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Concepts of Health-Related Quality of Life of Australian Aboriginal and Torres Strait Islander Children: Parent Perceptions

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Abstract

Health-related quality of life (HR-QoL) is a valued patient-related outcome measure. HR-QoL is typically measured using a psychometric tool. Although there are a number of general and illness-specific HR-QoL measurement tools available globally, no tool has been validated for Australian Aboriginal and/or Torres Strait Islander children. The purpose of this study was to gather Australian Aboriginal and Torres Strait Islander parent/carer perspectives of HR-QoL in children in order to inform the development of a culturally appropriate tool. Yarning circles and face to face interviews were used to document the experiences of parents and carers of Aboriginal and Torres Strait Islander children who had experienced a chronic illness. Participants were recruited through word of mouth and via established social and professional networks in Queensland and the Northern Territory of Australia. Information collected was transcribed and analysed thematically and placed into a concept map. HR-QoL was defined as more than just physical, social and psychological wellbeing. Family and social support were valued aspects of HR-QoL, as was knowledge, communication and the relationship with the health system. Participants described the importance of being heard; their voice trusted and valued by health practitioners. Racism and prejudicial behaviour had negative impacts on HR-QoL. The concepts of HR-QoL identified in this study are not included in conventional HR-QoL measurement tools. Consideration should be given to concepts proposed by Australian Aboriginal and Torres Strait Islander populations in order to adequately capture perceived HR-QoL.

Keywords Quality of life · Wellbeing · Indigenous · Qualitative · Patient related outcome measure

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Background

Health-related quality of life (HR-QoL) is an important patient-related outcome, now commonly used for evaluation in contemporary health settings. HR-QoL provides a valuable patient-centred metric in addition to traditional physiological diagnostics (Hand 2016). Many HR-QoL measurement tools are available but the homogeneity of these tools have been criticised in the context of the subjective nature of HR-QoL and the diversity of populations globally (Chenhall et al. 2010). A concern is that many tools are ‘expert-driven’, having been designed by clinicians, and have failed to adequately consult and incorporate the perceptions of the populations to which they are intended to be applied, particularly ethnic minority populations (Chenhall et al. 2010; Priest et al. 2017).

Within Australia, Aboriginal people and Torres Strait Islander people (hereafter respectfully referred to collectively as Indigenous Australians), represent approximately 3.3% of the total Australian population (Australian Bureau of Statistics 2017). As a result of colonisation, Indigenous Australians have experienced considerable social and economic marginalisation. These conditions have had negative consequences across all health indicators and there remain well documented health disparities compared to non-Indigenous Australians (Australian Institute of Health and Welfare 2015). These experiences along with cultural differences are thought to influence how Indigenous Australians conceptualise HR-QoL (Australian Institute of Health and Welfare 2015), which makes available tools inadequate for measuring the HR-QoL of Australia’s Indigenous people (Kite and Davy 2015; Angell et al. 2016).

Current HR-QoL measurement tools typically reflect Western definitions of health, which focus on the physical, mental and emotional health of an individual (Hand 2016). Indigenous Australian concepts of health are different as they are defined more broadly and include not only the health of the individual but also the health of the family and community (Priest et al. 2012). Although little research has investigated the perceptions of ‘HR-QoL’ of Indigenous Australians specifically, there has been considerable work defining ‘health and wellbeing’ and ‘quality of life’ in general (Butler et al. 2019). Few studies have tried to adapt and/or validate existing HR-QoL measures for Indigenous Australians (Angell et al. 2016). However, studies (Butler et al. 2019; Le Grande et al. 2017; Angell et al. 2016) indicate that further consultation with Indigenous Australian people is needed to properly define HR-QoL and create a measurement tool that is inclusive of culturally relevant domains and indicators.

Childhood has been targeted as a key area for health interventions and evaluation because of the understanding that many chronic conditions have their origins in childhood due to both physical and environmental factors (Brumana et al. 2017). Like adults, Indigenous Australian children experience a greater burden of chronic illness and disease compared to non-Indigenous Australian children (Australian Institute of Health and Welfare 2015). While it is preferable that children self-report their HR-QoL, there are instances when this cannot occur due to age and/or illness. If children are unable to report their HR-QoL, a parent-proxy report can be used (Eiser and Varni 2013). Despite documented discrepancies between child and proxy reports, a parent-proxy report is preferred to no evaluation and, although not interchangeable, they provide valuable insight into health care utilization and family values regarding potential treatment options (Eiser and Varni 2013).

In the absence of a validated HR-QoL tool for Indigenous Australian children, we undertook this study to identify key concepts that Indigenous parents and carers consider fundamental to HR-QoL in their young children with a chronic illness. These data will be used to inform the development of a valid culturally-specific parent-proxy HR-QoL measurement tool for Indigenous Australian children.

Methods

Design

We used a qualitative phenomenological approach to explore parents' and carers' perceptions of HR-QoL of Indigenous children with a chronic illness. Phenomenology refers to understanding a person's experience through their eyes and understanding how they experience a phenomenon - in this case, HR-QoL (Al-Ghabeesh 2014). We used this approach as it is important for data collection and for decolonising the research process. Historically, research with Indigenous Australians has been paternalistic and failed to privilege Indigenous ways of knowing (Lin et al. 2016). A phenomenological approach is flexible and is able to incorporate Indigenous research methods such as yarning (D'Antoine et al. 2019). Yarning is a traditional method of communication within Indigenous Australian culture, involving the sharing of stories and knowledge in a mutually respectful way (Leeson et al. 2016). Yarning has become an accepted method of qualitative enquiry within Australia and has also been used in community-based epidemiology studies (Valery et al. 2003). The yarning process aims to step away from the one-sided, research-led approach of data collection and instead places value on symbiotic dialogue between the researcher and participant (Leeson et al. 2016). The oral traditions of yarning and story-telling therefore provide an appropriate phenomenological platform because the knowledge is constructed by the participant and is privileging their voice. Yarning methods were used to conduct individual and group discussions during the data collection process.

Setting and Participants

Two researchers worked in partnership to facilitate the recruitment of participants, data collection and analysis. MT, an Aboriginal woman, is one of the study's chief investigators and co-researcher, KB's PhD supervisor, and provided cultural oversight for the entire study. KB is a non-Indigenous Canadian/Australian woman.

Parents and carers were eligible if they identified as being of Aboriginal and/or Torres Strait Islander descent and were, or had been, the carer of an Indigenous child aged <18 years with a chronic illness (defined as any condition which affected the child's daily life and required them to attend the doctor and/or hospital regularly) (Eiser 1996).

Convenience sampling was used; participants were recruited through word of mouth and via established social and professional networks in Queensland (QLD) and the Northern Territory (NT) of Australia. The study protocol was explained verbally and through a written plain language statement that was provided to potential participants.

Signed consent was obtained. Yarnings (individual or group sessions) were held at times and places that were convenient for the participants.

Data Collection

Yarning requires a rapport to be developed between the researcher and participants (Leeson et al. 2016). In this study, time was spent with participants getting to know each other over morning or afternoon tea before commencing data-collection. This involved the researchers sharing information about themselves, including personal information in the context of the research question and discussing why they were conducting the research and how they related as mothers in caring roles. This balance of sharing continued throughout the yarning sessions, as both researchers and participants contributed to the yarn, sharing information and asking questions of each other.

Data collection was semi-structured. We used a list of questions (Table 1) that guided discussion, but these were not utilised in order or verbatim. As HR-QoL was not a concept or phrase that everyone was familiar with, the researchers utilised questions to prompt discussion if needed around 'health and wellbeing'. For example, going off script, asking 'how can you tell when your child is sick or unwell' prompted discussion around some of the attributes of wellness as perceived by parents and carers. The researchers were then able to follow up with participants and ask what was important to them and their child when they were sick. Likewise, asking 'what are some ways you know your child is feeling good and you know their quality of life is good?' provided talking points that the researchers could explore further with participants, identifying what values were important to participants in terms of health, wellbeing and HR-QoL. All yarning sessions were recorded with a digital audio recorder (Philips Digital Voice Tracer LFH662, Korea).

Analyses

The recordings were transcribed by a transcribing service (Smart Docs., Lexical Ventures, Brisbane, Australia). The data were entered into the software package NVivo 11.4 (QSR International Pty Ltd. Version 11.4.1.1064). KB coded the data, guided by Braun and Clarke's '6 Steps (Braun and Clarke 2006), which includes becoming familiar with the transcripts, initial coding, searching for themes, reviewing themes,

Table 1 Focus questions to guide the yarning sessions

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- What does health, healing and wellbeing mean to you?
 - What areas of being healthy are important to you?
 - What does health, healing and wellbeing as it relates to your child's health mean to you?
 - What areas of your child's life do you think are most affected by his/her health?
 - When you think about your child's health, what worries you most?
 - What areas of your life are affected most by this child's health?
 - Thinking of your own family and relationships with others, in what ways are these influenced by this child's health?
 - Thinking of this child's relationships with others, in what ways are these affected by his/her health?
 - The World Health Organization (WHO) categorises health and wellness aspects into physical, mental, and social well-being. Do you think these categories capture aspects of health for Indigenous Australians?
-

defining the themes and writing them up. This approach was used because it is focused on reporting the data as opposed to interpreting it through any type of lens or theory, which may be biased by the researcher. Oversight of these steps was provided by MT, who also guided data interpretation and accuracy of the codes from an Indigenous Australian perspective. Definitions of health and wellbeing as described by participants were coded first, with like codes grouped together and then further refined into specific concepts which were illustrated on a concept map (Fig. 1). Remaining data were coded and organised thematically before being refined into more specific concepts to be placed on the concept map. All data were included on the concept map regardless of volume or repetition by participants. These concepts were discussed between both researchers before finalisation of the concept map.

Ethical Statement

This study was approved by the Queensland Children's Hospital and Health Service Human Research Ethics Committee (HREC/16/QRCH/281) and Human Research Ethics Committee of Northern Territory Department of Health and Menzies School of Health Research (HREC 2017–2866).

Results

Twenty-six participants were screened and recruited: none declined (Table 2). The majority of participants (18 females and 8 males) were the biological parents of children with a chronic illness. Although specific demographics were not collected from participants, the majority were parents/carers to children aged <13 years, the others to adolescents aged 13 years and over. The illnesses and chronic conditions experienced by children of participants varied in severity and included, but were not limited to: asthma, chronic ear problems, developmental delay, rheumatic fever, bronchiectasis, osteomyelitis, and chronic liver and heart disease.

Participants defined their child's HR-QoL as being multi-faceted. Physical, social, emotional and cultural health were described as important components. Other components of child HR-QoL described were concepts such as: having knowledge, having support, ease and effectiveness of communication between parties and the nature of interactions with the health system. The 'health system' in this context pertained not only to clinicians, but to the many stakeholders within a health system, including allied health, Indigenous Health Workers and administrative staff. These concepts were complex, inter-related and described in relation to both the child and their primary carer (see Fig. 1). In addition, although not raised with each concept, there were undertones of perceived racism and discrimination in many topics discussed. Parents and carers explained what they valued in relation to HR-QoL, and this was often the absence of prejudicial behaviour from health services, be it overt or sub-conscious. As systemic racism and discrimination can be facilitated in many different ways it is acknowledged as a floating concept within the map (Fig. 1) and is apparent in a number of the concepts raised.

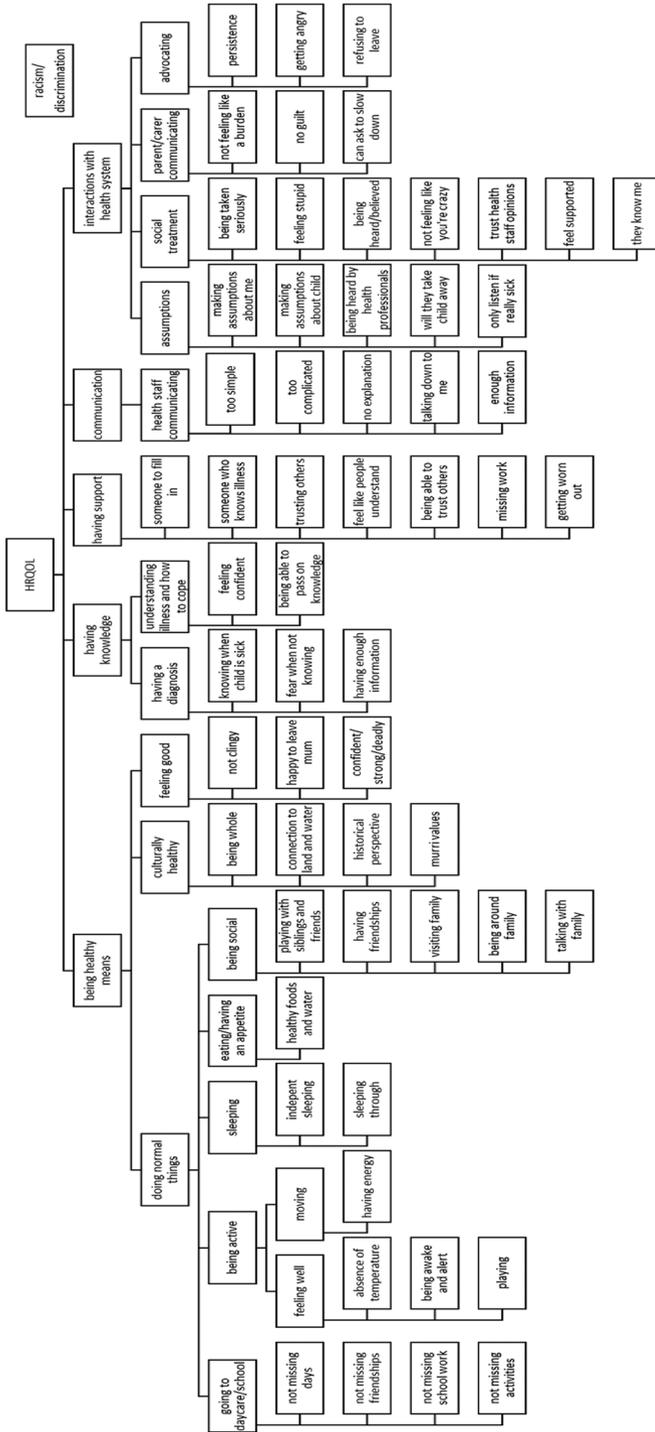


Fig. 1 Concept map

Table 2 Description of the yarning sessions

Yarning	Participants ($N=26$)	Location	Researchers present
Group 1	8 participants, 4 males, 4 females	Toowoomba, QLD	Indigenous researcher
Group 2	3 participants, all female	Toowoomba, QLD	Indigenous researcher
Group 3	3 participants, all female	Darwin, NT	Both researchers
Interview 1	Female	Darwin, NT	Both researchers
Interview 2	Female	Darwin, NT	Both researchers
Interview 3	Male	Darwin, NT	Both researchers
Interview 4	Male	Darwin, NT	Both researchers
Interview 5	Male	Darwin, NT	Both researchers
Interview 6	Male	Toowoomba, QLD	Both researchers
Interview 7	Female	Toowoomba, QLD	Both researchers
Interview 8	Female	Darwin, NT	Non-Indigenous researcher
Interview 9	Female	Brisbane, QLD	Non-Indigenous researcher
Interview 10	Female	Brisbane, QLD	Non-Indigenous researcher
Interview 11	Female	Caboolture, QLD	Non-Indigenous researcher
Interview 12	Female	Caboolture, QLD	Non-Indigenous researcher

What Does Being Healthy Mean?

The notion of being healthy was attributed to more than just physical health. While participants indicated that being healthy meant their child being able to do normal things in life, such as go to school, be active, sleep, eat and be social, being culturally healthy and feeling good mentally and emotionally was also part of health. Social wellness contributed to HR-QoL for their children and being away from school or day-care because of illness had social implications as well as developmental and academic consequences.

Yes, because the ongoing effect of them not being at school and not participating and thinking 'why is it always me', they start to internalise and think there's something wrong with them. 'What did I do? What do I do differently? Why can't I do this? I missed out on this. Everyone else went to camp and they all bonded and I missed out. I can't go to sports day because I'll never make it around that track like everybody else'. Absolutely, it's not just a physical thing, yeah. (Female, Interview 9, Brisbane).

As well as friends and social interactions, being able to spend time with family and stay connected to cultural traditions was important for child HR-QoL. Parents explained that visiting family regularly, as well as regularly visiting traditional environments such as family land or wherever the family felt culturally connected, such as the beach or bush (countryside), was important for child HR-QoL. Participants shared the heartache of being absent from family during hospital stays or having to leave their home or land for long term treatment. Family was described as having a 'strengthening' capacity for

individual health and children, parents and carers described feeling bolstered to conquer anything if they had their family near. The absence of family was seen as detrimental to child wellbeing and HR-QoL.

I think that's something - people often think that health is just all about the person and they don't think about the bigger picture, that you need some people around you as well. (Female, Interview 7, Toowoomba).

Also raised was the notion of 'feeling whole'. This was a challenging concept to articulate, as it was something that was more felt and understood, than could be defined by any one term. In defining health and wellbeing, participants raised different ideas that contributed to this idea of holistic health and wellbeing. This was associated with having traditional values specific to being Indigenous, as well as an awareness of the past (in the context of colonisation). It was related to identity and understanding who you are and where you came from and feeling connected to family and country. It was not clear whether this notion was age-specific and how these values manifested for children specifically. However, participants indicated that it was important for children to participate in their culture and families prioritised upholding cultural knowledge and practices.

I feel that you've got to have (connection to country) - because of our culture, you've got to stay in touch with that, and if you don't, you can lose yourself and get sick. (Male 1, Group 1, Toowoomba).

It's always good to go back to country and heal. I go back - we probably go back twice or three times a year. (Female C, Group 1, Toowoomba).

'Feeling good' was an important aspect of HR-QoL and parents explained that this could be expressed by a child's temperament and how clingy they were to their main parent/carer. Children who have good HR-QoL were reportedly more confident to be independent, requiring less reassurance or cuddles. Feeling good was not age specific, as parents indicated that even older children would express more neediness when they were unwell, not wanting to be alone and having their parents/carers close by. A child's energy levels and whether they were eating and sleeping as normal were also indicators for HR-QoL. Lethargy was associated with poor HR-QoL, even for older children. Many parents and carers explained that for older children (who may have an interest in technology for recreation), wanting to go out, and being able to go out and be outside, was a good indicator of the child's HR-QoL.

She is a bit more like happy and really energetic - like, do things, go to school and get up in the morning. Not like before, she was a bit lazy - not lazy, but weak, tired all the time, and not getting up in the morning. (Male, Interview 3, Darwin).

Having Knowledge

Knowledge and self-efficacy were described by participants as aspects of child HR-QoL. The health-related circumstance of the child and carer determined what

knowledge and level of self-efficacy was needed to improve HR-QoL. For instance, participants described the importance of having a diagnosis for child HR-QoL. Without a diagnosis, parents and carers felt unable to navigate their child's illness effectively and properly support them. It also contributed to fear and stress for both child and parent/carer, as they felt ignorant.

It was just getting that diagnosis and knowing that I wasn't going crazy. Because it lifted a lot of weight off my shoulders. Yeah, it just – I was crying a lot too, because I knew that there was something not right, but then not being heard is like – yeah, it's not the nicest thing. (Female, Interview 1, Darwin).

Adequate knowledge was judged by feeling confident in how to help their child cope and being able to teach their child and help them feel confident as well.

He knows what his body is doing, so he knows when to take his medications, if he's got to take the medications; if he doesn't need it then he'll go 'I don't need it'. So they, themselves, knowing what their own body's doing is good - yeah. (Female A, Group 1, Toowoomba).

Teaching family about the child's health situation was also valued, because without this, children could become isolated from their family. For children who were school-aged or attended day-care, the ability to pass on knowledge to the child's school was important to HR-QoL. Teaching and sharing knowledge was explained as an important cultural practice; passing on information to the younger generation was valued and contributed to the HR-QoL of both the individual receiving the information and the person delivering it.

We got to teach our generation that to come to terms with an illness, they need to understand what it's all about and they can actually live a normal life without thinking what's coming in front of them. (Female B, Group 2, Toowoomba).

Having Support

A lack of social support for parents and carers was explained as having both direct and indirect effects on child HR-QoL. For example, emotionally fatigued parents acknowledged that their moods affected their children's moods. Parents described the importance of having someone to provide emotional and physical respite if they needed it, as well as allowing them to participate in paid work if they had to take time off to be a carer. In both group discussion and interview, participants shared how there was a ripple effect when support was not available, which affects emotional wellbeing immediately and extends to resources and opportunities, which again compounds wellbeing issues. For instance, not being able to have a break from routine and both child and family becoming isolated because of decreased earning capacity of the parent/carer. However, having a good support system was described as having more than just someone to call on to provide respite. Parents and carers expressed their reluctance to leave their children with

anyone including family who did not have the capacity to provide for their child's health needs.

I don't trust her with anyone else, because I'm frightened if she has an asthma attack, they're not going to do what I do. You're wrapping them up in cotton wool, because you can't trust anyone else to give you a break. (Female B, Group 2, Toowoomba).

In addition to practical support, parents and carers explained that an emotionally supportive environment also contributed to child HR-QoL. Parents and carers explained that at times, family, community and schools would question or make judgements about their child and their illness; either not understanding the severity of their child's illness, or in contrast, feeling threatened by their child's illness. This type of thinking increased isolation for children and carers and affected their social and emotional wellbeing.

You wish a friend would turn up or give you a call but no one does. So, yeah, unless you're one of those people that you're always making the phone calls, you don't get it back. Or if people know that you're sick, they don't want to come near you anyway. And once again, you just go, "Well, just suck it up and just do it," yeah, but it does drive you nuts, wears you out. (Female, Interview 11, Caboolture).

Communication

Strong and respectful communication between the health system and families was essential for child HR-QoL according to parents and carers. They described how appropriate communication allowed them to navigate the health system in a meaningful and effective way, ensuring their child received the best care possible. When communication was perceived as being insufficient, too complex or disrespectful, families were left feeling disenfranchised from the health system and its stakeholders. A breakdown in communication had ramifications at home as well. Parents and carers described the challenges and frustrations of not having enough information or resources communicated to them so that they could confidently manage their child's care at home.

Communication and listening has got a lot to do with it as well, because like us, we're Indigenous, the three of us, but we can speak up and we know - like, where if you get some of our mob from communities, and even family mob in town they're like, come to the doctor with me and that's why liaison officers, they're okay, but the majority of the time we know what we're talking about more than them. They don't listen. They just think they can send you home, or you don't know what you're talking about; you're not a doctor. (Female A, Group 3, Darwin).

They need to explain more because for me, sometimes I don't understand what my son's condition is. I know he has a problem with his lung but it's a hard word that I don't understand what it's really called. (Female, Interview 2, Darwin).

Interactions with the Health System

Parents and carers shared the multiple ways they had experienced judgement from the health system and the ramifications these experiences had on child HR-QoL. Negative assumptions about parents and carers were described as commonplace and related to their capacity as a parent and/or their Indigenous identity. Issues raised included: health professionals making negative assumptions about children and their families; not believing or trusting parents/carers; and unwelcoming environments where parents/carers felt judged and unable ask questions or engage with health professionals confidently.

I didn't trust the welfare and all that sort of stuff, because when my daughter was born, this lovely social worker thought that I shouldn't have her, because I was only 21. She had spina bifida, my husband worked away, so I have a trust issue because they were trying to take her off me. So, that in turn, took away a lot of me wanting to get any help. So, that was 27 years ago. It's a big difference, but what it has also done, by not getting the help, you lose it, so then your whole family becomes unravelled. (Female A, Group 2, Toowoomba).

From their experiences, participants shared the additional advocacy they had to undertake. A common theme raised by participants was that they had to invoke negative stereotypes, such as 'the angry black woman' in order to get what they needed from the health system, be that attention, information, or physical care for their child. The additional stress and energy from having to advocate at such a high level had detrimental effects on families and, as participants explained, it perpetuated the judgement cycle. However, participants, particularly mothers, felt like they did not have any other options except to speak loudly and get angry.

Racism

While participants describe situations of feeling judged in general, they also reported being treated differently because of their Indigenous identity and were victim to negative stereotyping, particularly with respect to their capacity to care for their child.

The problem is, they see you come in and they think because we're Indigenous, we don't know, and they automatically put us in that box. (Female B, Group 3 Darwin).

Yeah, he bruises really easily. I actually had a coronary one day, because he came home and he's had these bruises on him; I said 'where did you get them from mate?' and he said 'I've just bumped my shins on the thing'. So he could

bump himself and within an hour or so he'd have a bruise, and you go 'oh God, hope they don't get a hold of me' [laughs]. Because that's the biggest fear; because he bruises so easily it's just constant bruising all the time, but if he breaks a bone the blood can bleed into the bone, and that causes major infection and that sort of stuff... it's a big concern that I had when he was younger; but because it's been documented in his medical journal/papers (I call it) I can actually say 'look, this is what it is, it's not me bashing him, it's actually his medical condition'. (Female B, Group 1, Toowoomba).

Discussion

In recent years there has been increasing awareness of the potential lack of suitability of available health psychometrics for Indigenous Australians. Developed from Anglo-centric and biomedical notions of health and wellbeing, available tools are reported to lack the relevant concepts needed to reflect Indigenous Australians perceptions of health and wellbeing (Angell et al. 2016; Le Grande et al. 2017; Butler et al. 2019). The findings of our study support this viewpoint, demonstrating that other concepts are important from the perspective of parents and carers of Indigenous Australian children.

What Being Healthy Means

When considering health and wellbeing, our participants described the importance of children being able to participate in day-to-day life and feel well while doing so. Everyday physical, emotional and social functioning is often reflected in established HR-QoL measures (Jo et al. 2017). However, participants also emphasised the importance of family and engaging with family regularly for health and wellbeing. The significance of family to Indigenous Australian notions of health and wellbeing is well reported (Butler et al. 2019), yet few studies have specified whether these concepts are representative of all age groups within the Indigenous Australian population. Our findings contribute a parent-proxy perspective to this growing understanding of family and health and align with Priest et al.'s (2017) research with urban Indigenous children. Yarning with children aged 8 to 12, Priest et al. (2017) reflected that, like the broader population, children view family as central to their health and wellbeing, and the same is found for other Indigenous children globally.

Cultural health was also raised as an attribute of overall health and wellbeing. A multi-dimensional concept, as our participants explained, culture can transcend practice and ceremony and also be about identity and your place in the world (Martin 2017). Other parents and carers have shared similar thoughts on culture during the Longitudinal Study of Indigenous Children (LSIC), stating that a strong sense of culture and identity are key components of Indigenous Australian children's strength and wellbeing as they grow (Martin 2017).

Emotional domains are common within HR-QoL measures and typical proxy indicators require the subjective assessment of feelings such as being sad, angry or afraid (Solans et al. 2008). In contrast to this normative approach, our participants suggested some practical ways of assessing whether or not their children were 'feeling

good', using physical cues such as their child's level of clinginess or fatigue. These insights were useful, as there is considerable evidence that proxy measures of less observable domains, such as emotions, are less reliable (Eiser and Morse 2001; Varni et al. 2007; Rajmil et al. 2013). Likewise, the language our participants used in describing emotional states, such as feeling good, has important implications for future tools. Examination of culturally specific sub-populations have shown that some indicators of wellbeing are 'lost in translation', skewing results (The Getting it Right Collaborative Group 2019). Utilising the suggested cues, as well as the language of parents and carers, could assist in overcoming these issues of reliability and interpretation.

Having Knowledge

In conceptualising what factors contributed to HR-QoL, having health knowledge and information were raised as key factors by participants. Studies of both Indigenous and non-Indigenous populations have demonstrated that when you are unwell, having ample information and knowledge about your situation is important for patient wellbeing and satisfaction (Alyson et al. 2007; Dyson et al. 2017; Jennings et al. 2018; Fletcher et al. 2007), and the same has been found for parents/carers of chronically ill children (Smith et al. 2015). Research into cancer care and survivorship of Indigenous Australians has demonstrated that patients having enough information and knowledge about their health condition not only contributes to their wellbeing, but can increase their chance of survival (Meiklejohn et al. 2018; Garvey et al. 2012; Green et al. 2017). This is because, as our participants elucidated, information is not just about peace of mind, but navigating a health journey and the practicalities of daily life with a health condition. Similar sentiments have been raised with respect to Indigenous Australian children with chronic wet cough (D'Sylva et al. 2018). In gathering parent/carer perspectives, D'Sylva et al. (2018) reported having usable information was not only highly valued by participants but was a key indicator of whether they sought and/or received appropriate care for their child. Although knowledge and information are more typically utilised as indicators in patient care experience measures (Doyle et al. 2013), our findings suggest that they should be considered in a HR-QoL context as well.

Having Support

Participants in our study were adamant that parental/carer social support had implications for child HR-QoL, and their assumptions are supported empirically (Newland 2015). Newland (2015) advocates that a child's wellbeing stems from family wellbeing and when 'families are struggling, a child's wellbeing suffers'. Parents/carers supporting chronically ill children experience greater emotional and financial adversity and are at risk for worse HR-QoL themselves than parents/carers of children with no health issues (Fisher 2001; Hatzmann et al. 2009). Support, connection and social capital have been found to be protective factors for both children and parents/carers when dealing with chronic illness (Fisher 2001; Smith et al. 2015) and as our participants have indicated, they reflect potential

indicators of HR-QoL. The inclusion of parent-proxy measures in tandem with child measures in child HR-QoL tools to capture additional indicators is supported by Varni et al. (2007), who attributed the need for greater consideration of parent indicators to the expanding role parents/carers have in managing their child's conditions.

Communication

The findings of this study are consistent with other research that has investigated the effect of health service communication on patient health outcomes. Doctor-patient communication can affect both patient satisfaction and physical health outcomes (Zill et al. 2014; Pinto et al. 2012). As participants in our study conveyed, appropriate communication is more than just positive interactions with health services, it is a pathway for care and knowledge, which ultimately affects other aspects of health and wellbeing. A systematic review which included 65 papers on Indigenous narratives of culturally safe healthcare communication in Australia reported 'talk' as central to the experience of healthcare for Indigenous Australians (Jennings et al. 2018). Talk and/or communication was found to influence patients' physical health and feelings of wellbeing (Jennings et al. 2018). The nexus between communication and health within an Indigenous Australian context is likely so highly regarded because of the continued communication gap within Indigenous Australian health settings (Lin et al. 2016). There is considerable evidence to suggest that health communication continues to be problematic and impact on concepts related to Indigenous Australian HR-QoL (Amery 2017), yet there are limited methods of understanding or measuring the effect.

Interactions with the Health System and Racism

As previously discussed, our findings are in accordance with current evidence that suggests that there remain inequities in the delivery of health care for Indigenous Australians (Jennings et al. 2018). Participants in our study viewed their interaction with the health system as contributing to their child's HR-QoL status. The causal pathway is complex and related to the aforementioned concepts of communication and information/knowledge, as well as the more nuanced interactions which concern how the health system views Indigenous Australians and how Indigenous Australians feel they have to respond to the treatment they receive. Jennings et al. (2018) highlighted the power differentials experienced by Indigenous Australians and the negative effects they have on health and wellbeing. As our participants shared, other Indigenous Australians report that their interactions with the health system influence the accessibility of care and their emotional wellbeing (Jennings et al. 2018). Although there appears to be no research that examines these experiences in a HR-QoL context, there is evidence to suggest that these experiences do undermine aspects central to wellbeing. Autonomy, empowerment and recognition have been found to be profoundly relevant to Indigenous Australians notions of wellbeing and these qualities are eroded when people are unable to experience equitable health care and experience both subtle and overt racism (Butler et al. 2019). These experiences have an historical context that is specific to Australia and

the transgenerational prejudice that Indigenous Australians have dealt with because of colonisation. This prejudice is based not only on ‘othering’ with respect to a person’s race, but on inequities that have manifested in social determinants, such as employment, education and health (Durey and Thompson 2012).

As depicted in Fig. 1, there are multiple concepts to be considered in relation to HR-QoL. Due to space limitations, we have only touched on the main branches of the map in an aim to highlight the core concepts raised. However, many of the concepts are interrelated and could be interpreted with greater detail in their own right. The findings provide a platform for investigating whether additional indicators should be included in future culturally-specific HR-QoL tools.

Limitations

In our findings, many questions related back to the parent and family. This is potentially a bias of the parent-proxy approach but is also likely connected to the cultural perceptions of health; the emphasis on the collective as opposed to the individual. For example, participants explained the importance of having knowledge and information. This was described in the context of both the parents and child having information and the importance of being able to share that information with their wider community. As we did not collect any data from a child’s perspective (limited by the children’s age), we cannot comment on whether children value information or knowledge in the same way expressed by their carers. However, as mentioned above, participants described that, like themselves, their children valued knowing what was happening with their illness and how to manage it. These findings may have limited generalisability and more research is needed to understand whether the concepts raised are reflective of broader populations.

Although the congruence of data suggests that data saturation was achieved, additional concepts may be raised by more geographically and linguistically diverse populations. The majority of the participants were from urban or regional areas, or had been living in urban areas due to their child’s illness and all spoke English. It is possible that perceptions of HR-QoL could be different or ‘lost in translation’ for those who speak English as their 2nd, 3rd or 4th language and/or live in rural and remote locations. Another limitation is the participation of a non-Indigenous researcher. While the participation of a non-Indigenous researcher within an Indigenous health setting could potentially influence participant responses, the similar experiences expressed across the yarning sessions and data collection suggest that participants were comfortable and the study methodology was culturally appropriate. Similarly, cultural oversight was provided by an Indigenous Australian researcher with substantial qualitative research experience (Toombs et al. 2019) who also participated in the data collection and analyses. Finally, concepts were not reviewed or confirmed by the participants after the coding process and as such, the study is limited to the initial reporting and analysis. Further research will be needed to validate these concepts. This process will be conducted with a larger population when evaluating the appropriateness and acceptability of a HR-QoL psychometric tool we are developing that is informed by these concepts.

Conclusion

Given the growing demand for patient reported metrics to inform health care services and improve health and wellbeing, accurate representation of HR-QoL is needed. The concepts of HR-QoL identified in this study are not included in conventional HR-QoL measurement tools. Consideration should be given to concepts proposed by Australian Aboriginal and Torres Strait Islander populations in order to adequately capture perceived HR-QoL.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Declarations The authors have nothing to declare.

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