregivers and SCHN staff.

Setting

The study setting comprised of the two tertiary paediatric hospitals incorporated within SCHN: The Children's Hospital at Westmead and the Sydney Children's Hospital, Randwick. The SCHN cares for up to 170,000 children each year across both hospital sites [33]. Of the total number of inpatient admissions (253,934) and ED attendances (446,924) for CYP between January 2015 and December 2019, priority populations made up approximately one-third of both admissions (34.6%) and attendances (33.3%) [34].

Advisory groups were formed during the inception of PEACH to guide and direct the initiative. Members of

the advisory groups include SCHN staff who work with, are a part of, or have a particular interest in the priority population groups. Throughout the life cycle of the initiative, children and caregivers became active participants within the advisory groups. More detail can be found within our protocol [22].

Participants and recruitment

Purposive and convenience sampling methods were used to recruit CYP and parents or caregivers (hereafter referred to as caregivers) from one or more priority population groups who had accessed care at SCHN. Definitions of the priority population groups include the following: (i) Indigenous if they self-identified as either Aboriginal and/or Torres Strait Islander origin; (ii) CALD if their preferred language was ‘non-English’, or country of birth was a non-English speaking country; (iii) living in OOHC, foster care, kinship care, or ‘looked after’ children; (iv) CYP from refugee or asylum seeker backgrounds; and (v) living with disability if the individual has been approved for Australia’s National Disability Insurance Scheme (NDIS) [31]. Recruitment approaches included contacting key service leaders and clinicians working with priority populations and placing flyers and brochures at hospital sites for children and caregivers to connect with the research team. A QR code directed families to a Microsoft Forms page, where they could express interest and provide their contact details and which priority population group they identified with. Healthcare clinicians were requested by the research team to nominate eligible children and caregivers, and the research team held stalls in the hospital foyer and café areas, approaching and discussing the project with families, extending invitations to participate in the study. A total of 27 1:1 and dyadic interviews were carried out with 37 participants from priority population groups (Table 1). Some participants identified with more than one priority population group. At the request of some participants, dyadic interviews were carried out with two

participants (such as a CYP and caregiver, two CYP, or two caregivers).

Researcher positionality

This study was conducted by a team with diverse clinical and research backgrounds shaping our interpretation of the data. The interview team was comprised of priority population care navigators (SW, AK, SM, AT) with varying levels of clinical experience in hospital and community health settings. One member of the team (SW) identifies as an Aboriginal woman and works in an identified role, bringing an important cultural lens and lived experience that informed the study’s design, conduct, and interpretation. We acknowledge that our social positions—particularly our professional roles within the healthcare system—carry inherent power that may have influenced how participants engaged with us. This was especially salient in working with children and families from priority populations, whose past experiences with systems of care may include marginalisation or mistrust. While our varied perspectives brought depth and reflexivity to the research, we were continually mindful of the potential for unconscious bias and the ways our presence might have shaped the data collection and analysis. We approached interviews with a shared commitment to cultural safety, humility, and equity, striving to create a space where children and caregivers felt heard and valued. Filming of the interviews was incorporated to preserve the richness of participant narratives, including non-verbal cues and emotional expression. While this method added depth to the data, we acknowledge it may have also shaped participant responses. Some individuals may have felt more self-conscious or hesitant to speak openly due to the presence of a camera. We sought to mitigate this by clearly explaining the purpose of filming, obtaining informed consent, and allowing participants to opt out of being filmed at any stage.

Initial coding of the data was conducted collaboratively by the interviewers, ensuring a continuity of

Table 1 Number of interviews carried out with priority population participant combinations

Priority population group(s)	Participant combination present in interview					Total no. of interviews (participants)
	Individual CYP	Individual caregiver	CYP and caregiver	Two CYP	Two caregivers	
Indigenous	1	2			1	4(5)
Refugee/ asylum seeker		3*	3			6(9)
NDIS (disability)	3		3	1		7(11)
CALD		1			2	3(5)
Indigenous and NDIS	1	3				4(4)
OOHC and NDIS	1	1				2(2)
OOHC and Indigenous		1				1(1)
Total number of interviews	6	11	6	1	3	27(37)

Note * Interpreters were used during two ‘individual caregiver’ interviews from the ‘refugee/asylum seeker’ population group

interpretation grounded in firsthand engagement with participants. Further analysis and final thematic development were led by two additional researchers (AN, MH) with both clinical and qualitative research experience. Their involvement brought a fresh perspective while maintaining alignment with the study's values of inclusivity and respect. Throughout the research process, we remained reflexive about our own positions and the potential influence of our identities, experiences, and professional roles. We recognise that our interpretations are shaped by these factors, and we are committed to transparency and integrity in how we have represented participants' voices.

Data collection

Children and caregivers interested in participating in the study were provided a participant information sheet and interview details arranged by phone or email correspondence. Data collection was carried out through virtual Microsoft Teams ($n=11$) and in-person interviews ($n=16$) between July 2022 and January 2023. Participants signed a written consent form outlining their consent to audio (including transcription) or visual recording. As required, qualified healthcare interpreters were used to aid in ensuring that participants understood what they were signing. Using a semi-structured interview guide co-developed by the research team and Advisory Groups, we explored participants' experiences accessing and receiving care at SCHN including strengths and barriers, and suggestions for improvements (see Additional file 1). Ten interviews were audio recorded only, and the remainder of the interviews ($n=16$) were video recorded. Eight of these were carried out with the presence of videographer for the purpose of developing short vignettes to use in future co-design workshops and staff education. Interviews lasted between 15 min and 1.5 h. Interpreters were utilised as required ($n=2$). Following recommendations for qualitative research and purposive sampling, the sample size was determined subjectively, taking into account the team's available time and resources, while aiming to provide a sufficient representation of experiences to draw conclusions for the population group [35]. Otter.ai, a third-party speech-to-text transcription application, was used to transcribe the audio/video recordings. All interviews were transcribed. To ensure that the interviews were transcribed verbatim, each transcript was reviewed and edited against the audio by members of the research team (SW, AK, SM, KY, AT).

Data analysis

Following the six-step framework outlined by Braun and Clarke (2022), an inductive thematic analysis was carried out to explore and identify recurring patterns and meanings within the dataset. This involved becoming familiar

with the dataset, coding, generating initial themes, developing and reviewing themes, refining, defining and naming themes, and writing [36]. The data management software NVivo (Version 14) was used to facilitate the coding and organisation of identified themes. Initial open coding was carried out by a small group of the research team, most of whom had facilitated the interviews (SW, AK, SM, KS, AT). For further validation and checking of the initial codes, another qualitative researcher (AN) listened to the audio recordings and read through the interview transcripts while documenting memos on initial impressions and insights regarding the data. Valuable insights pertaining to meaningful patterns within individual populations were considered and guided a more thorough analysis of the complete dataset. NVivo version 14 was used to manage data for analysis. The themes evident within the entire dataset were generated and then discussed and revised with members of the PEACH research team (AN, SW, AK, KZ, JK, RL, MH) to ensure that the full range of data was reflected in the findings.

Our inductive analysis led us to focus on the concept of identity. Therefore, the analysis focused on and was influenced by theory relating to identity. The concept of identity is complex and often contested, with various perspectives presented within the literature [37–41]. Among these diverse viewpoints, Fearon's analysis of the meaning of identity presents two interconnected facets: personal identity and social identity [39]. Personal identity, categorised as a 'personal self', encompasses the unique qualities and attributes that are important to an individual and contribute to shaping their self-worth. It reflects an individual's sense of self, distinguishing between 'me' and 'not me', ultimately highlighting the unique ways in which individuals perceive themselves and, in this context, their specific health needs, as being unique and 'different' from others. Social identity, akin to a 'collective self', represents a social group or category characterised by shared labels and characteristics such as gender, ethnicity, or religious beliefs, or, as in the case of PEACH, identity as an indigenous person or person living with disability for example. It shapes an individual's view of themselves as a group member, emphasising attributes that differentiate the in-group from the out-group. These social identities are defined by 'similarities' among group members rather than differences. Identity is dynamic and influenced by ongoing interactions with both the external world and internal experiences. Our analysis considered children and caregivers' reported experiences through the lens of personal and social identity.

Ethical considerations

Ethics approval was obtained from the SCHN Human Research Ethics Committee (2022/ETH00145) and the Aboriginal Health and Medical Research Council (1920/22).

Findings

The overarching theme generated was the concept of identity, which could be delineated into personal and social identity. The sub-themes of person-centred care and cultural responsiveness have been considered as they relate to the overarching theme of personal versus social identity. The coding tree containing the overarching theme and sub themes is presented in Fig. 1. Person-centred care and cultural responsiveness are used here as sub-themes of personal and social identity as they are a useful way of thinking about how organisations should respond to the needs of people accessing health services. However, we acknowledge the limitation of this framing within an organisational context, given social and individual identities are shaped in the wider relational, social economic and political contexts of participants lives.

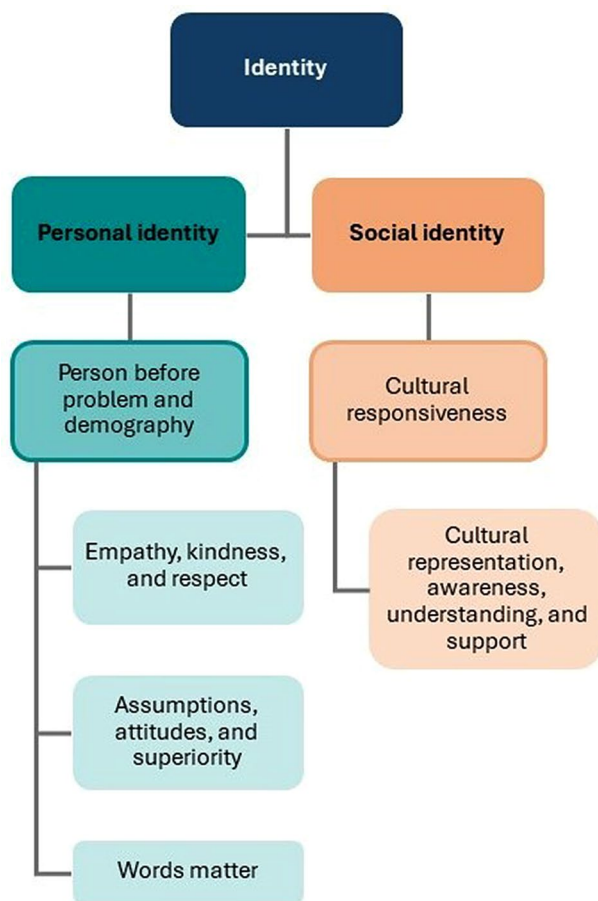


Fig. 1 Overarching theme and sub-themes

Overarching theme: identity

Underpinning many children and caregivers’ reported experiences was a balancing act between the way services cater to either personal or social identity. Children and caregivers emphasised both the significance of social identities in health service design, advocating for cultural responsiveness and inclusivity, and the importance of an individualised approach to health service design that recognises and respects their unique personal identities within a broader social context. Children and caregivers reported a range of experiences across this spectrum of individual and social identities, which provided an overarching canvas for the five main themes generated through our analysis.

As presented in Fig. 2, the findings indicating reciprocal person-centred communication and acknowledging the person before the problem and demography (diverse backgrounds) underscore the value of adopting an individualised approach when interacting with children and caregivers. In contrast to individualised elements, findings related to cultural responsiveness are more aligned with understanding children and caregivers as part of a broader collective or group identity. The diagram provides a visual representation of the dynamic relationship between an individual’s personal and social identities, emphasising that these identities are intertwined and do not exist in isolation from each other.

Personal identity: person before problem and demography

In the context of children and caregivers’ experience, attending to personal identity in health service delivery was reflected keenly in the notion of person-centred approaches that recognise individuals as unique and not inherently defined by their medical conditions or demography.

Children and caregivers emphasised the need for healthcare professionals (HCPs) to go beyond focusing solely on their medical condition and stressed that their lives extend beyond their medical needs and time spent in the hospital. Their medical needs are inseparable from other aspects of their lives and HCPs need to acknowledge and respond to this interconnectedness:

“Person over problem. That’s the way I word it. Because I’m a human being with emotions and a life outside the hospital before I am my chronic illness.” (NDIS CYP 01).

Caregivers emphasised the impact on the broader family unit associated with having a CYP with complex medical needs and the need for a holistic approach to treatment and support:

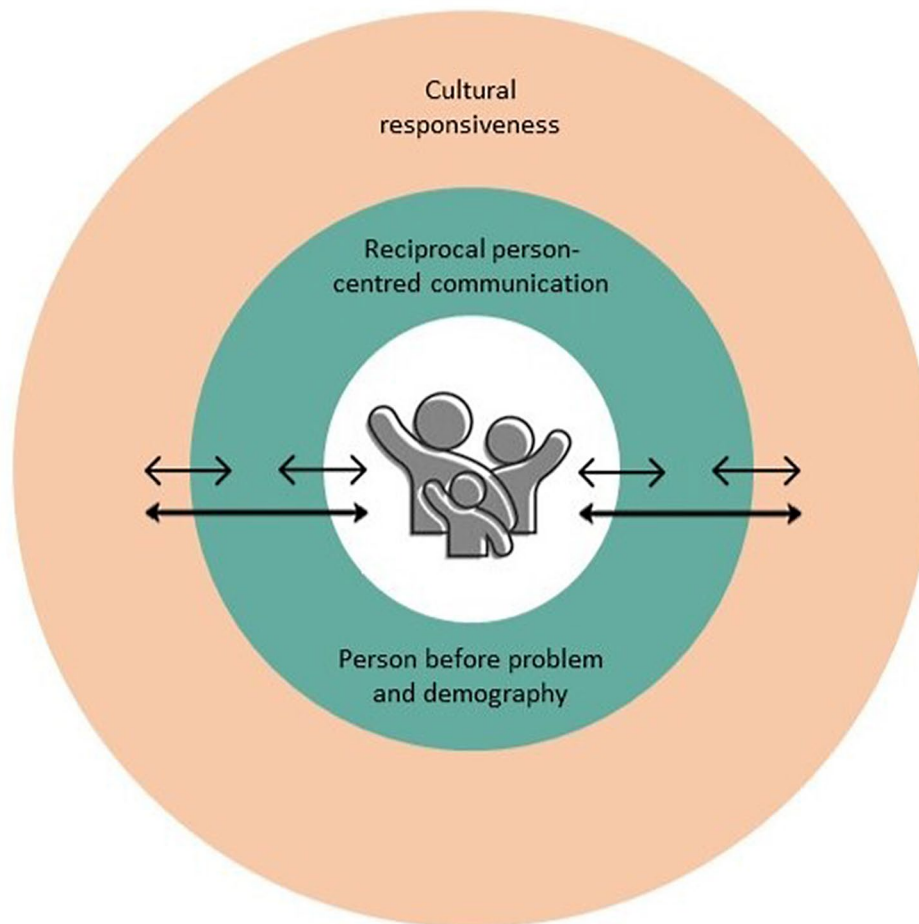


Fig. 2 The dynamic relationship between children and caregivers and personal and social identities. The central circle represents the children and caregiver, while the middle circle embodies themes linked to aspects of personal identity. The outermost circle encapsulates the theme associated with elements of social identity. Arrows denote the interconnections between the children and caregiver and both personal and social identities

“You’re so disjointed and you’re worried about your child but as a family that’s also really, really important. We had two older daughters... they were going to school and I was battling, my husband was trying to work. We were you know, calling on all these people, juggling, and there was really no support... like I sometimes felt I was neglected.” (NDIS caregiver 03).

Empathy, kindness, and respect

To acknowledge the person before their problem and/or demography, children and caregivers expressed a desire for HCPs to interact and engage with them in a manner that reflects empathy, kindness, and respect. When these essential qualities are lacking, this contributes to negative experiences that leave a lasting impression:

“Understand that it could be lifelong for us and that a little bit of empathy or any kind of kindness is gonna make a massive difference to us because we

will remember it forever. And if it’s not offered, we will also remember that forever.” (NDIS CYP 02).

Children and caregivers highlighted the positive impact of HCPs who invest time in building rapport and understanding individual children and caregiver needs. Rather than attributing positive experiences to the healthcare system as a whole, children and caregivers frequently reported favourable encounters associated with individual SCHN staff members who demonstrated empathy, active listening, and a holistic approach:

“Some doctors might even spend 5 or 10 minutes to get a bit of a picture of who we are, and how we work together. And that seems to work. [Child] feels more comfortable. I feel more comfortable and it’s amazing.” (NDIS caregiver 03).

Respecting children and caregivers’ privacy and confidentiality by refraining from discussing their personal

details and medical treatment in the presence of others, such as during bedside handover in a shared room with other patients, was reported as essential:

“And one of the worst things... is bedside handover. It's disgraceful. So, if you're in a four bedded ward, and there's, you know, four people in there plus their parents, and then, 10 people come in to do hand over because, you've got both shifts and doctors and whatever. And they're all standing around talking about all the things that you're struggling with every day in front of everyone. I really dislike that process, and I find it to be a significant breach of privacy and confidentiality.” (NDIS caregiver 01).

Additional suggestions for enacting person before their problem and/or demography included respecting the children and caregiver's voice. Children and caregivers emphasised that they hold expertise regarding their own situations and bodies, and often, this knowledge is disregarded or overlooked when they advocate for themselves:

“When it comes to like, medical health care, obviously the doctor is like an expert in that area. But then the child is an expert on their own body most of the time, especially if you're someone who has a chronic condition or complex condition, and you've kind of been at all your appointments and you kind of know a lot.” (NDIS CP 06).

The recognition of children and caregivers as experts in their own situations emphasises the importance of incorporating their voices into healthcare decisions, fostering a sense of agency, and validating their personal identities within the healthcare context. Caregivers and young people emphasised the need for more avenues that enable them to share their feedback, experiences, and potential solutions in service design and delivery:

“If I was in charge, what would I do? I would definitely hold interview like this and ask what people would like to see change. I wouldn't do things that I feel like I want to change, I would ask my co-workers would like to see and what people who come and visit the hospital.” (Refugee/asylum seeker caregiver 03).

Assumptions, attitudes, and superiority

Children and caregivers shared experiences of feeling subjected to stereotypical treatment from HCPs due to their association with a particular sociocultural group. They believed that merely identifying with a specific group should not automatically imply that they conform to the generalised expectations and needs assigned

to that particular group. Instead, they advocated for the acknowledgment of their individuality and the provision of equal opportunities for personalised treatment, while avoiding stereotypes based on sociocultural factors. Despite this, it remained important for them to be informed about the different services and support they were eligible for based on their group identity, for example, disability or Aboriginal healthcare worker support. This way, they would have a clear understanding of the options available to them should they align with their specific circumstances:

“The other one I get at the hospital. ‘Oh, it's easier for you and your group to come to [location] isn't it?’ Don't assume that I can't get to the hospital. Ask me first. And I'll be like, no, we can get to the hospital. ‘Oh how?’ Drive, bus, cab. I can do it. I don't live that far. Stop judging me or jumping to conclusions.” (Indigenous caregiver 05).

The stigma surrounding some conditions was highlighted as influencing the attitudes of HCPs towards them. One example involved a young person with chronic pain who felt that their need for stronger medication was questioned, causing them to worry about being perceived as a drug seeker or as someone trying to exploit the healthcare system. Additionally, young people with a history of mental health concerns often face stigma and negative assumptions:

“I think my biggest barrier to accessing health-care services has been my label as a mental health patient. I had an eating disorder and within that sort of system, you're not listened to, anything you say is assumed to be a lie. And I think that that's just followed me throughout the rest of my sort of experience within the healthcare system once you're sort of labelled a liar.” (NDIS CYP 02).

Children and caregivers reported experiences of feeling belittled and unheard by HCPs. They described encounters where professionals dismissed their concerns and displayed an air of superiority, creating a hierarchical dynamic. This power imbalance contributes to children and caregivers feeling invalidated, leading to some avoiding accessing services altogether:

“We have kind of stopped going to the children's hospital unless it's for her outpatient appointments. Only because most of the time, my voice, my concerns, and all that aren't heard. They're not listened to.” (Indigenous and NDIS caregiver 01).

Both caregivers and young people highlighted various challenges associated with speaking up for themselves. Participants noted that feeling judged, dismissed and/or not listened could influence a children and caregiver's motivation and/or confidence to advocate for themselves. Feeling that they have not been listened to may influence the trust a children and caregiver has in their HCPs, thereby affecting the overall quality of their relationship:

"They need to take people seriously, like listen to them, like believe them. Because if they're gonna have a doctor who doesn't believe them, then what's the point of treating them if you don't trust them?" (OOHC and NDIS CYP 01).

Caregivers highlighted that many people lack the confidence or skills to advocate for themselves, and even for those who do, achieving the right balance between speaking up and avoiding being overbearing can be challenging:

"I would have fallen through the cracks if I didn't know how to speak up and say what I mean. But not everybody can do that." (Indigenous caregiver 06).
"Difficult to find that balance between speaking up and not coming across as overbearing. If I stood up and said too much I felt like I was that parent who was being a whinger and it wasn't that, we wanted the best for our child." (NDIS caregiver 03).

Experiencing poor communication from HCPs, including feeling unheard, encountering dynamics of superiority, and facing unfavourable assumptions from HCPs negatively influences how individuals perceive themselves and their healthcare experiences. In some cases, not being listened to resulted in poorer health outcomes for children and caregivers. This lack of attentiveness may also contribute to issues around trust and result in children and caregivers being hesitant to voice their concerns in future situations:

"I've been dismissed by doctors. I've been misdiagnosed. I received treatments that are not suitable and have made my illness much much worse... I do feel like I wouldn't have had to access a hospital for so long and I wouldn't still be so sick if I'd been listened to and if I had people who stood up for me essentially." (NDIS CYP 02).

The importance of HCPs being more flexible in adjusting their behaviour and communication to match the specific situation was commented upon by children and caregivers. This included examples such as involving children and young people in developmentally appropriate

conversations about their treatment, thereby ensuring their participation and inclusion in their own care. One young person shared a favourable encounter with HCPs who involved them in conversations about their care:

"They took X-rays and MRIs and stuff. And they showed me and they didn't just speak behind my back to another doctor, they were involving me in it, and it made me understand what was going on." (Indigenous CYP 01).

Words matter

Children and caregivers emphasised the importance of the language and words that are used when interacting with them. They highlighted the need for HCPs to use recovery-oriented and person-centred language, as it greatly influences how they perceive and experience their healthcare journey:

"And recovery-oriented language, the way that we talk to people about their experience is fundamental to how they experience it." (NDIS caregiver 01).

This was supported by a young person impacted by disability who expressed dissatisfaction with the terminology and categorisation of being called "sick kids". They explained how this term misrepresents the diverse needs of children and caregivers, many of whom are not sick but require healthcare support for various reasons:

"I hate all the things saying that's for sick kids. I hate being referred to as a sick kid.... I'm disgusted when I read that because I'm not a sick kid. When I've accessed the hospital, I've gone in as healthy as I've ever been. I can't grow a finger back. I can't grow muscle back. I can't unamputate myself." (NDIS CYP 01).

A caregiver shared experiences of inappropriate dialogues that had occurred in front of her children, impacting their self-esteem. This caregiver appreciated the importance of open communication regarding healthcare conversations, but advocated for more mindful approaches to discussing sensitive matters:

"... they talk about his weight in front of him. They done that to my other daughter to the point where she had scissors trying to cut her stomach." (Indigenous caregiver 05).

Social identity: cultural responsiveness

The emphasis on cultural representation underscores the need for a diverse healthcare workforce that reflects the social identities and languages of the community it

serves. Additionally, the importance of cultural awareness and understanding among HCPs, along with the need for culturally responsive services and support, recognises the impact of social identity on healthcare access and experiences for individuals from diverse cultural backgrounds.

Cultural representation, awareness, understanding, and support

The significance of enhancing cultural diversity in the healthcare workforce was emphasised by children and caregivers. The healthcare environment could then become a place where individuals from different backgrounds can connect with others who share their ethnicities and languages, creating a more relatable and inclusive experience that aligns with their own social identities and experiences:

“My son is 10 and even he could ask me why is there no Aboriginal nurse?” (Indigenous caregiver 06).

A lack of cultural representation within SCHN may prevent some families from accessing healthcare services:

“I feel like with families that come to Australia that don’t particularly speak English really well. Where I hear from them is that they much prefer going to someone who speaks their language or who’s from their own background, which is not something I can necessarily find in the hospital. So, I think that stops them from coming to the hospital even if they might be in need of doing that.” (CALD caregiver 01).

Children and caregivers highlighted the importance of cultural knowledge and sensitivity among HCPs for delivering culturally competent care and achieving positive health outcomes:

“Some Aboriginal people they don’t look you in the eye cause that’s their culture, and they look at the floor, the doctors like, ‘Are you understanding what I’m saying?’ And they’re like, ‘Yeah,’ and then it comes across as that child’s rude or the parents are rude, but they’re not. It’s just the way they’re cultural. They’re showing you respect.” (Indigenous caregiver 05).

Children and caregivers stressed the importance of culturally responsive services and support for those from Indigenous, CALD, and refugee populations, including better coordination of culturally relevant care, ensuring people know their rights and how to access cultural support if required. This could include interpreters or

native-language information to improve communication and understanding:

“I think we just need to publicise a lot more. Who are the blackfullas? And what are the contact points? And how do we access them? Because I think that I only know because I work in system.” (OOHC and Indigenous caregiver 01).

“I think something that might be very helpful for those families that have the language barrier might be the translated information in their languages, whether it be like posters or pamphlets that easily accessible that they can see.” (CALD caregiver 01).

Inadequate cultural support discourages some families from accessing SCHN due to language barriers and the apprehension associated with accessing an English-dominant environment:

“Especially parents who bring in kids, those who don’t speak proper English. If they don’t speak and they have that fear when they go they might not be able to express their thoughts or if they’re not aware that they can actually get someone to translate. So sometimes they make those decision where they should be bringing their kid to hospital, but they’re not pulled back to themselves and just stay at home and they try to do their own medicine or medicine when they used to do when they were in their own country.” (CALD caregiver 02).

Discussion

The exploration of priority population consumers’ experiences and challenges within healthcare services is critical for improving overall service delivery and ensuring equitable access to care. A core message arising from this research is the importance of recognising and accommodating child and caregivers’ social or group identities, as evidenced in sub-themes related to cultural responsiveness. Concurrently, participants expressed a desire for a nuanced and individualised approach that goes beyond generalised sociocultural categories. This twin emphasis suggests a duality wherein priority population children and caregivers seek acknowledgment of their unique personal identities while remaining aware of and valued within the broader context of their social identities. Recent research has emphasised a growing recognition of the intertwined nature of personal and social identity, revealing how they interact and influence each other [42, 43].

Challenges may arise when HCPs make assumptions about children and caregivers based on their association with a social identity such as age, culture, or diagnosis,

instead of acknowledging their individuality. The ethos behind PEACH focuses on identifying priority population children and caregivers and aims to facilitate earlier, supported, and integrated access to SCHN services, primarily recognising and grouping them from a social identity perspective. However, this research emphasises that while acknowledging the social identity and group affiliation of those in priority populations is important, priority population children and caregivers also seek acknowledgment of their unique personal identities to ensure holistic and tailored care.

The interplay between children and caregivers' personal and social identities in the provision of healthcare services, along with the significance of affirming a child and caregiver's self-identity, is a topic that has not been extensively addressed in literature. The published focus is often centred around contexts related to sexuality or uncertainties surrounding gender identity [44, 45]. Relevant to the context of PEACH, ongoing variabilities surrounding disability identity remain, particularly concerning the choice between identity-first language, such as 'disabled person', and person-first language, such as 'person with disability' [46]. Individuals with disabilities typically have strong preferences for one type of language over the other, therefore it is important for non-disabled individuals to follow, respect, and validate the language choices of each person with a disability regarding how they wish to be referred to [47].

Previous literature recognises that categorising children and caregivers into specific groups is required for research and data analysis to effectively identify and analyse variations and inequities among different social subgroups. However, as supported by the findings of this study, it is also important for HCPs to ask individuals how they personally identify, as assumptions based on categorisations may be inaccurate [48]. For example, people show varying levels and ways of committing to their ethnic group, contributing to congruent and incongruent cultural behaviours, particularly for bicultural individuals [49].

Priority population children and caregivers frequently attributed their positive experiences at SCHN to the favourable interactions they had with individual staff members who exhibited empathy, active listening, and a holistic approach. Our work resonates with previous literature calling for holistic service delivery that integrates a person-centred approach and fosters effective interpersonal communication between HCPs and children and caregivers from various healthcare presentations and population groups. When HCPs establish trust and actively involve CYP in discussions and decisions, this leads to greater satisfaction, increased happiness, and improved willingness to share concerns. Healthcare professionals achieve this by being friendly, knowledgeable,

and genuine, connecting with CYP on a personal level, including them in conversations, and using developmentally appropriate language. Conversely, when HCPs fail to connect with or involve CYP, communicate in overly technical terms, or place CYP in a passive role between HCPs and parents, CYP experience fear, anger, resistance, and disengagement [50].

Implications

This study supports adopting an enhanced centeredness approach to address the complex relationship between personal and social identities. Although terms like family-centred, child-centred, and person-centred care vary, they share core principles—partnership, participation, dignity, and respect [51, 52]. Centeredness in care is linked to better quality, satisfaction, and health outcomes [52]. Importantly, it should also reflect the cultural and social contexts of CYPs. Strengthening centeredness at SCHN could improve care experiences for priority populations and enhance provider interactions across all groups.

Our findings suggest pursuing the dual aims of both identifying priority population children and caregivers and working towards minimising inequities in their healthcare experiences and outcomes as well as prioritising the delivery of individualised, person-centred care. By identifying individuals within priority population groups, HCPs can consider relevant risk factors and guide them towards appropriate healthcare pathways that are tailored to their unique circumstances. For example, facilitating connections with Aboriginal healthcare workers where appropriate. As perceived by priority population children and caregivers, an individualised approach to care includes acknowledging the interconnectedness of individuals' lives, building meaningful connections, ensuring effective interpersonal communication, and demonstrating respect for their diverse identities.

As a result of this research and the quality improvement objectives of SCHN, a key aspect of PEACH implementation will involve embedding a priority population tile into the electronic medical records (eMR) to enhance the identification of priority population children and caregivers. An educational module and script for initiating discussions will be developed and disseminated to staff to enhance their ability to sensitively engage with children and caregivers and determine their personal identification status. It is anticipated that as staff engage in identification conversations with children and caregivers more frequently, this practice will become more ingrained, contributing to enhanced children and caregiver interaction, trust, and quality of care.

While it may take time for changes aimed at addressing inequity to become apparent, this research provides a preliminary perspective of priority population children

and caregivers' experiences before the implementation of PEACH initiatives. Following the integration of PEACH interventions into SCHN service provision, post-implementation experiences can be investigated to better understand the impact on subsequent experiences and inequity reduction.

Limitations

Targets for sample size were realised based on judgement that holding 5–10 interviews with children and caregivers from each priority population group would offer a blend of in-depth individual children and caregiver experiences while also achieving data saturation [35]. However, it's important to note that the experiences shared by these participants may not fully represent the experiences of all children and caregivers within the same population group, nor be generalised to experiences outside of the context of SCHN. Despite CALD populations making up the largest proportion of priority population children and caregivers at SCHN and efforts to make recruitment pathways equitable through translated materials, recruitment among CALD individuals proved particularly challenging because CALD is a healthcare-imposed identity rather than a person-centred identity. Most individuals from CALD backgrounds tend to self-identify by their specific background (e.g., Chinese, Indian, Lebanese) rather than as CALD, resulting in very low response rates to recruitment posters and advertising. Moreover, conducting recruitment stalls in the foyer posed difficulties for CALD individuals requiring interpreters, as spontaneous conversations were not feasible. Therefore, CALD individuals needing interpreters may be underrepresented compared to those who are bilingual but also have a CALD background.

By employing purposive and convenience sampling techniques, participation in this study likely attracted individuals who were particularly passionate about the topic and/or confident in sharing their experiences. It is probable that children and caregivers who are less confident, less engaged with services, and less inclined to advocate for themselves may be underrepresented in the study. One objective of recruitment was to ensure the representation of various SCHN departments in the experiences of priority population children and caregivers. However, given the extensive range of hospital departments and treatments, it was not feasible for the study to include representation of every department.

As required, interpreters were used with non-native speakers of English. The use of an interpreter may introduce challenges in effectively capturing the nuances of participants' experiences and perspectives. While bounded by a code of ethics in which interpreters have a responsibility to uphold linguistic neutrality, the act of interpretation inevitably involves biases or cultural

assumptions which may subtly influence the portrayal of the children and caregiver's perspective. Additionally, the presence of an interpreter, particularly if they are from the same community as the participant, may have limited what participants felt able to openly discuss.

Conclusion

Understanding the experiences and challenges faced by children and caregivers from priority populations is essential to improving healthcare services and promoting equity. Actively involving children and caregivers' from priority populations helps uncover the complex challenges and opportunities within healthcare systems. This engagement empowers individuals, gives them a stronger voice in shaping policies and practices, and ensures that changes are rooted in the real-world needs and preferences of those most affected. Through this process, our research highlights the need for care that acknowledges and respects the social and cultural identities of families, particularly through culturally responsive practices. At the same time, children and caregivers emphasised the importance of being seen and treated as individuals, not just as representatives of a broader group—calling for a more personalised, nuanced approach to care.

Abbreviation

CALD	Culturally and linguistically diverse
CYP	Child and young person / children and young people
ED	Emergency department
HCPs	Healthcare professionals
NDIS	National Disability Insurance Scheme
OOHC	Out-of-home care
PEACH	Providing enhanced access to child health services
SCHN	Sydney Children's Hospitals Network

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Author contributions

AN: Methodology, data curation, formal analysis and interpretation of data, findings feedback/refinement, writing – original draft. SW and AK: Conceptualisation, methodology, data collection, interview transcription, initial data analysis, findings feedback/refinement, writing – methods, review, and editing. SM and AT: Conceptualisation, methodology, data collection, interview transcription, initial data analysis, writing – review and editing. AvB: Conceptualisation, methodology, writing – review and editing. KS: Data collection, interview transcription, initial data analysis, writing – review. JRK: Conceptualisation, findings feedback/refinement, writing – review. RL and KZ: Conceptualisation, methodology, findings feedback/refinement, and critical review of the manuscript. MH: Conceptualisation, methodology, data curation, findings feedback/refinement, critical review of the manuscript. All authors have read and approved the final manuscript.

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Data availability

The datasets collected and analysed during the current study were collected after children and caregivers signed a consent form assuring them of confidentiality and therefore are unable to be shared.

Declarations

Ethics approval and consent to participate

Ethics approval was obtained from the SCHN Human Research Ethics Committee (2022/ETH00145) and the Aboriginal Health and Medical Research Council (1920/22). Participants signed a written consent form outlining their consent to audio (including transcription) or visual recording. For those who required an interpreter, interpreters were used to aid in ensuring that the participant understood what they were signing. Participants were informed of the nature of the study and any benefits or risks associated with participating in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

- Singer R, Zwi K, Menzies R. Predictors of in-hospital mortality in aboriginal children admitted to a tertiary paediatric hospital. *Int J Environ Res Public Health*. 2019;16(11):1893.
- Carville KS, Lehmann D, Hall G, Moore H, Richmond P, De Klerk N, et al. Infection is the major component of the disease burden in aboriginal and non-Aboriginal Australian children: A population-based study. *Pediatr Infect Dis J*. 2007;26(3):210–6.
- Guo XY, Woolfenden S, McDonald G, Saavedra A, Lingam R. Discharge against medical advice in culturally and linguistically diverse Australian children. *Arch Dis Child*. 2019;104(12):1150–4.
- Hadgkiss EJ, Renzaho AM. The physical health status, service utilisation and barriers to accessing care for asylum seekers residing in the community: A systematic review of the literature. *Aust Health Rev*. 2014;38(2):142–59.
- Amarasena L, Zwi K, Hu N, Lingam R, Raman S. Changing landscape of paediatric refugee health in South Western Sydney, Australia: A retrospective observational study. *BMJ Open*. 2023;13(10):e064497.
- Hanes G, Chee J, Mutch R, Cherian S. Paediatric asylum seekers in Western Australia: identification of adversity and complex needs through comprehensive refugee health assessment. *J Paediatr Child Health*. 2019;55(11):1367–73.
- Mimmo L, Harrison R, Travaglia J, Hu N, Woolfenden S. Inequities in quality and safety outcomes for hospitalized children with intellectual disability. *Dev Med Child Neurol*. 2022;64(3):314–22.
- Meehan E, Reid SM, Williams K, Freed GL, Babl FE, Sewell JR, et al. Tertiary paediatric emergency department use in children and young people with cerebral palsy. *J Paediatr Child Health*. 2015;51(10):994–1000.
- Smiles M, Savaglio M, Morris H, Bruce L, Skouteris H, Green R. Surviving not thriving: experiences of health among young people with a lived experience in out-of-home care. *Int J Adolescence Youth*. 2020;25(1):809–23.
- Australian Institute of Health and Welfare (AIHW). A picture of Australia's children report: Australian Government. 2012 [Available from: <https://www.aihw.gov.au/reports/children-youth/australias-children/contents/about>]
- Zwi K, Rahman Khan J, Wallace S, van Beek A, Kearns A, Keogh C, et al. Assessing inequities in hospital outcomes for Australian children from underserved populations. *Hosp Pediatr*. 2025;15(5):423–32. <https://doi.org/10.1542/hpeds.2024-007902>
- Solar O, Irwin A. A conceptual framework for action on the social determinants of health. WHO Document Production Services; 2010.
- Australian Institute of Health and Welfare. What are determinants of health? Canberra: AIHW; 2024.
- Marmot M, Wilkinson R. Social determinants of health. Oup Oxford; 2005.
- Pourat N, Lu C, Huerta DM, Hair BY, Hoang H, Sripipatana A. A systematic literature review of health center efforts to address social determinants of health. *Med Care Res Rev*. 2023;80(3):255–65.
- Goldfeld S, Woolfenden S, Asher I, Bauert P, De Lore D, Elliott E et al. Inequities in child health position statement. 2018.
- United Nations. Convention on the Rights of the Child 1990 Available from: <https://humanrights.gov.au/our-work/childrens-rights/convention-rights-child>
- Phillips C, Fisher M, Baum F, MacDougall C, Newman L, McDermott D. To what extent do Australian child and youth health policies address the social determinants of health and health equity? A document analysis study. *BMC Public Health*. 2016;16(1):1–12.
- Smith J, Griffiths K, Judd J, Crawford G, D'Antoine H, Fisher M et al. Ten years on from the World Health Organization Commission of Social Determinants of Health: Progress or procrastination? 2018;29(1):3–7.
- Newman L, Baum F, Harris E. Federal, state and territory government responses to health inequities and the social determinants of health in Australia. *Health Promotion J Australia*. 2006;17(3):217–25.
- The Sydney Children's Hospitals Network. Sydney Children's Hospitals Network strategic plan 2023–2027. 2023.
- Zwi K, Majidi S, Khan JR, van Beek A, Kearns A, Rana R, et al. Providing enhanced access to child health services (PEACH) at Sydney children's hospital network: a study protocol. *BMJ Open*. 2025;15(3):e086107.
- Department of Health and Aged Care. National consumer engagement strategy for health and wellbeing. 2023.
- Gualandi R, Masella C, Viglione D, Tartaglino D. Exploring the hospital patient journey: what does the patient experience? *PLoS ONE*. 2019;14(12):e0224899.
- Rapport F, Hibbert P, Baysari M, Long JC, Seah R, Zheng WY, et al. What do patients really want? An in-depth examination of patient experience in four Australian hospitals. *BMC Health Serv Res*. 2019;19:1–9.
- Wiles LK, Kay D, Luker JA, Worley A, Austin J, Ball A, et al. Consumer engagement in health care policy, research and services: A systematic review and meta-analysis of methods and effects. *PLoS ONE*. 2022;17(1):e0261808.
- Al-Abri R, Al-Balushi A. Patient satisfaction survey as a tool towards quality improvement. *Oman Med J*. 2014;29(1):3–7.
- Marshall C, Zambeaux A, Ainley E, McNally D, King Miss J, Wolfenden L, et al. NHS England always Events® program: developing a National model for co-production. *Patient Experience J*. 2019;6(1):154–65.
- Bjertnaes OA, Sjetne IS, Iversen HH. Overall patient satisfaction with hospitals: effects of patient-reported experiences and fulfilment of expectations. *BMJ Qual Saf*. 2012;21(1):39–46.
- Boulding W, Glickman SW, Manary MP, Schulman KA, Staelin R. Relationship between patient satisfaction with inpatient care and hospital readmission within 30 days. *Am J Manag Care*. 2011;17(1):41–8.
- Zwi K, Majidi S, Kahn JR, Hodgins M, Wallace S, van Beek A et al. Providing enhanced access to child health services (PEACH) project: a study protocol. *BMJ Open*. [In press].
- Donetto S, Tsianakas V, Robert G. Using experience-based co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions. 2014.
- The Sydney Children's Hospitals Network. About us 2024 Available from: <http://www.schn.health.nsw.gov.au/about>
- Zwi K, Khan J, Wallace S, van Beek A, Kearns A, Keogh C et al. Assessing inequities in hospital outcomes for Australian children from priority populations. [In press].
- Sandelowski M. Sample size in qualitative research. *Res Nurs Health*. 1995;18(2):179–83.
- Braun V, Clarke V. Thematic analysis: A practical guide. United Kingdom of Great Britain & Northern Ireland: SAGE Publications Ltd; 2022.
- Abrams D, Hogg MA. Comments on the motivational status of self-esteem in social identity and intergroup discrimination. *Eur J Social Psychol*. 1988;18(4):317–34.
- Bloom W. Personal identity, national identity and international relations. Cambridge University Press; 1990.
- Fearon JD. What is identity (as we now use the word)? 1999.
- Jenkins R. Social identity. 3rd ed. Routledge; 2008.
- Wendt A. Collective identity formation and the international state. *Am Polit Sci Rev*. 1994;88(2):384–96.
- Crocetti E, Albarello F, Meeus W, Rubini M. Identities: A developmental social-psychological perspective. *Eur Rev Social Psychol*. 2023;34(1):161–201.

43. Crocetti E, Prati F, Rubini M. The interplay of personal and social identity. *Eur Psychol*. 2018;23(4):300–10.
44. Conard LE. Supporting and caring for transgender and gender nonconforming youth in the urology practice. *J Pediatr Urol*. 2017;13(3):300–4.
45. Rossi AL, Lopez EJ. Contextualizing competence: Language and LGBT-based competency in health care. *J Homosex*. 2017;64(10):1330–49.
46. Grech LB, Koller D, Olley A. Furthering the person-first versus identity-first Language debate. *Australian Psychol*. 2023;58(4):223–32.
47. People with Disability Australia (PWDA). What do I say? A guide to language about disability. 2019.
48. Sloboda A, Mustafa A, Schober J. An approach to discussing personal and social identity terminology with patients. *Clin Anat*. 2018;31(2):136–9.
49. Hsu L-H. Linguistic intergroup bias tells ingroup/outgroup orientation of bicultural Asian Americans. *Int J Intercultural Relations*. 2011;35(6):853–66.
50. Davison G, Kelly MA, Conn R, Thompson A, Dornan T. How do children and adolescents experience healthcare professionals? Scoping review and interpretive synthesis. *BMJ Open*. 2021;11(7):e054368.
51. Carter B, Young S, Ford K, Campbell S. The concept of child-centred care in healthcare: A scoping review. *Pediatr Rep*. 2024;16(1):114–34.
52. Coyne I, Holmström I, Söderbäck M. Centeredness in healthcare: A concept synthesis of family-centered care, person-centered care and child-centered care. *J Pediatr Nurs*. 2018;42:45–56.

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