



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?

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