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Research

Communication and context are important to Indigenous children with physical disability and their carers at a community-based physiotherapy service: a qualitative study

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KEYWORDS

Qualitative research
Oceanic Ancestry Group
Disabled persons
Child
Caregiver



ABSTRACT

Question: What are the experiences of Indigenous children with physical disability and their carers of their community-based physiotherapy service? What factors influence their experiences of the physiotherapy service and how could the service be improved? **Design:** A qualitative study using in-depth, semi-structured open-ended interviews consistent with the researchers' interpretivist perspectives and ethical principles of Indigenous health research. Interviews were audio recorded, transcribed and coded for themes with qualitative research software using inductive analysis. The interviews were then checked for transcription accuracy and the themes were confirmed with the participants. **Participants:** Nine parents and foster carers of children with physical disability aged 0 to 21 years, five children and youth with physical disability aged 8 to 21 years. **Results:** The data generated three themes, which informed practice recommendations: carers of children with physical disability experience increased demands and complexity in their lives; relationships involving caring, consistency and communication are important to consumers using the physiotherapy service; and being Indigenous influences consumers' experiences in ways that may not be obvious to non-Indigenous service providers. The issue of communication underpinned the participants' experiences throughout these themes. **Conclusion:** The research highlighted the importance of effective communication, developing relationships, viewing the child wholistically and recognising the influence of being Indigenous on clients' healthcare needs and experiences. The results suggested that community-based physiotherapists adopt a family/person-centred, context-specific approach when working with Indigenous children with a physical disability and their carers. [Greenstein C, Lowell A, Thomas D (2016) **Communication and context are important to Indigenous children with physical disability and their carers at a community-based physiotherapy service: a qualitative study.** *Journal of Physiotherapy* 62: 42–47] © 2015 Australian Physiotherapy Association. Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Introduction

Indigenous Australians experience a higher rate of disability throughout their lifespan when compared with their non-Indigenous counterparts.¹ Although accurate statistics are difficult to obtain,² Indigenous Australians are twice as likely, and Indigenous children are 30% more likely, to have a disability than non-Indigenous Australians of the same age, with the majority having a physical disability.²

Although the World Health Organization describes people with disability as among the most marginalised and vulnerable populations in the world,³ Indigenous Australians with a disability are considered to be 'doubly disadvantaged' due to the additional disadvantage in socially determined areas of health.⁴ Indigenous children with disability can be considered to have a 'triple disadvantage' due to the additional limitations they may experience during their critical early years of development when they are most vulnerable.

Despite this added disadvantage, little has been published about the needs and experiences of Indigenous children with a physical disability and their carers.^{5–7} No research reflecting the perspectives of Indigenous children with a physical disability could be found in Australian literature. This deficit was highlighted in a recent audit of disability research commissioned by the National Disability Research and Development Agenda. This audit recommended dedicating funding to 'stimulating disability research that addresses the needs and experiences of Aboriginal and Torres Strait Islander carers'⁷ and research that pertains to the 'experiences of people with disability as specialist service users'.⁷

Physiotherapy has a role to play in supporting children with disability by providing 'treatment, management and education to enhance the participation of children aged 0 to 18 years'.⁸ However, there is no published peer-reviewed physiotherapy literature, to date, exploring practice for Indigenous Australians with physical disability. The few articles addressing physiotherapy practice in Indigenous healthcare have been editorials and letters

noting the scarcity of attention to Indigenous health,⁹ outcomes,¹⁰ or communication guidelines¹¹ in physiotherapy research.

Therefore, the research questions for this study were:

1. What are the experiences of Indigenous children with physical disability and their carers of their community-based physiotherapy service?
2. What factors influence their experiences of the physiotherapy service and how could the service be improved?

Method

Design

A qualitative research design using open-ended, semi-structured, in-depth interviews was chosen to provide a means of exploring the experiences of children with a physical disability and their carers, who have used a community-based physiotherapy service.

The design of the study was informed by the Indigenous values and ethics highlighted in the National Health and Medical Research Council guidelines¹² and reflects an interpretivist theoretical position.¹³ Semi-structured, in-depth interviews were conducted to enable the participants to delve deeper into topics that they considered to be important in a flexible and iterative process. Interviews were guided by a set of questions based on a feedback tool designed for Indigenous consumers with chronic health conditions.¹⁴ Participants were selected to reflect a diversity of perspectives, and the research process recognised the power dynamics inherent between the service provider/researcher and the participant/service user.¹⁵ We ensured that participants knew their care would not be disadvantaged if they declined to participate or withdrew from the study and used a semi-structured interview in which the participant could control the topics discussed and the depth in which they were discussed. We also met participants after each interview was transcribed and analysed to discuss emerging themes and offered to meet later to share the results of the study. This study was limited to a specific community-based physiotherapy service due to the researchers' beliefs that more impact could be made on a service in which both researcher and participants were involved, reflecting the principle of reciprocity.¹²

The study was part of a larger research project combining a continuous quality improvement approach and client interviews to examine and improve physiotherapy service provision at the participating facility where the principal researcher was a non-Indigenous physiotherapist.

Participants

Participants were recruited from a community-based physiotherapy service within a regional town in northern Australia with a population of 140 400¹⁶ and an estimated Indigenous population of 15 500.¹⁷ The physiotherapy service consisted of a maximum of four physiotherapists situated in a larger paediatric team that included speech/language pathologists and occupational therapists. Health services located within the area included a hospital, a non-government early intervention service, several public community care centres and an Aboriginal community controlled health service.

Participants met inclusion criteria if they were either: 1) children/youth with a physical disability aged 8 to 21 years, identified as an Indigenous Australian, and capable of participating in an interview; or 2) carers looking after Indigenous children or young adults who had a physical disability and were aged 0 to 21 years. Participants were excluded if they had since moved interstate, were not cognitively capable of participating or communicating, aged under 8 years, or were undergoing stressful circumstances in their lives in which the additional demands of an interview request may have been detrimental. People that met the criteria were identified through the physiotherapy records as previous or current clients of the service.

To ensure confidentiality from staff in the clinic and other members of the community, the principal researcher individually approached by telephone or in person the carers who satisfied the criteria. Participants who were unknown to the researcher were screened through their primary therapist to find out if they were interested in being contacted. Participant selection was initially conducted using purposive sampling, as the principal researcher sought a diverse group of participants with a range of experiences who were '... able to articulate what they have lived through, or describe their embodied experiences.'¹⁸ Emerging themes influenced the participants who were selected; as new concepts emerged, participants who could enable further exploration of these concepts were approached.¹⁵

Data collection

Each interview occurred at the time, date and location of the participant's choice. An interview guide was used to provide a general list of topics for conversation (see [Box 1](#) and [Box 2](#)).

Box 1. Sample interview guide and prompt questions for carers

Client story

- How did you become involved with this physiotherapy service?
- What have been the good things about the physiotherapy service?
- What have been the bad things?

Participation in care

- Have you required any help from your physiotherapist to understand your child's physical issues?
- Did the physiotherapist give you information that you understand about your child's issues and treatment options?
- Did you get asked about your concerns for your child?
- Did you get asked what areas you would like the physiotherapist to work on?
- Did you have a say in the type of physiotherapy treatment? (For example, were you asked what areas you would like the physiotherapist to work on and where sessions were held?)

Respectful care

- Did the physiotherapist ask you about your language, culture and beliefs when providing care for your child?
- How did you feel about this?
- Did you feel staff responded to your needs as an Indigenous person?
- Did the physiotherapist ask you about your home and family when planning your care?
- Did you feel comfortable asking questions if you needed to?

Care providers

- Do you feel that your care was well organised?
- Have you had different physiotherapists involved?
- If so, did you get the same messages and advice about your child's condition and physiotherapy activities?
- Did you get linked in with other care providers (eg, occupational therapists, doctors, disability coordinators?)

Follow up

- Did the physiotherapist or the office remind you when your child's next physiotherapy appointment was?
- Was this helpful?
- Do the physiotherapists contact you when you have not been able to attend an appointment?

Advice

- If you were talking to a physiotherapist who was just starting to work with children, what advice would you give them?
- What do you think could be done to make the service better?

Box 2. Sample interview guide and prompt questions for children/youth.

Comfortable introductory questions

- How old are you?
- Were you born in this town?
- Where do you go to school?
- Do you like school?

Client story

- Do you remember when you started seeing a physiotherapist from my team?
- What was he or she like (eg, scary, mean, confusing, nice)?
- What sort of stuff did you do with him or her?
- What things do you like about physiotherapy?
- What things were bad with physiotherapy?
- What do you think I could do to make the service better?

Participation in care

- Do you feel comfortable talking to and asking questions of your physiotherapist?
- Do you ever get asked what you would like to work on? Are you given a choice of activities?
- Do you prefer to see the physiotherapist at his or her office, school or home? Does this depend on the things you work on?

Experiences

- What do you like to do after school and on weekends?
- Do you like your equipment (eg, ankle foot orthotics, wheelchair, walking device)?
- What do you like most about school? What do you like least about school?
- What physiotherapy activities do you like (eg, swimming, exercises, bicycling, playing ball games)?

Box 3. Participants^a

- 1 Betty
- 2 Mother of Betty
- 3 Mother of Ariel
- 4 Ellen
- 5 Mother of Ellen
- 6 Noah
- 7 Mother of Noah
- 8 Foster mother of Tiana
- 9 Foster father of Tiana
- 10 Katy
- 11 Foster mother of Katy
- 12 Foster mother of Brandon and Steve
- 13 Mary
- 14 Mother of Mary

^a Pseudonyms have been used to ensure confidentiality.

Interviews were audio recorded and transcribed verbatim either by a professional service or the first author. Carers were interviewed independently of their children in all but one interview; children were interviewed with their carers present. The principal researcher checked all transcripts for accuracy by comparing the audio recording with the transcript. A paper copy of the emerging themes and associated transcript were also reviewed with the participant to confirm themes and allow the participant to clarify, modify, introduce or elaborate on any further topics. Interviews were conducted until coding saturation was reached.¹⁵ Memos and a journal were maintained to document the process, decisions concerning participant selection and interview topic inclusion.¹⁵

Data analysis

Transcripts were examined using inductive analysis. Emerging codes were identified and recorded using qualitative analysis software^a. Throughout the process, interview data were constantly compared, which stimulated the development and refinement of the themes. In this way, data collection and data analysis occurred simultaneously and informed the sampling and interview topics introduced. During this process, codes were grouped into several themes that were further distilled into three main themes. A journal was maintained and memos were entered into the software to document the coding process.

Results

Fourteen of the 17 people who were invited to participate took part in the study, constituting eight client families (see Box 3). Two parents and one child declined the invitation. Four children and one youth (one male, four females aged 12 to 19 years) with neurological conditions participated. Diagnoses included: cerebral palsy Gross Motor Function Classification System II to IV¹⁹ (n = 3), spina bifida (n = 1), and a rare non-progressive neurological

condition (n = 1). These participants demonstrated varying mobility, speech and cognitive abilities, but all were deemed suitable to voice their perspectives. The nine participating carers (one male, eight females) included four parents and five foster carers in long-term, organised care arrangements. This group included carers of the participating children/youth as well as carers of other children with cerebral palsy that did not meet the eligibility requirement or were no longer in the service area. All participants spoke English at home. Two participants also spoke an Indigenous language but learned English at school and did not wish for an interpreter to be present. All participants were Indigenous, with the exception of two non-Indigenous parents and one non-Indigenous foster carer, and had been involved with the physiotherapy service for at least a year. We cannot present more detailed information about functional mobility without compromising the confidentiality so important with this vulnerable population.

Themes

The following themes were identified through the iterative and inductive analysis process.

Lives filled with complex and multiple demands

Discussions associated with this theme garnered the greatest number and most emotional responses. All carers described lives filled with multiple and complex demands relating to raising children with a physical disability, with most describing physically and emotionally taxing experiences. Carers described juggling numerous appointments:

I think it was 9 days straight [of medical appointments]. (Foster mother of Tiana, age 9)

Many carers described stress associated with arranging and attending appointments:

... it takes me over an hour to get each child ready, I've got to feed each child, I've got to prepare their meals, then I've got to get all their outfits out. ... I'm doing this on an empty stomach ... I may not be able to have a bath, just dress myself and I'll take off out the door ... if I feel stressed getting ready and then I come to my appointment and I feel like I'm not being [present] you know? (Mother of Noah, age 13)

A few carers also described appointments that were extremely stressful:

... [the doctors] said that Ariel's hips were showing that they were slightly out of when they had her x-ray ... because now I'm freaking out like, 'oh God what's wrong with her hips?' ... I remember when Ariel had her first x-ray, she screamed. So there's no way she would have been in the right position. I was pregnant so

I wasn't allowed in, so my husband took her in and she screamed, I could hear her screaming from the waiting room, so there's no way in the world she would have been laying nicely for them to take the x-ray. (Mother of Ariel, age 4)

Other carers described the demands that followed in their wake:

It's really hard to try and meet all of those recommendations; at one stage we had physio recommendations and we had OT recommendations, the optometrist gave us recommendations. She went to Hearing and they said 'She may need grommets, you've got to follow up with this.' You go to everybody and everybody gives you negativity and you just think 'Where is it going to end, I'm a human, there's only so much I can do?' (Mother of Betty, age 12)

There was the challenge of balancing their children's needs with their changing health status:

And that priority changes all the time with us because then her health improves and she's back on track, so then we go back into the worrying about her learning and her long-term independence and life skills, all those sorts of things. Our priorities change all the time for her ... (Mother of Betty, age 12)

Carers also described efforts to balance the needs of their other children:

Pull on a trolley and push the wheelchair at the same time, try and keep two little girls together. I've got to leave all that to run after them and things like that. It takes a lot out of me, and I don't feel like doing anything. (Mother of Noah, age 13)

The need to negotiate their children's experience within the greater community was also identified by some carers. This included ensuring participation without being made to feel different by children and others in the community, dealing with gaps in information within school curricula that were pertinent to their children's needs, and preparing their children mentally (especially those with cognitive delay) for appointments with unfamiliar service providers, especially doctors.

Relationships: consistency, communication and caring

Comments from the children and carers reflected the value that they placed on having a consistent and caring relationship with their therapist. All nine of the participants who were asked preferred to have one physiotherapist for a longer time rather than dealing with multiple therapists. Carers felt that it was important for the child to feel comfortable with the therapist and activities, and to have consistency of care:

Because they [the children] get scared and then they forget what they're doing and they're not happy to go because it was someone new there. (Foster mother of Brandon, age 12)

They emphasised the need for the therapist to get to know the child, see the child holistically and be in a position to see change over time:

... she understands the situation because she has been there since day one and she knows Ariel now. And she knows Ariel better than the paediatricians or anybody else because she's worked the most with Ariel and she knows, you know. (Mother of Ariel, age 4)

Participating children emphasised the importance of having their therapist speak to them about their condition, show them pictures and demonstrate their exercises. They preferred the therapists to include their foster carers or parents, meet their families, and make the sessions fun. Four of the five children enjoyed the sessions; one child did not like physiotherapy and felt that exercise was boring:

... we can sit down and talk about the exercise, about learning about it and doing it and helping my leg. (Betty, age 12)

When I was ... [with] the same people all the time because when youse did it, you made it fun and happy and put a – let out a good vibes, it was good. (Ellen, age 19)

Responses regarding positive experiences with the physiotherapy service highlighted the importance of their relationship with their physiotherapist. They described their therapists as open, approachable and helpful, and described successful instances when therapists were easily reached, easy to talk to and collaborative:

When I talk to you and the ball rolls and I just come out with this and that, I would not speak like that with anyone else, because they kept it strict with me every time I went there. (Mother of Noah, age 13)

Carers who highlighted negative experiences described therapists' lack of caring, communication and willingness to see children in the context of their family environment. Carers also felt excluded in their own children's care:

So I asked her, 'How would you like to sit on a seat that was made of plastic for 4 hours?' ... and she just fobbed it off ... And I refused to go along with that, I am after her [Tiana's] comfort, not her [physiotherapist's] stupidity. (Foster father of Tiana, age 9)

Being Indigenous influences lives

Indigenous culture emerged as an influence that intrinsically shaped consumers lives through cultural practices and expectations:

... these boys, have to go through their culture and Brandon's supposed to go through it, man business ... that's most important for these boys. Steve [previous foster child with physical disability] went through it, I made sure Steve went through it, he's well known now ...' (Foster mother of Brandon, age 12)

Being Indigenous makes it a bit harder, especially the cultural stuff ... I've missed out a bit on my father's side [through lack of physical mobility]. I haven't got the chance to do all those things that I probably would have done, but sometimes it's hard if you've got a disability to keep up with the cultural perspective of traditions ... like the cultural dances and going out hunting and the women, when they go looking for fruits and periwinkles and stuff ...' (Ellen, age 19)

and conduct:

... when we have children with disabilities or low IQs that consistency of knowing a face and being able to approach them because in the Indigenous culture to look at someone and give an answer showing that eye respect is not something that these children do.' (Foster mother of Katy, age 16)

In addition, indigeneity left participants exposed to the external social forces of racism in the wider community, which may influence their expectations of and willingness to access government services. Two carers described overt racism, such as seeing racist Facebook comments and having hate messages sent to them. Others perceived racism within the healthcare systems:

There was one physio, it just felt like because I was coloured, she thought I wasn't going to take care of the equipment, that's what it felt like ...' (Mother of Noah, age 13)

We are left waiting at the bottom of the line [at hospital clinic]. Other people would be treated before Tiana 'cause she's only an Aboriginal.' (Foster father of Tiana, age 9)

Carers also actively ensured that their children knew how to handle racism:

... and I tell her 'we know, don't forget, like if someone is being racist to you, you can always get them back to us [ie, come and tell

us]. That way people can't be racists to you.' And I tell them what to be expecting. I tell them what kind of words to be expecting ... my Mary knows, my Jordan knows when someone is being racist to them. (Mother of Mary, age 17)

This influence is often hidden from a service provider's view, but can be a very damaging part of the participants' experience:

I feel a bit discriminated against yes I do. I can tell the difference, experienced through that life, who is slightly different with racial and who is not. ... I can tell the difference, the tone is different, just having no time, the looking at me. When they're looking at me, it's just like they don't feel like it, I can tell. So them things makes my day really horrible and it's hard to deal with my children when I feel upset like that. (Mother of Noah, age 6)

The issue of communication underpinned all themes and influenced the experiences of the children and families, interpersonal practices and organisational systems. Positive interactions with the children and carers were influenced by the timing, content and way in which topics were raised or managed. Good organisational communication between the therapist and other departments assisted with linking services, accessing equipment or advocating for the child's needs, as well as helping carers relay their needs to unfamiliar service providers. Conversely, carers identified the lack of communication as their number one concern when experiences were negative.

Although the main themes were shared, not all people wanted the same service delivery or interpreted a given phenomenon in the same way. For instance, one carer welcomed a more directive service delivery style, whilst another felt disempowered by it. Similarly, one carer regarded imposed school expectations as racist, whilst another carer felt it respectful to have her child held to the same standards as non-Indigenous students. The findings of this study point to a number of recommendations at an individual and organisational level (see Box 4) and are supported in physiotherapy literature and standards.^{20,21}

Discussion

These themes parallel similar findings in other areas of health and disability research. However, this is the first study to represent the views of Indigenous children and carers using physiotherapy services. Non-Indigenous and Indigenous populations consistently report complex, multiple demands and stress associated with raising children with a physical disability.^{1,6,22,23} Literature also supports the value placed on relationships by Indigenous children and carers receiving other health services,²⁴ as well as by non-Indigenous children and carers receiving physiotherapy.^{25,26} The pervasive and sometimes unrecognised influence of Indigenous culture as well as racism on relationships, values and healthcare experiences is reflected in allied health,²⁴ disability^{6,27} and cross-cultural research.²⁸

The importance of communication within Indigenous health-care is highlighted in other literature. Alford emphasised its importance in physiotherapy practice in Indigenous health;¹¹ whilst Cass, Lowell and others wrote of the absence of effective communication and its devastating consequences in other areas of Indigenous health.²⁹ Significantly, the Australian Physiotherapy Council Standards of Care states that tailored, culturally appropriate communication is a physiotherapy standard and human right for all clients.²¹

There were several limitations to this study. The design involved a small sample within one service, which limits its generalisability. Twelve of the 14 participants spoke English as a preferred language, so the findings may not reflect the experiences of populations whose primary language is not English. While the children's views were represented, few of their quotations were included, as their interviews involved more non-verbal responses and much less detailed verbal content.

Box 4. Recommendations for community-based physiotherapy service providers.

Individual level

Develop personal attributes

- Openness
- Respectfulness
- Patience with families
- Ability to see situations holistically
- Non-judgementality
- Flexibility

Actions

- Actively listen
- Tailor language to client's need
- Spend time to ensure shared understanding of information
- Allow time for clients to form thoughts, ask questions and develop trust
- Practise two-way communication
- Develop cultural (including gender-related) awareness
- Recognise and develop both clinical and practice skills
- Speak with children (who are interested) about their bodies and activities, using pictures and other media as needed
- Make activities pleasant and fun for the child; include the child's family; ensure that siblings are attended to so that carer can attend to session

Organisational level

Intra-organisational

- Maintain same therapist with client to ensure consistency of care
- Ensure that all therapists attend cultural awareness or cultural competency course
- Develop systems enabling staff cohesion which allow familiar therapists to overlap with new therapists taking on clients' care during staff transitions
- Develop systems to encourage easy service access for carers
- Allow flexibility in location service provided
- Ensure good documentation and handovers

Inter-organisational

- Develop open lines of communication with Indigenous health and other services
- Support joint client appointments between therapists and other involved health providers
- Support video-conferencing into clients' interstate appointments

The study only included those willing to use the physiotherapy service and participate in the study and therefore does not highlight the needs of those unable or unwilling to use the service. As most participants were female, the representation of a male perspective is limited. The inherent power imbalance between the service provider and consumer may have prevented participants from sharing how they truly felt, (or compelled them to provide a response believed to please the interviewer). Furthermore, the research was inevitably influenced by the enculturated view of a non-Indigenous physiotherapist.

Future research would benefit from an Indigenous physiotherapist exploring a similar population to provide a shared Indigenous and physiotherapy perspective. To get a wider view, future research should also include a younger population of Indigenous paediatric physiotherapy consumers in other demographic or healthcare settings. Data could also be explored through other frameworks such as the International Classification of Functioning, Disability and Health³⁰ or the Indigenous Standpoint Theory,²⁷ which places the context of Indigenous culture and history more centrally within analysis.

Whilst community-based services adapt to a national effort to reshape disability services and support fiscal responsibility, physiotherapists are in a position to improve their service

provision in ways that are not entirely resource dependent. Carers and children described positive situations when their physiotherapists were open and easy to talk to, worked to their interests instead of forcing another agenda, listened to and gave them time and information to make choices either independently or in collaboration with the therapist, and provided useful information or training promptly when requested. Physiotherapy skills that could improve the experience of Indigenous children and carers include the ability to build partnerships with them, understand the demands and complexity in their lives, and appreciate how being Indigenous may influence their healthcare needs and experiences.

The results of this study do not point to a specific physiotherapy clinical practice, but suggest that community-based physiotherapists adopt a person/family-centred, context-specific approach. This involves developing relationships and effective communication skills in collaborative pathways, in which knowledge is understood, shared and valued by both therapist and client.

What is already known on this topic: Indigenous Australian children experience higher rates of disability than their non-Indigenous peers. The needs and experiences of these children and their carers in accessing physiotherapy services are not well understood.

What this study adds: When accessing physiotherapy services, carers of Indigenous children with a disability value relationships involving caring, consistency and communication. Being Indigenous influences these consumers' experiences in ways that may not be obvious to non-Indigenous service providers.

Footnotes: ^aNVivo software, QSR International Pty Ltd, Version 10.5, Melbourne, Australia.

Ethics approval: The Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research approved this study. All participants gave written informed consent before data collection began. (HREC-2012-1912).

Competing interests: Nil.

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