Interacting with providers: an intersectional exploration of the experiences of carers of Aboriginal children with a disability

Abstract

Intersectionality has potential to create new ways to describe disparities and craft meaningful solutions. This study aimed to explore Aboriginal carers' experiences of interactions with health, social, and education providers in accessing services and support for their child. Carers of Aboriginal children with a disability were recruited from an Australian metropolitan Aboriginal community-controlled health service. In-depth, semi-structured interviews were conducted with 19 female carers. Transcripts underwent interpretative phenomenological analysis. Intersectionality was applied as an analytical framework due to the inherent power differentials for Aboriginal Australians and carers for people with a disability. Marginalisation and a lack of empowerment was evident in the experiences of interactions with providers due to cultural stereotypes and racism, lack of cultural awareness and sensitivity, and poverty and homelessness. Community-led models of care can help overcome the intersectional effects of these identities and forms of oppression in carers' interactions with providers and enhance access to care.

Introduction

Disability compounds social and economic disadvantage (World Health Organization & The World Bank, 2011). In Australia, racism towards Aboriginal and Torres Strait Islander peoples results in disproportionate social, health and economic disadvantages (Hollinsworth, 2013). Aboriginal and Torres Strait Islander children experience a higher prevalence of disability than other Australian children (Biddle, Yap, & Gray, 2013). Failing to address developmental disability can negatively impact speech, language, and employment outcomes (Morris, 2005; Burrow, Galloway, & Weissofner, 2009; Burns & Thomson, 2013; Australian Institute of Health and Welfare (AIHW), 2014). Investing in early childhood—through policies that address the social determinants of health—is fundamental to addressing health inequity (Burns & Thomson, 2013; Commission on Social Determinants of Health, 2008; Queensland Health, 2009; Thorne, 2003/4; Goldblatt et al., 2015). However, Aboriginal and Torres Strait Islander children and their informal carers face a number of barriers to accessing services for intervention. Barriers to service access include a lack of culturally appropriate services (DiGiacomo, Davidson et al., 2013), mistrust of mainstream (non-Aboriginal community controlled) services and their providers (Biddle, Yap, & Gray, 2013; DiGiacomo, Davidson et al., 2013; Australian Health Ministers' Advisory Council, 2004; Gilroy, 2012), and racism (Australian Health Ministers' Advisory Council, 2004; Gilroy, 2012; DiGiacomo, Davidson et al., 2013; DiGiacomo, Delaney et al., 2013).

Children with a disability require both formal and informal caregiving. Informal carers (hereafter, carers) are unpaid and may be a family member or friend, as opposed to paid formal care providers (Vasileiou et al., 2017). For purposes of this research, the term "provider" refers to a person employed to provide a service for individuals involving assessment, management or treatment of their health condition or disability, addressing both

medical and environmental factors (e.g., working in the health care, educational, or social service sectors). Carers play a vital role in the healthcare of children, particularly in early childhood. As a representative of the child, they navigate management and treatment pathways. Carers are often responsible for facilitating a child's adherence to treatment and have expert knowledge on their needs (Mitchell & Sloper, 2001; Young et al., 2002). Women commonly undertake the role of carer and this has social and economic implications (Goddard et al., 2008). Moreover, socioeconomic differentials can impact the capacity of carers to advocate for and access health care (Mactavish et al., 2007; Edwards et al., 2008; Emerson et al., 2011).

The need for partnership between carers and providers recognises carer expertise in knowing the needs of their child (Law et al., 2003; Shields, Pratt, & Hunter, 2006), and is viewed as *'best practice'* (Raghavendra et al., 2007). The aim of this article is to explore carers' experiences of interactions with providers while accessing services and support for their child.

The important role of provider-carer interactions in service access
Provider-carer interactions play a key role in family satisfaction with services (MacKean, Thurston, & Scott, 2005). Satisfaction with provider-carer interactions increases adherence with recommendations for treatment and management (Law et al., 2003). Time spent listening, being open, and conversing facilitates positive provider-carer interactions (Sloper, 1999). Conversely, mismatched expectations around carer roles and inefficient communication can negate open discussion and shared decision-making, negatively impacting carer experiences of service access (Corlett & Twycross, 2006).

Negative experiences in provider-carer interactions may involve inadequate communication or prejudice and stigma. Power and social inequity are particularly important considerations (Mitchell & Sloper, 2001). Power differentials in the interactions between providers, patients, and carers are well-documented across care settings (Mitchell & Sloper, 2001). Aboriginal and Torres Strait Islander women have to contend not only with the oppression of patriarchy, but also with the ongoing impact of colonisation (Maddison & Partridge, 2014). Aboriginal people can be reluctant to seek help for their children with a disability for fear of stigma, shame, and, in the worst cases, removal of custodial care of children (DiGiacomo, Davidson et al., 2013; DiGiacomo, Delaney et al., 2013).

Implicit bias between providers and patients from different racial backgrounds has been linked to communication that is less patient-centred and less positive (Dovidio & Fiske, 2012). Moral judgments and stereotypes of patients by providers can serve to exclude vulnerable groups from accessing services (Hunting, Grace, & Hankivsky, 2015). Workload pressures including limited consultation times and high cognitive demands have been linked to providers reverting to implicit biases (Dovidio & Fiske, 2012). An intersectionality framework can help to elucidate the unacknowledged biases and structural power relationships contributing to adverse health and social outcomes of marginalised populations as well as pave the way for solutions (Manning, Johnson, & Acker-Verney, 2016).

The Aboriginal Community Controlled Health Organization (ACCHO) model of care was developed in response to the Western biomedical approach to health care, seeking to better meet the needs of Aboriginal and Torres Strait Islander peoples in a culturally safe context that is community controlled (Haynes et al. 2014). The model views health *as more than just the physical well-being of an individual, but also the social, emotional and cultural well-being of the whole community'* (Couzos et al., 2005). ACCHOs are governed by local

communities and deliver comprehensive primary health care that has been found to improve health outcomes, reduce barriers to service access, and reduce exposure to racism for Aboriginal and Torres Strait Islander peoples (Panaretto et al., 2014). In the disability journey, however, Aboriginal families regularly interface with services and providers external to ACCHOs in order to manage their children's treatment and other needs.

Intersectionality as a guiding framework to address health disparities

The application of an intersectionality framework has the potential to create new ways of understanding health disparities and also suggestions for improvement (Weber & Fore, 2007; Bauer, 2014). Intersectionality refers to categories of identity which mutually construct each other to inform experiences of discrimination and oppression (Hankivsky & Christoffersen, 2008; Collins, 1998; Collins, 2015). Public health research often focuses on one identity at a time when exploring health disparities (Bowleg, 2012). Acknowledging multiple intersecting identities enables appreciation of the multidimensional complexity of health disparities (Bowleg, 2012; Hankivsky & Christoffersen, 2008; Powell Sears, 2012). Hankivsky et al. (2008) argue that intersectionality

> *'has the potential to create more accurate and inclusive knowledge of human lives and health needs which can inform the development of systematically responsive and socially just health systems and policy' (pp. 279-80).*

Debates around definition—particularly around the shift from the traditional focus on women of color and the intersection of race and gender—can be considered a key strength of intersectionality because it allows for multiple applications (Bowleg, 2012; Carbado et al., 2013). Intersectionality is now applied in a wide variety of clinical and social settings (Cho, Crenshaw, & McCall, 2013). Although its application in health is relatively new and

continually emerging (Bowleg, 2012; Powell Sears, 2012), it has been employed in areas such as HIV/AIDS (Weber & Fore, 2007; Yoshida et al., 2014; Doyal, 2009), disability (Yoshida et al., 2014; Cramer & Plummer, 2009), reproductive health and infant mortality (Carbado et al., 2013), and smoking and pregnancy (Weber & Fore, 2007). Calls have been made to apply intersectionality to new and unexplored areas to further develop the application of the framework in health (Bowleg, 2012; Carbado et al., 2013).

Methods

A phenomenological approach using semi-structured interviews has facilitated exploration of carers' experiences and the meanings they ascribe to these (Malterud, 2001; Pope & Mays, 1995). Parents or informal primary carers of Aboriginal children with a disability were recruited from a developmental clinic for children aged zero-eight years at a metropolitan ACCHO in Australia. One member of the research team was an Aboriginal community elder (PD) who co-led the project. She and an additional community elder (JD) were involved at all stages of the research and also provided cultural oversight of the research. A purposive sampling strategy was employed to recruit carers of children with a range of physical, intellectual, or developmental conditions. Eligible carers were approached by staff at the clinic and were put in contact with a researcher who arranged an interview after obtaining informed consent. Participants were reimbursed for their time and travel costs.

In-depth semi-structured interviews lasting 20-60 minutes were conducted in private rooms at the health service and were audiotaped. Two non-Aboriginal members of the research team conducted the interviews. Both were women who had been affiliated with the service for nearly a decade or more, were simultaneously employed as university academics, and were experienced qualitative researchers. One interviewer (PA) was a family physician, the other

(MD) had qualifications in psychology. Use of two interviewers enabled participation of carers who had limited time available. Interview topics explored participants' lived experiences with the child's disability and their journey to access services and support. Recruitment continued until no new information emerged from interviews.

Follow-up interviews were conducted approximately 12 months after the initial interview either face-to-face at the health service or via phone, according to participants' preferences. These were used to update the families' journeys and to confirm the analytic themes arising from the first interviews. Participants were mainly re-interviewed by the same interviewer. Another member of the research team (AG) was a doctoral student who conducted follow-up phone interviews and contributed to data analysis. All data were collected between April 2013 and June 2015.

Data analysis

Findings related to carers' experiences of navigating systems at the community, organization, and policy levels are reported elsewhere (Green et al., 2016). This article focuses specifically on the ways in which carers experienced and made meaning of interactions with individual providers while accessing care. Complexities inherent in carers' experiences of interactions with providers and their influence on service access became apparent. For this reason, an intersectionality lens was applied to the analysis because it reflects the inherent power differentials in the interactions related to carers' cultural identity as well as to their identity as carers of a child with a disability. In this context, providers inevitably enter interactions with carers from a position of power as representatives of wider healthcare and social systems.

Interpretive phenomenological analysis (IPA) (Smith & Osborn, 2008) was used to analyze carers' experiences of interacting with providers and how they ascribe meaning to these experiences. Following verbatim transcription and de-identification, two researchers (MD, PA) independently analyzed transcripts. Analysts examined their interpretations with each other and the larger research team. To ensure comprehensiveness of analysis, findings were presented to staff at the ACCHO, some of whom were also carers of a child with a disability.

Approval to conduct this study was granted by the Aboriginal Health and Medical Research Council (AH&MRC) [762/10] and University of Technology Sydney Human Research Ethics Committee [2011-417R]. Key principles for research with Aboriginal and Torres Strait Islander peoples (AH&MRC Ethics Committee, 2013) were adhered to and are reported in detail elsewhere (Green et al., 2016).

Results

Participants were 19 carers of Aboriginal children with a disability, 16 of whom were mothers and 3 were grandmothers. Over half (n=10) were sole carers (without a partner/spouse). Two participants disclosed current or previous employment in social or health service roles. The participants were caring for 30 children with disabilities, as well as an additional 30 children without a disability. The disabilities represented included intellectual disability, autistic spectrum disorder, attention deficit hyperactivity disorder, language and communication disorders and hearing impairment, cerebral palsy, and associated conditions such as epilepsy and genetic disorders.

Experiences of interactions with providers reflect the intersection of Aboriginality and disability and disempowerment experienced by carers. Access to care and services was

impeded by providers' cultural stereotypes, racism, and lack of cultural awareness. Although not directly featured in interactions with the range of providers, other forms of oppression, including poverty and homelessness, also challenged access to care. Knowledge of healthcare systems was described as empowering.

Cultural stereotypes and racism impact on care access

Carers perceived that they were looked down on and judged by mainstream providers, both because they were Aboriginal and a carer of a child with a disability. Some had experienced being treated differently when accessing care for their children and believed this was due to racism and cultural stereotypes.

> *Because I'm Aboriginal, like, it's harder to get things done because half the time…doctors, hospitals, like, they look down on me, like because of my color, yeah, the color of my skin and, like, they talk to me like I don't know nothing...they just talk to me in a rude tone and, like, they, like, give me attitude.*

Another participant perceived that providers treated her as though she was a bad parent:

> *They don't respect me, in a way, like with the kids. Well, mostly with her [child with disability]. I have got one doctor that is really rude and everything…. The way they talk, and just the actions… Well, when they go to check her over … just mostly they are thinking that, in my eyes, that I am a bad parent.*

She interprets the way the provider spoke and behaved towards her as communicating disrespect. As described in the following excerpt, a consequence of a disrespectful or insensitive encounter between an Aboriginal carer and a healthcare provider could be that a child may ultimately not receive appropriate management because the carer will not return to a provider who has been disrespectful or risk a similar experience with other providers.

> *It's hard as to a new situation when it comes to Aboriginals…but* [the health care provider] *might have had a bad day, and something* [the health care provider] *said*

and they [Aboriginal carer] *just walk out and they'll never come back, and that child goes without because of that happening.*

Another participant described having witnessed racist behaviour in service settings:

I've been in, um, different places and you've seen an Aboriginal family walk out and then you've had people talking and you've just sat there and you've let it go for a while and then you actually stand up and say, "Well look, I'm Aboriginal too. I actually know that family. How dare you do that?" and they're gobsmacked. Because they think well, how come you're nicely dressed and everything else and you don't talk the way they do… you're disgusted with some of the agencies how they actually describe an Aboriginal family.

Past experiences of racism, or those experienced by family or community members, may continue to influence carers' decisions to seek care and support for their child with a disability.

It's heartbreaking to look at your child and know that there's something wrong. And being Aboriginal as well, you kind of think, oh look, they'll pick up soon enough. … you've got your elder saying to you, "No, they're right. They're right. Don't worry about it. They'll pick up in their own time," … Black fellas are very sceptical of getting outside help. They'd rather go to their own people and feel like they're not judged, but they're not judged anyway because it doesn't matter what race it is, kids still do have things wrong.

This excerpt illustrates the complicated position of the carer who wants to respect the advice of her Aboriginal community elders, but feels that additional assistance may be needed for her child. She links the advice to Aboriginal culture, but also cites the community's lack of trust in mainstream services based on past experiences. This is an example of how previous bad experiences with providers and services impacts healthcare access in disability.

Lack of provider cultural awareness impacts healthcare access

Independent of the experiences of racism, poor cultural understanding demonstrated by some mainstream providers, and the resultant lack of cultural safety for carers led to disengagement from services. Respectful recognition of cultural differences was perceived as vital.

> *There is no allowances whatsoever, they just feel that because you're Australian, we've got to be the same as any other Aussie person. Well, it's not. We're Indigenous. We've got our beliefs and everything, and people don't understand that.*

Carers expressed frustration with the way some providers interacted with them, feeling dismissed and disempowered. Rushed consultations, hastily prescribed medications and little questioning about the child and family led to dissatisfaction.

> *I had* [child] *to another paediatrician before we started here* [ACCHO] *with him, and I wasn't impressed…he just looked at her and he said, I think I will medicate her. He didn't explain anything to me…I just went away and I thought well that's not good enough, you haven't really asked me anything…*[Doctor from an ACCHO] *took ages to explain to me what the medication is, what it does, how it works.*

One carer described her experience of accessing a paediatrician as defined by a lack of empathy. After receiving a difficult diagnosis, the paediatrician requested that she not look for information on her own while also not planning a face-to-face discussion for over a week.

> *We saw a paediatrician there, um, and I – I didn't like him at all…I mean there was absolutely no empathy towards me as a mum finding out, you know, what was happening and told me over the phone you know, what her diagnosis was, um, and, sort of, said, you know, we can't have a meeting with you until, you know, a week-and-a-half and please don't look up stuff on the internet and, you know, we'll see you then, um, which – I mean she was four months old…It was ridiculous. So – and when*

we finally went to see him, I mean, he just wasn't interested. I mean, he was just there

to, sort of, do what he had to do and that was it.

In the excerpt below, a carer recalls that she presented concerns about her child to providers and was dismissed as having other competing issues involving family. For this carer, provider judgments obstructed their ability to hear what she needed.

I can go to the doctor's, like, you know, she won't sleep, this and that and I feel

stressed, "You're tired, you've got too many kids, your husband's got [health

condition]", you know, the usual, "blah, blah, blah". And a clinic nurse; she said to

me, she said, "Oh, no, no, there's nothing wrong with her". I'm telling you there is.

Providers positively influenced interactions by not dismissing carer concerns and by engaging in therapeutic relationships not solely focused on medication. Participants preferred interacting with providers at the ACCHOs because they had an understanding of cross-cultural communication, which facilitated better quality care for their child. In effect, the ACCHO helped to overcome the intersectional effect of being Aboriginal and dealing with disability. Culturally competent providers and culturally secure services were important to increasing carer satisfaction with interactions and willingness to engage with services.

They're culturally sensitive and they understand Aboriginal issues…And you don't

even have to explain things, 'cause they know you, know what I mean?…"I want to

discuss that, but I'm a bit shame about that". And they won't go further…'Cause they

understand the word shame. Or there's just a way that you feel more comfortable

…'Cause it's very serious, your child needing to have behaviour altering medication.

This excerpt depicts the intersection of Aboriginality and cross-cultural health care. Preference for interacting with ACCHO providers reflected respect, ease of communication, and feeling understood without too much explanation, which facilitated trust:

You know that you are going to be treated well when you come (to the ACCHO).

Another example of the intersection of Aboriginality and disability was depicted in the following excerpt regarding interactions with education providers. A carer described a delay in her child's school notifying her of behavioural issues due to what she perceived as school personnel's fear of approaching her brother. The school only approached the family once the child's behavioural issue had escalated, leading to a delay in diagnosis and treatment.

> *Because we were the only Aboriginal family there, and we – my brother - used to take her to school because I was working, and my brother was a chav, so he looked chav himself and they didn't want to approach us. And my brother's black, see…So, I think that school was scared to approach my brother. When they did approach, it (child's behaviour) was beyond anything that they could control.*

This participant perceived that school staff may have been unsure of how to approach the child's uncle, possibly because of his appearance, and thus avoided communicating important information to the family and may have escalated the problem. Another carer conveyed the following experience with her child's school principal:

> *They're looking at you like to say 'well, are you doing the right thing? Are you helping this child?' The school actually told me that they would not help until (child) did have an MRI to see if there was something wrong…Well, with him saying that to me, that felt like they didn't care. They didn't give two hoots if he would be at the bottom of his class forever. That's not their problem. They've got other children that they can put the effort into, so that's what they'll do.*

At the beginning of this excerpt, the participant described her perception that the school questioned whether she was taking the necessary steps to help her child. The principal then told her that until investigations identified a problem, the school could not help the child. She perceived this as a withdrawal of support, which compounded her disempowerment.

Aboriginal carers experience poverty and homelessness that challenge access to care

Inherent in participants' descriptions of their experiences were features of social marginalisation including poverty, homelessness, and in some cases being a single mother and caring for several children with competing needs. These problems affected their ability to access care. Participants described receiving some government financial support or subsidies to pay for treatment for their children, but highlighted the additional out-of-pocket costs they encountered. A complete description of carer perceptions of economic and non-economic costs in Aboriginal childhood disability are reported elsewhere (DiGiacomo et al., 2017). In addition to financial challenges in providing care for their children, some carers interacted with government agencies in seeking assistance to manage the costs of the care or family housing needs. The following excerpt reflects a participant's understanding of the effect of homelessness on carers. Drawing from her professional role, she provided context regarding ongoing problems faced by some Aboriginal carers of children with disability:

> *Homelessness is a major issue for heaps of our families. And I always feel that if we can sort out the homelessness, that everything else has fallen into place. Because when they are living so transiently, it's hard to ensure that they attend services. And it's the ones in temporary accommodations and the ones that are literally homeless. They are living in motels, going from motel to motel and all of that… So, therefore, the child misses out.*

This is an example of how multiple forms of oppression shape life experiences of carers and Aboriginal children with a disability. Racism, poverty, homelessness, and being a single mother intersect to take away power.

Knowledge of health systems is empowering

Knowledge of how to interact with mainstream systems and providers and previous caregiving experiences empowered some carers. Knowledge acquired from employment backgrounds, often in government or social service organizations, helped carers to proactively interact with providers. Previous experience of caring for a child with a disability could assist carers to know which providers to see and what information was required to enable productive interactions. Carers who were comfortable playing the role of advocate also recognised that those carers who were less able to advocate were disadvantaged.

> *'I feel sorry for people that don't understand because I don't know what they are getting. If I can't get anywhere, you know with a bit of knowledge…Yeah, you know like they just get pushed aside...'*

Discussion

Power differentials between providers and patients are well described (Mitchell & Sloper, 2001; Corlett & Twycross, 2006). As understood in the intersectionality framework, an individual's experiences are not informed by a single identity (Hankivsky, 2012); rather, different identities combine to increase experiences of marginalisation and disadvantage. This study demonstrates that focusing solely on issues of cultural identity may blind providers to those experiences related to being a carer of a child with a disability and vice versa. Addressing the intersection of carer identities is important in improving carer-provider interactions, thereby improving access to services for their children. The study provides new insights into how the intersectionality framework can be applied to address healthcare disparities.

The ACCHO model of care positively influenced interactions for many carers by facilitating culturally appropriate health care. Culturally aware communication within the ACCHO

model of care was seen as a key facilitator to carers' positive experiences with providers, which resulted in better quality care for the children. In our research, this holistic approach to service provision was seen to address not only issues related to carers' identity as Aboriginal people but also issues related to being a carer of a child with a disability. It is argued that the ACCHO model of care supports delivery of a wide range of health and well-being services, whereas mainstream services are more tied to clinical specialties (Mitchell & Hussey, 2006). Further, primary healthcare settings, such as in an ACCHO, may be more enabling of an intersectional approach. Panaretto et al. (2014) argue that the holistic family-centred approach of the ACCHO model extends care to a child's family and increases the ability of providers to manage complexity in consultations by supporting the necessary resources and time. This is opposed to general consultations in mainstream services (Panaretto et al., 2014). Healthcare providers in ACCHOs who are not Aboriginal benefit from cultural mentorship working in collaboration with Aboriginal community members, Aboriginal Health Workers, and cultural mentors (Abbott et al., 2014). The authors recommend the need for more support in terms of policy and funding of ACCHOs to improve access to primary health care. Our findings highlight the importance of this recommendation particularly in light of the positive role of the ACCHO model of care in approaching the intersection of identities for carers.

It is argued that as a social movement, the adoption of intersectionality by organizations does not necessarily lead to improvements in the political and social marginalisation of minority groups (Laperrière & Lépinard, 2016). In the context of grassroots women's organizations in Quebec employing intersectionality as an inclusion tool for providing services and support to immigrant and Native women, Laperrière and Lépinard (2016) found tension between recognising the diverse intersecting needs of these women and the need to maintain a common overarching feminist political platform privileging gender as the dominant identity.

Similar challenges may be faced by ACCHOs in further developing their strength as organizations well positioned to address the intersecting needs of carers.

Carers' descriptions of the effect of culture and disability on their interactions with providers reflects a core component of intersectionality theory. Solely focusing on one category of identity can render other categories invisible and negate the notion of cumulative disadvantage. It is argued that when disability service providers focus solely on disability in providing services to Aboriginal and Torres Strait Islander people with a disability, it can lead to a lack of awareness of the need to also address the *'disabling experiences of being Indigenous in 'white' Australia'* (Hollinsworth, 2013). The First Peoples Disability Network (FPDN) (Australia) (2016) reports that the intersection of racially and disability-based institutionalised discrimination is an emerging finding related to interaction with healthcare systems. The organization advocates the importance of considering the *'intersectional aspects of institutionalised discrimination'* experienced by people who are Indigenous with a disability, in securing their rights to access to healthcare services (FPDN (Australia), 2016). Additionally, when applying an intersectionality lens to service provision for Aboriginal and Torres Strait Islander children with a disability and their families, it is important to recognise that carers may have other identities beyond their cultural background and that being a carer might influence interactions, such as socioeconomic status, gender, or their own health conditions. In particular, participants in this study were all women, a number of whom also reported the strain of being a sole carer in the face of the economic costs of caregiving. Globally, indigenous women from low socioeconomic backgrounds have been identified as particularly vulnerable to discrimination and oppression based on the intersection of race, low socioeconomic status, and gender. A Canadian intersectional study of the experiences of Aboriginal mothers accessing health care found that women were reluctant to engage with

mainstream services due to negative experiences of providers' perceptions of being *'bad mothers'* in relation to ongoing effects of colonisation, the imposition of *'Western models of mothering'*, and lack of financial resources (Anne Van Herk, Smith, & Andrew, 2011). This is similar to the experiences of carers in this study who reported feeling looked down upon and judged by providers, both because they were Aboriginal and carers of a child with a disability.

The racism experienced by some carers contributed to them feeling judged by some mainstream providers and was a significant barrier to effective interactions and willingness to access mainstream services for their children. A study of cultural mentors' and Aboriginal Health Workers' views on what is needed for family physicians to work effectively with Aboriginal patients found that providers being respectful and taking a non-judgmental approach was important (Abbott et al., 2014). Reported barriers to culturally competent service provision in mainstream settings include high workloads and lack of provider interest in cultural competence training (DiGiacomo et al., 2010). Bond (2005) asserts that the fields of public health and medicine have inevitably been influenced by *'the politics of colonialism'* and that healthcare professionals need to abandon claims of being objective and be willing to reflect on how their own *'cultural practices'* may influence the health of Aboriginal and Torres Strait Islander peoples (Bond, 2005). The adoption of an intersectional approach to service provision by organizations has been reported to encourage the self-reflexivity of providers in reflecting on their own *'privileged social position'* as experts in relation to their clients (Laperrière & Lépinard, 2016). Dovidio and Fiske (2012) argue that the first step to addressing the impact of implicit bias in health care is for providers to recognise the influence of discrimination on healthcare disparities. Unexamined bias can adversely impact interactions with patients. Intersectionality promotes provider use of reflexivity to examine

implicit bias and potential power differentials to facilitate positive carer-provider interactions (Hunting, Grace, & Hankivsky, 2015). The nature of intersectionality in not seeking to come to a single consensus but rather leaving analysis open, lends itself particularly well to addressing implicit bias in avoiding assumptions based on single identities in isolation (Maddison & Partridge, 2014; Manning, Johnson, & Acker-Verney, 2016).

Cultural competence training for some healthcare professionals begins at university as a way to improve attitudes and knowledge of patients from minority cultural backgrounds (Powell Sears, 2012). Yet, acknowledging implicit biases and the social, political, economic and cultural histories of healthcare systems is required. The use of culture as a narrow prism through which to view patients can have the unintentional consequence of encouraging healthcare professionals to homogenise cultural groups that can fuel stereotypes, lead to victim-blaming, and overlooking the important diversity among populations (Hollinsworth, 2013; Powell Sears, 2012; Viruell-Fuentes, Miranda, & Abdulrahim, 2012). Intersectionality provides a way to overcome some of these critiques of cultural competence training. Powell (2012) argues that an intersectional framework should be integrated into the cultural competence training students receive in university. Rather than replacing cultural competence training, an intersectional framework should be seen as a complementary force to better inform healthcare professionals' interactions with patients and recognition of the impact that intersecting identities can have on healthcare (Powell Sears, 2012). When healthcare professionals enter the workforce, they should have *'intersectional competence'* as well as cultural competence (Powell Sears, 2012). Weber and Fore (2007) also argue that intersectionality as a framework presents an alternative to the traditional biomedical approach focused on individual bodies, which is an important aspect of addressing healthcare disparities. Carers may benefit from initiatives to raise awareness of and provide training in

how to advocate with mainstream systems and their providers. Knowledge acquired from employment backgrounds and previous experience of caring for a child with a disability helped to empower some carers to advocate for their needs with providers. Supporting carers to enhance their existing strengths and capacities to advocate is an important area for future research.

Limitations

This study was not initially driven by intersectionality theory, but future research in this area should consider using this framework in designing exploration and application of this important area. Although unintended, all of the participants recruited for this study were female. The perspectives of male carers may facilitate a deeper understanding of carer experiences in this area. Potential drawbacks of having more than one interviewer may be that rapport is more difficult to establish with a second interviewer, which may affect credibility of findings. Over half of the follow-up interviews were conducted by the same interviewer who conducted initial interviews with the same participants. At the beginning of follow-up interviews, the interviewer summarised content of the first interview and explained the purpose of the follow-up. By doing this, the participant knew that they would not have to repeat their stories and the interviewer had an understanding of their experiences, which appeared to mitigate any challenge establishing rapport. Interviewers met regularly to debrief and all contributed to analysis, which helped to ensure consistency and rigour of our approach and interpretations.

Conclusion

Addressing the disparity in Aboriginal and Torres Strait Islanders' childhood disabilities requires improving access to services for intervention as well as addressing inherent

differentials contributing to disadvantage and healthcare disparities. Carer-provider interactions play a key role in influencing the willingness of carers to engage with services to obtain support for their children. The intersection of identities as Aboriginal carers of a child with a disability is experienced simultaneously in interactions with providers and needs to be considered interdependently. Community-led models of care can help carers overcome the intersectional effects of these identities in their interactions with providers, and can enhance access to care for this vulnerable group. Increasing cultural competence, recognising implicit bias, appreciation of social determinants of healthcare, and being aware of inherent power differentials between providers and carers will also assist in breaking down barriers to care.

Acknowledgements

Declaration of conflicting interests

The Authors declare that there is no conflict of interest.

Funding

References

Abbott, P., Dave, D., Gordon, E., & Reath, J. (2014). What do GPs need to work more effectively with Aboriginal patients? Views of Aboriginal cultural mentors and health workers. *Australian Family Physician, 43(1-2)*, 326.

Aboriginal Health and Medical Research Council (AH&MRC) Ethics Committee. (2013). *AH&MRC Guidelines for Research into Aboriginal Health: Key Principles*. Sydney: Aboriginal Health & Medical Research Council of New South Wales.

Australian Institute of Health and Welfare (AIHW). (2014). *Stronger Futures in the Northern Territory: Hearing Health Services 2012-2013*. Canberra: Australian Institute of Health and Welfare.

Anne Van Herk, K., Smith, D., & Andrew, C. (2011). Identity matters: Aboriginal mothers' experiences of accessing health care. *Contemporary Nurse 37(1)*, 57-68.

Australian Health Ministers' Advisory Council. (2004). *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004-2009*. South Australia: Department of Health South Australia.

Bauer, G. R. (2014). Incorporating intersectionality theory into population health research methodology: Challenges and the potential to advance health equity. *Social Science & Medicine, 110*, 10-17.

Biddle, N., Yap, M., & Gray, M. (2013). *CAEPR Indigenous Population Project 2011 Census Papers. Paper 6 Disability*. Canberra: Australian National University.

Bond, C. J. (2005). A culture of ill health: public health or Aboriginality? *Medical Journal of Australia, 183(1)*, 39.

Bowleg, L. (2012). The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health. *American Journal of Public Health, 102(7)*, 1267-1273.

Burns, J., & Thomson, N. (2013). *Review of ear health and hearing among Indigenous Australians*. Western Australia: Australian Indigenous HealthInfoNet.

Burrow, S., Galloway, A., & Weissofner, N. (2009). *Review of educational and other approaches to hearing loss among Indigenous people.* Western Australia: Australian Indigenous HealthInfoNet.

Carbado, D. W., Crenshaw, K. W., Mays, V. M., & Tomlinson, B. (2013). Intersectionality. *Du Bois review: social science research on race, 10(2)*, 303-312.

Cho, S., Crenshaw, K. W., & McCall, L. (2013). Toward a field of intersectionality studies: Theory, applications, and praxis. *Signs, 38(4)*, 785-810.

Collins, P. H. (1998). It's all in the family: Intersections of gender, race, and nation. *Hypatia, 13(3)*, 62-82.

Collins, P. H. (2015). Intersectionality's definitional dilemmas. *Annual Review of Sociology, 41*, 1-20.

Commission on Social Determinants of Health. (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health*. Geneva: World Health Organization.

Corlett, J. & Twycross, A. (2006). Negotiation of parental roles within family-centred care: a review of the research. *Journal of Clinical Nursing, 15(10)*, 1308-1316.

Couzos, S., Lea, T., Murray, R., & Culbong, M. (2005). 'We are Not Just Participants – We are in Charge': The NACCHO Ear Trial and the Process for Aboriginal Community-controlled Health Research. *Ethnicity and Health, 10(2)*, 91-111.

Cramer, E. P., & Plummer, S. B. (2009). People of color with disabilities: Intersectionality as a framework for analyzing intimate partner violence in social, historical, and political contexts. *Journal of Aggression, Maltreatment & Trauma, 18(2)*, 162-181.

DiGiacomo, M., Davidson, P.M., Abbott, P., Delaney, P., Dharmendra, T., McGrath, S.J., Delaney, J., & Vincent, F. (2013). Childhood Disability in Aboriginal and Torres Strait Islander Peoples: a literature review. *International Journal for Equity in Health*, *12*:7.

DiGiacomo, M., Delaney, P., Abbott, P., Davidson, P.M., Delaney, J., & Vincent, F. (2013). Doing the Hard Yards: Carer and provider focus group perspectives of accessing Aboriginal childhood disability services. *BMC Health Services Research, 13(3),* 326.

DiGiacomo, M., Green, A., Abbott, P., Davidson, P.M., Patradoon-Ho, P., Delaney, J., & Delaney, P. (2017). Experiences and needs of carers of Aboriginal children with a disability: a qualitative study. *BMC Family Practice*, *18*, 96.

DiGiacomo, M., Thompson, S. C., Smith, J. S., Taylor, K. P., Dimer, L. A., Mohammed, A. A., Wood, M. M., Leahy, T. G., & Davidson, P. M. (2010). 'I don't know why they don't come': barriers to participation in cardiac rehabilitation. *Australian Health Review*, *34*, 452-457.

Dovidio, J. F., & Fiske, S. T. (2012). Under the radar: how unexamined biases in decision-making processes in clinical interactions can contribute to health care disparities. *American Journal of Public Health, 102(5)*, 945-952.

Doyal, L. (2009). Challenges in researching life with HIV/AIDS: an intersectional analysis of black African migrants in London. *Culture, Health & Sexuality, 11(2)*, 173-188.

Edwards, B., Higgins, D. J., Gray, M., Zmijewski, N., & Kingston, M. (2008). *The nature and impact of caring for family members with a disability in Australia. Research Report No. 16*. Canberra: Australian Institute of Family Studies.

Emerson, E., Madden, R., Graham, H., Llewellyn, G., Hatton, C., & Robertson, J. (2011). The health of disabled people and the social determinants of health. *Public Health, 125(3)*, 145-147.

First Peoples Disability Network (Australia) (FPDN). (2016). *Intersectional Dimensions on the Right to Health for Indigenous Peoples – A Disability Perspective*. Sydney: First Peoples Disability Network (Australia).

Gilroy, J. (2012). *The participation of Aboriginal people with a disability in disability services in New South Wales, Australia*. PhD diss., University of Sydney.

Goddard, L., Davidson, P. M., Daly, J., & Mackey, S. (2008). People with an intellectual disability in the discourse of chronic and complex conditions: an invisible group? *Australian Health Review, 32(3)*, 405-414.

Goldblatt, P., Siegrist, J., Lundberg, O., Marinetti, C., Farrer, L., & Costongs, C. (2015). *Improving health equity through action across the life course: Summary of evidence and recommendations from the DRIVERS project. Report produced as part of the DRIVERS for Health Equity project*. Brussels: EuroHealthNet.

Green, A., Abbott, P., Delaney, P., Patradoon-Ho, P., Delaney, J., Davidson, P.M., & DiGiacomo, M. (2016). Navigating the journey of Aboriginal childhood disability: a qualitative study of carers' interface with services, *BMC Health Services Research*, *16(1)*, 680.

Hankivsky, O. (2012). Women's health, men's health, and gender and health: Implications of intersectionality. *Social Science & Medicine, 74(11)*, 1712-1720.

Hankivsky, O. & Christoffersen, A. (2008). Intersectionality and the determinants of health: a Canadian perspective. *Critical Public Health, 18(3)*, 271-283.

Haynes, E., Taylor, K., Durey, A., Bessarab, D., & Thompson, S. (2014). Examining the potential contribution of social theory to developing and supporting Australian Indigenous-mainstream health service partnerships. *International Journal for Equity in Health, 13(1)*, 75.

Hollinsworth, D. (2012). Decolonizing indigenous disability in Australia. *Disability & Society, 28(5)*, 601-615.

Hunting, G., Grace, D., & Hankivsky, O. (2015). Taking action on stigma and discrimination: An Intersectionality-Informed Model of Social Inclusion and Exclusion. *Intersectionalities: A Global Journal of Social Work Analysis, Research, Polity, and Practice, 4(2)*, 101-125.

Laperrière, M. & Lépinard, E. (2016). Intersectionality as a tool for social movements: Strategies of inclusion and representation in the Québécois women's movement. *Politics, 36(4)*, 374-382.

Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M., & Rosenbaum, P. (2003). Factors affecting family- centred service delivery for children with disabilities. C*hild: care, health and development, 29(5)*, 357-366.

MacKean, G. L., Thurston, W .E., & Scott, C. M. (2005). Bridging the divide between families and health professionals' perspectives on family- centred care. *Health Expectations, 8(1)*, 74-85.

Mactavish, J. B., MacKay, K. J., Iwasaki, Y., & Betteridge, D. (2007). Family caregivers of individuals with intellectual disability: Perspectives on life quality and the role of vacations. *Journal of Leisure Research, 39(1)*, 127-155.

Maddison, S. & Partridge, E. (2014). Agonism and intersectionality: Indigenous women, violence and feminist collective identity. In *Intersectionality and Social Change (Research in Social Movements, Conflicts and Change, Volume 37)*, edited by Lynne M Woehrle, 27-52. Online: Emerald Group Publishing Limited.

Malterud, K. (2001). Qualitative research: standards, challenges, and guidelines. *The Lancet, 358(9280)*, 483-488.

Manning, S. M., Johnson, P., & Acker-Verney, J. (2016). Uneasy intersections: critical understandings of gender and disability in global development. *Third World Thematics: A TWQ Journal, 1(3)*, 292-306.

Mitchell, M. & Hussey, L. M. (2006). The Aboriginal health worker. *Medical Journal of Australia, 184(10)*, 529.

Mitchell, W. & Sloper, P. (2001). Quality in services for disabled children and their families: what can theory, policy and research on children's and parents' views tell us? *Children & Society, 15(4)*, 237-252.

Morris, P. S., Leach, A. J., Silberberg, P., Mellon, G., Wilson, C., Hamilton, E., & Beissbarth, J. (2005). Otitis media in young Aboriginal children from remote communities in Northern and Central Australia: a cross-sectional survey. *BMC pediatrics, 5(1)*, 27.

Panaretto, K. S., Wenitong, M., Button, S., & Ring, I. T. (2014). Aboriginal community controlled health services: leading the way in primary care. *Medical Journal of Australia, 200(11)*, 649-652.

Pope, C. & Mays, N. (1995). Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ: British Medical Journal, 311(6996)*, 42.

Powell Sears, K. (2012). Improving cultural competence education: the utility of an intersectional framework. *Medical Education, 46(6)*, 545-551.

Queensland Health. (2009). *Deadly Ears, Deadly Kids, Deadly Communities: 2009-2013*. Queensland: Queensland Government.

Raghavendra, P., Murchland, S., Bentley, M., Wake- Dyster, W., & Lyons, T. (2007). Parents' and service providers' perceptions of family- centred practice in a community-based, paediatric disability service in Australia. *Child: care, health and development, 33(5)*, 586-592.

Shields, L., Pratt, J., & Hunter, J. (2006). Family centred care: a review of qualitative studies. *Journal of Clinical Nursing, 15(10)*, 1317-1323.

Sloper, P. (1999). Models of service support for parents of disabled children. What do we know? What do we need to know? *Child Care Health and Development, 25(2)*, 85-99.

Smith, J., & Osborn, M. (2008). Interpretive Phenomenological Analysis. In *Qualitative Psychology: A Practical Guide to Research Methods Second Edition*, edited by J., Smith, 53-80. London: Sage.

Thorne, J. A. (2003/4). Middle ear problems in Aboriginal school children cause developmental and educational concerns. *Contemporary Nurse, 16(1-2)*, 145-150.

Vasileiou, K., Barnett, J., Barreto, M., Vines, J., Atkinson, M., Lawson, S., & Wilson, M. (2017). Experiences of Loneliness Associated with Being an Informal Caregiver: A Qualitative Investigation. *Frontiers in Psychology, 8*, 585.

Viruell-Fuentes, E. A., Miranda, P. Y., & Abdulrahim, S. (2012). More than culture: structural racism, intersectionality theory, and immigrant health. *Social Science & Medicine, 75(12)*, 2099-2106.

Weber, L. & Fore, M. E. (2007). Race, ethnicity, and health: An intersectional approach. In *Handbooks of the sociology of racial and ethnic relations*, edited by H., Vera and J.R., Feagin, 191-218. United States: Springer.

World Health Organization (WHO) & The World Bank. (2011). *World Report on Disability*. Geneva: WHO.

Yoshida, K., Hanass-Hancock, J., Nixon, S., & Bond, V. (2014). Using intersectionality to explore experiences of disability and HIV among women and men in Zambia. *Disability and Rehabilitation, 36(25)*, 2161-2168.

Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: conceptualising mothers of children with cancer. *Social Science & Medicine, 55(10)*, 1835-1847.