

BMJ Open Ageing with cerebral palsy; what are the health experiences of adults with cerebral palsy? A qualitative study

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ABSTRACT

Objective: To enhance understanding of the experiences of ageing with cerebral palsy (CP) in adulthood with a particular focus on experiences with health services.

Design: A qualitative descriptive methodology was applied to capture adults' views of ageing with CP and related interactions with health services. Semistructured interviews were undertaken with data systematically coded and interpreted by grouping information into categories. Themes that encompassed the categories were identified through thematic analysis.

Setting: All healthcare settings.

Participants: 28 adults (14 women) with CP, aged 37–70 years.

Results: 5 themes covered the breadth of participants' experiences: (1) acceptance of change; (2) exploring identity: cerebral palsy as only one part of self; (3) taking charge of help; (4) rethinking the future and (5) interacting with health professionals. Being seen and being heard were the features described in positive healthcare interactions. Participants also valued health professionals who reflected on who holds the knowledge?; demonstrated a willingness to learn and respected participants' knowledge and experience.

Conclusions: Our findings could, and arguably should, inform more responsive strategies for disabled people in health services and, indeed, all health consumers. Our study supports other findings that impairments related to CP change and, for many, severity of disabling impact increases with age. Increased interactions with health and rehabilitation professionals, as a consequence of these changes, have the potential to impact the person's healthcare experience either positively or negatively. A 'listening health professional' may bridge their knowledge gap and, in recognising the person's own expertise, may achieve three things: a more contextualised healthcare intervention; a better healthcare experience for the person with CP and positive impact on the person's sense of autonomy and identity by recognising their expertise. Future research should identify whether this approach improves the healthcare experience for adults living with CP.

Strengths and limitations of this study

- This study identifies key issues which matter to people with cerebral palsy (CP) about ageing and ageing well and describes how health professionals might better respond to people's health needs as they age.
- Findings indicate that when health professionals fail to recognise the knowledge and skills the person with CP brings to healthcare episodes, there are wide-ranging, and for some, enduring consequences.
- Further research is needed to quantify how health outcomes might be improved if health professional interventions and/or services were responsive to findings.
- Although this study is limited by not representing diverse ethnic groups or people who lived rurally, participants were diverse in other personal characteristics.

INTRODUCTION

The global population is ageing with the consequence that we are more likely to acquire age-related disability and to live longer with any acquired disability.¹ It is timely, and increasingly relevant, that we refocus the concept of 'ageing well' away from the medical model viewpoint of living without disability or impairment and towards a viewpoint that encompasses a more holistic view of the health of older people. There is increasing recognition that health services should be responsive to the criteria considered central to those people experiencing what they perceive to be optimal ageing.² However, little is known about what adults with childhood acquired physical disability consider central to optimal ageing.^{3 4}

One of the most common causes of life-long physical disability acquired in childhood is cerebral palsy (CP). The term CP describes 'a group of permanent disorders of the development of movement and posture,

causing activity limitations that are attributed to non-progressive disturbances in the developing foetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensations, perception, cognition, communication and behaviour; by epilepsy and by secondary musculoskeletal problems'.⁵ International prevalence figures report 2.0–2.5 cases of CP per 1000 live births, figures that have remained stable for the last 40 years.^{6–8} However, compared with mortality data from 50 years ago, the life expectancy for adults with CP who have mild to moderate disability is now only slightly reduced compared with the non-disabled population.⁹ The net effect of stable incidence rates and increased longevity is that the prevalence of CP within the adult community is increasing. Adults with CP, just like those without CP, are living longer and, in doing so, are also more likely to acquire impairments and illnesses associated with later life.

While CP is the result of a static insult to the developing brain, the subsequent signs and symptoms may alter as the person matures. This is acknowledged in the growing body of literature documenting changes associated with ageing in the health, function and mortality of adults with CP.^{3 10–19} This literature has shown that age-related physiological changes occur earlier in adults with CP, and the prevalence of secondary conditions such as pain, osteoporosis, fatigue and musculoskeletal and joint problems is higher in adults with CP compared to age-matched adults without CP.

Given the early and accelerated age-related changes in function, adults with CP are likely to have greater need for health services as they age. The first objective of the current study was therefore to provide the opportunity for adults with CP in New Zealand (NZ) to describe their experiences of ageing in the context of CP and voice the strategies they use to age positively. A second objective of the study was to explore participants' experiences in healthcare encounters and to consider how health services could be improved to assist health and well-being across the adult lifespan.

METHODS

Methodology

We used a qualitative descriptive methodology and thematic analysis methods to identify, analyse and report the patterns within the data.^{20 21}

Research team

The research team comprised women who were all health professionals (physiotherapists (SM, JR, DT, NS), nurse/midwife (KM) and a paediatric orthopaedic surgeon (SS)), all had an academic role and three worked clinically. Four of the team had PhDs, and two had Masters degrees. JR conducted all the interviews in this study. She had clinical experience working with adults with CP and received qualitative interview training

and support from KM, with many years' experience in qualitative research.

Participants

Adults with a diagnosis of CP, aged 35 years or older who had lived in NZ for 15 years or more (to ensure experiences relevant to the NZ context), were eligible for inclusion. We attempted to facilitate participation of those with complex communication needs through our recruitment and sampling approach. Individuals were excluded if unable to understand or communicate in English or unable (with assistance) to take part in an interview.

Purposive sampling²² was used to include a range of sociodemographic characteristics, including age, education, marital status, ethnicity, employment, living situation and mobility and communication ability. Participants were sought through invitations sent by a non-governmental CP organisation, advertisements on disability services web sites and a paid advertisement in a rural community newspaper. It was subsequently found that participants had also heard about the study from networks such as carer agencies and by word of mouth from other participants. After the first six interviews, participants with potentially different experiences (based on sociodemographic characteristics) were sought to challenge initial patterns in the data. Recruitment ceased when no new codes or themes were evident in the data.

Procedure

All interviews were face-to-face and lasted between 1.5 and 2 hours. Interviews started with an introduction to the study, and the interviewer provided a brief background of her clinical and research roles. She emphasised the participant's control over the depth of discussion. Informed consent was gained prior to the interview. Following exploratory questions around the participant's current situation, questions focused on the participant's experiences of ageing in the context of CP and experiences with health and disability services. Ongoing questioning was used to elicit further explanation and clarification where greater depth was deemed necessary. Strategies of repeating phrases to confirm content using a querying tone when repeating a word, seeking confirmation or sentence completion and requesting repetition were used to assist clarification.^{23 24} Requesting assistance from a support person, where available, was additionally used for interviews with participants with complex communication needs. Where a communication support person was present, and information was volunteered by that person, the participant was questioned to clarify whether the communication support person's statements aligned with their experience or beliefs. Communication supporter speech was not included as data. Four participants clarified or expanded their interview responses by subsequent email or letter, which was included in the analysis.

Data analysis

All interviews were audio recorded and transcribed verbatim. QSR NVivo V.8 software was used to store data, record coding and note memos associated with the interviews. Transcripts were coded line by line, and these codes grouped into categories. Categories identified were checked back against the data looking for statements that qualified, expanded, countered or supported them. In this way, themes that provided an explanation of participants' experiences and were strongly linked to the data were inductively derived.²⁰

Rigour

Validity of the data analysis process was tested by JR and KM comparing coding of early transcripts, thorough and systematic checking back to interview transcripts to confirm the scope of codes, categories and themes. SM subsequently reviewed all transcripts, codes, categories and themes. Differences in interpretation were resolved by discussion between the researchers. Each participant received a copy of his/her transcript following the interview and subsequently a summary of findings. Participant feedback was invited on both occasions to confirm whether the findings captured their experiences; no participants chose to provide feedback.

FINDINGS

Sociodemographic factors

Twenty-eight adults with CP (14 men, 14 women) aged between 37 and 70 years, median age 47 years, were interviewed at their workplaces (n=2) or homes (n=26). Sociodemographic details of participants' employment and relationship status, highest education level, gross motor function classification score (higher score indicates greater assistance required for mobility), main form of indoor mobility at the time of interview, presence of complex communication needs and self-reported limb involvement with CP are set out in [table 1](#). We were successful in achieving a diverse sample in these domains, however were unsuccessful in recruiting participants with diverse ethnic identity or place of residence (urban/rural).

Of the 28 participants, 13 had complex communication needs defined by scoring 6 or less out of 7 on the 'expression' item of the Functional Independence Measure;²⁵ meaning that some degree of modification of communication was required to enable intelligible speech or clear expression of language ([table 1](#)). Most of these participants preferred to use natural speech as their method of communication; two participants relied exclusively on speech generating devices to participate in their interview. Four participants had either a carer or family member acting as a communication support person to assist or enable them to take part.

Themes

Five themes: (1) acceptance of change; (2) exploring identity; cerebral palsy as only one part of self; (3)

Table 1 Sociodemographic characteristics of participants

Sociodemographic variable	Number of participants
Employment	
Unwaged	19
Employee	6
Self-employed	2
Retired	1
Relationship	
Single	15
With partner	13
Highest education	
Did not complete high school	15
Completed high school	4
University	7
Post graduate	2
GMFCS	
2	5
3	8
4	12
5	3
Indoor mobility	
Unassisted	9
Walker	5
Wheelchair—self-propelled	4
Wheelchair—powered	8
Other	2
CCN (FIM)	
6	11
5	1
4	1
Limb involvement (self-reported)	
Diplegia	2
Hemiplegia	5
Quadriplegia	18
Unspecified	3

Sociodemographic information has been pooled rather than attributed to each participant in order to minimise the possibility of identification of individual participants.

CCN, complex communication needs; FIM, functional independence measure—expression (higher score indicates less assistance required with expression); GMFCS, gross motor function classification system (higher score indicates more assistance required for mobility).

taking charge of help; (4) rethinking the future and (5) interacting with health professionals; appeared to cover the breadth of participants' experiences of ageing with CP and experiences of healthcare. In the following section, the main categories of each theme will be described and links between categories and themes highlighted. Quotes in support of the analysis are identified by pseudonyms and age bracket.

Acceptance of change

Recognition of the way in which ageing impacted on their bodies and an acceptance of change was first needed before participants could respond by altering daily routines or by using other coping strategies. Many participants were aware that compared to adults without

disability or impairment, they were experiencing, or would experience, accelerated changes as they got older.

I think that having a disability and the fact that your body takes such a hiding, for want of a better word, on joints and things over the years because of that disability that the ageing process is probably quicker for someone with a disability than someone who is able bodied. [Amelia, 40s]

A common thread was a growing awareness that physical resources were limited; participants described increased fatigue, diminishing energy and a general slowing down occurring at earlier ages than non-disabled peers. The idea of 'pushing myself' was identified as a contributing cause to now reduced energy by a few participants.

I think it's part of ageing; I know everyone who ages slows down but I think people with CP do at a younger age than most people. Mainly, I think, from forcing my body over its physical limits; I think that's the main cause. [Louise; 40s]

Participants described the need to manage external factors such as social or work obligations to address increasing fatigue with age. Other solutions to address changes in physical capabilities associated with ageing included modifying activity by scheduling rest periods, adapting the environment or greater use of equipment. Acceptance of a changing body and greater need for help from others were also required in consequence.

I used to try and go—and get frustrated because I couldn't. But I think I'm more willing...I know I'm more willing to say, "It's hard, can I have some help?" [Sharon; 40s]

The acceptance of change with ageing, although difficult, proved liberating for many participants and resulted in being able to achieve more and participate in a greater range of activities.

And I think that it was more of a pride thing, I didn't want a walking aid. I wanted to be independent without the use of aids but now—admittedly I'm a bit self-conscious. Yeah. Oh well, I just use it because I need it. [It was hard] because you want to look as 'normal' as possible but when you've got this walker out in front of you and—but now I just enjoy getting around! [Maria; 40s]

However, coming to terms with a need to modify activities or the environment or change priorities in response to physical changes often created a tension for some participants, as physical and psychological capacity was perceived as fluid, not fixed; at risk of diminishing but also capable of being maintained or improved. Maintenance and optimisation of physical fitness were thus very

important for some participants as a strategy to manage age-related changes.

Exploring identity; cerebral palsy as only one part of self

All participants reflected on CP being a component but not the whole of their 'self'. For many participants, changes in their physical capacity and needs prompted reflection on their personal identity (how they saw themselves) and their social identity (how they were perceived by others). Ageing caused many participants to question 'who am I?' as a person with disability, with one participant attributing mental health issues to a split sense of self. The requirement to straddle 'disabled' and 'non-disabled' worlds was seen as a challenge by many participants.

I've always...been as, if you like, 'normal' as possible and that's the challenge that I'm finding, as I get older, that that kind of perspective is not working anymore. And I don't know how to bridge that gap between "this is who I am" and "this is me with CP." [Beth; 40s]

Participants discussed the effects of having a visible disability that was 'seen' before they were. However, having a less visible presentation of disability also caused participants to question whether their disability, as well as their personhood, was seen.

I don't mean to be molycoddled but something inside of me broke because I was dealing with this frustration of not being seen and not being heard.... I said [to my brother], "You don't see me as disabled do you?" And he said, "No, well you know, I've grown up with you."...And that's the key—they [my family] don't see me as disabled, which in some ways has been great—that normalisation. But it meant that some crucial needs haven't been met. [Beth; 40s]

Participants had different perceptions about the visibility of disability; several participants thought that they would be better accepted or understood if they used a wheelchair.

I'm not walking; I'm in a wheelchair. So in that respect no it doesn't, people don't, don't look at me [differently], they don't. Nothing happens but if I was walking that is a totally different, different story...because when I was walking, my head; I cannot keep still and it goes from side to side and all round and up and down. Because I have no control over my neck. [Marco; 50s]

Other participants' experience of visible disability was less positive and was an aspect of them being 'unseen'.

It's interesting because most people, even now, they see the wheelchair first and then...sort of looking round and they're hoping that, you know, they can talk to someone else, you know. [Fritha; 40s]

Social attitudes and assumptions around disability that prevented participants being seen as an individual or

accepted as ‘a whole self’ were perceived as disabling, more so, for some, than CP itself.

Sometimes I notice that I can only have superficial dealings with people other than, you know, my personal family, and that can be frustrating for me. That there’s, that I don’t have deeper friendships or more, you know, more enduring friendships. So that’s where I find it disabling and I feel that it, that it’s something to do with, not my disability but the, but the perceptions and the stigmas around that. [Neal; 30s]

Positive resolution of who ‘I am’ was connected with concepts of acceptance of self and encouragement and support from others.

It’s an interesting dichotomy for me because, you know, I’m, I’m in my nature I’m successful but I’m not a, you know, I’m also, I’m, I’m what’s the word? I’m, I am irresponsible and I’m disabled (laughs). You know, and I enjoy that about me but I’m at the point now, because of my CP, and probably because of my age, but I think my CP is making me think about this stuff. [Roger; 40s]

Some participants described developing a positive sense of self as the result of foundations laid by a historical cause, for example many participants discussed the influence of their childhood experiences and family attitudes in relation to their current view of their identity and CP. Other participants spoke of a discrete event that helped them develop a positive sense of self, for example attending psychological therapy or being able to publically acknowledge their needs. For others, establishing a positive sense of personal identity was couched in terms of being an ongoing process; the idea of ‘who I am’ continually evolving.

I just think when you get into your 40s you’re in this really neat time of your life where you just don’t worry so much like you did when you were 20 and 30—you just think, well I don’t care, I need this so I’m going to make it happen. I now don’t worry so much about my body image as I did when I was that age say, you know, and so that, that’s something else I don’t worry about anymore so maybe I’ve got more energy to put into the “I need this to happen so how can I make it happen?” [Laura; 50s]

Two participants discussed gender identity and sexuality as aspects of being whole; not being seen as a man or woman being sources of tension and distress. Participants had heterogeneous roles as parents, workers, siblings and as adult children. Being known as an individual and being known for or seen in a social role (eg, parent, employee) were concepts associated with positive expressions of sense of social identity.

Taking charge of help

Changes with ageing led many participants to reflect on a new or increased need to receive help. Situations

where participants had choices and were in control were common to descriptions of a positive experience of being helped. Participants explored changes in and tensions between their ideas of dependence and independence and the ageing of parent caregivers was a catalyst for some to reflect on the help they received. For some participants, family members’ lack of understanding of needs and changing needs acted as an impediment to getting help in a way they perceived as appropriate.

Now, what is it about families that they don’t listen to what you’re telling them? I mean, that also is more of a hindrance than your disability. [Travis; 40s]

A number of factors operated as barriers to requesting help, which increased participants’ sense of powerlessness when receiving help. For some participants, help was not provided in a way that met their needs.

I need some, some things done for me but that’s different from “I need to be taken care of”. I don’t need 24 hour care, I don’t need people making decisions for me, I don’t need people putting me on programmes where I can go and socialise because I can go down the [pub] and do that. [Laura; 50s]

Participants identified that setting their own priorities and knowing where to go for help made receiving help easier. Help needed to be on participants’ terms, as not to interfere with participants’ sense of independence and autonomy.

I mean, when I first moved into a place of my own I realised very quickly that I was either going to spend the whole day doing the dishes, doing the housework, doing the washing and eating or I would have somebody else do that and do stuff that was more important, you know. So and I see still a lot of disabled people struggling to, to do shit that is so meaningless. You know, and so and so mundane but somewhere there’s some sort of attachment to that independence and identity that I just gave away years ago. So, you know, so I have chosen that I will not do the dishes but I have to manage a team of people that will do the dishes for me. [Roger; 40s]

Some participants identified the effort of maintaining boundaries between public and private spheres while trying to ensure that their needs continued to be met. These boundaries were between themselves and carers and, for some, resisting pressures for family members and partners to take on a carer role. Assertiveness was a strategy described by participants to maintain what they perceived to be appropriate boundaries, as well as more generally taking charge of help.

I’ve learnt over the years to not be meek and mild, to actually speak up otherwise you’re just going to get sort of forgotten. So you’ve got to learn even though it’s hard, especially if speech is a problem, to actually speak up for yourself or get someone to assist you. [Amelia; 40s]

Rethinking the future

Many participants spoke about their future in terms of long-term goals and aspirations around work, education, family, leisure and sport. However, participants also reported being aware of likely ongoing physical changes related to ageing with CP. This meant that participants in their 30s and 40s were considering what adaptations they might need to employ in the future.

My fear is it's going to be harder—that's my fear, and I'm going to have some person who comes by and dresses me and puts me together and but...there's this determination there that no, it's not to be that way—I'm going to stay as fit and as mobile as I possibly can till the day I can't do it. [Travis; 40s]

One of the changes with ageing for some participants was a reduction in social engagement due to ageing of adult carers, particularly parents. Mismatches between individual needs and funding structures sometimes meant that needs previously met by parental carers fell outside the scope of services and were consequently unmet.

Mum ran out of puff. When I played [sport] I needed a full time carer...no other carer available so that job also fell to Mum to fit into my 24 hour care. I am still unable to get other assistance so I am not able to access [my sport] anymore. [Mike; 40s]

Some participants declined to discuss their thoughts on this topic, while others expressed worry, uncertainty or fear about what was likely to happen, many also had made a decision about how to deal with that uncertainty. Common responses to uncertainty about the future ranged from letting go or focusing on the present; to more proactive responses such as seeking advice and information (eg, from peers, health professionals, citizen advice bureau or the internet) or making a plan, which included strategies such as goal setting.

I worry about that stuff now and again and then I think, well there's no point worrying about something till you've sort of got there but, you know, I know that my mobility's decreased and I see it at work all the time about younger people being put in rest homes and I'm thinking, oh my gosh—hope that doesn't happen to me and then I just put it over there and think, "I'll worry about it when it does." [Laura; 50s]

The act of addressing uncertainty appeared to be more important than the strategy chosen to do so and was associated with more positive expressions about the future. A lack of purpose and lack of information about what will happen were concepts connected with increased uncertainty or expressions of concern.

Interacting with health professionals—being seen, being heard

Overall, participants in our study were generally well, requiring occasional rather than regular encounters with health services. Their experiences with health professionals were mixed. Positive interactions were often described as those in which health professionals respected and heard the participant as a person.

Oh my GP is really cool, because he gets right down to what you've got and he looks after us. He asks you how you've been and what have you been doing and he has a full conversation before he asks you what's wrong. [Verity; 40s]

Dave described how his dentist responded to his involuntary movements, reducing the discomfort and stress during the appointment, so that the treatment was efficient and effective.

He used to spend more time...instead of a half an hour he'd make them to an hour or 45 minutes so he had more time and make me feel more comfortable he would do it slower than try to rush the job. That's why he took things slowly because he knew me so well that I could, I could relax while he was working on me. [Dave; 50s]

However, participants also described experiences of being unseen as a person and unheard during interactions with health professionals; receiving the impression that they, as a person, were not a priority.

[The neurologist] tested my reflexes and stuff... and, you know, I was under a lot of stress at the time but I just, I just felt like I didn't have a relationship—it was like he didn't see *me* and I wanted him to see *me*. [Beth; 40s]

Participants had a spectrum of experiences that gave this impression; from health professionals failing to be courteous or 'human' during care and treatment, to participants' medical needs being disregarded when the participant as a patient was not listened to. These negative interactions occurred when participants perceived their disability alone was seen rather than their whole self.

I got so um anxious and panicked, I was panicking that I had to go into hospital. But when, but when I got into hospital they didn't want to know about my um my panic attacks, they discovered there was something wrong with my bowel. And I was in there because I was panicking, having panic attacks and they never did anything about that part. They just, they just concentrated on the bowel. [Dave; 50s]

Some identified a tension between needing to inform medical staff of the disability but anticipating, in the absence of knowledge, that assumptions would be made about the participant because of advising 'I have CP'.

For some participants, this occurred when they were treated as on display because of their CP. Others described situations where the health professional refused to interact with them when they were in the role of spouse or carer, or when they were in the role of patient, spoke to a carer or spouse and not to them. One participant described an occasion where the health professional's view of her CP overshadowed the health concern that led her to seek assistance.

Sometimes it puts a real barrier between you and the professional person when they're just looking at the disability and what you've done and they go, "...I really think you people are wonderful". It's like oh, you know, actually [I] just came in here because I've got thrush, you know, or something that's nothing to do with your disability. [Laura; 50s]

When participants' lived experience of their current health or their disability was 'unheard', they were at risk of experiencing threats to their sense of self and identity or having unmet health needs. Being known and being heard were concepts associated with positive interactions with health services.

Interacting with health professionals—who holds the knowledge?

Interactions where health professionals had expertise about CP or were open to an exchange of knowledge were valued by participants, but were not frequently encountered. Instead, participants attributed some of their poor experiences of healthcare to professionals lacking understanding of CP or how to assist a person with disability.

It's just they seem to see disability and if they haven't had very much experience of it they seem to go on the offensive [sic]. Like, you know, "I don't really want to deal with this—it's not an area that I know about so I'll walk off and leave it to whoever else is next after me." [Amelia; 40s]

Participants also described encounters when the health professional failed to listen to needs that were expressed or experience described but acted as if they 'knew best'.

Some occupational therapists think that they're god and think that they know it all and think that they're right and ah no turning around, "Yeah I'm right, you're wrong, this is how it's going to be." [Conrad; 40s]

Managing health professionals' assumptions and knowledge gaps was often part of the healthcare transaction. In the absence of knowledge on the part of the professional, with ageing came an emerging role for some participants as an educator; being more able to challenge and inform based on their experience.

They should know far more about CP in general, nurses, than they do. I've got to tell them about CP; we're basically always being the educators aren't we? All our life, you know, and we don't want to educate the health sector. I want to be sick! [Graham; 50s]

Adults with CP also encountered, from some health professionals, a willingness to learn which improved the health experience for participants. More positive encounters occurred when the health professional had prior experience, was willing to seek out information, keep the participant informed and demonstrated respect for the participant's knowledge and experience of their disability.

DISCUSSION

All participants acknowledged an accelerated ageing process associated with CP, congruent with observational studies documenting age-related changes.^{26 27} Consistent with other studies, *acceptance of change* was identified as a necessary step, enabling positive responses to changes with ageing, through making lifestyle modifications, maintaining fitness and using other coping strategies.³ Participants were clearly able to articulate the tensions related to a disabled and non-disabled self in *exploring identity; cerebral palsy as only one part of self*, consistent with other qualitative work of identity.²⁸ *Taking charge of help* reflects on ways participants received help, particularly in the context of changes experienced with ageing. Many participants experienced a tension between requesting and receiving help. It was easier to receive help if the nature of help was flexible and related to participants' needs. Taking charge, more generally, is universally valued,²⁹ and health professionals are in a position to facilitate people's preferred mode of taking charge.^{29 30} *Rethinking the future* involved considering the possible or probable physical changes associated with CP and the impact these might have on long-term goals and aspirations.

In contrast to other related health literature,^{31 32} participants in this study only infrequently referred to the impairments or symptoms of ageing in relation to the quality of interactions with health professionals. While getting help to relieve pain, treat illness or improve mobility may have been the impetus for the health transaction, what made interactions 'work' was less the intervention than how it was carried out. Participants in this study identified that how health professionals interacted with them impacted not solely their experience, but also their health outcomes. This sentiment is echoed in other studies^{33 34} and adds weight to the growing importance of person-centred care.³⁵ The importance of being treated the same as other adults, while having differences acknowledged and acted on, are themes common to the experiences of cultural minority populations^{36 37} and those with acquired disability^{35 38} in receiving healthcare.

Other research highlights the stark contrast in access to healthcare between adults with CP compared to their experience as children,^{26 32 39} that is typical of NZ where health services are available publicly for infants and school age children, but very little is available publicly after the age of 21. When they do access health services as adults, the specialised knowledge of health professionals that they experienced as children is much harder to find and there are fewer services available.²⁶ Formal undergraduate and postgraduate programmes, continuing education courses and in-house training (eg, patient experience programmes) are options to be considered to address this need for health professionals. Such initiatives would need to be tested to evaluate the impact on the experience of patients. Transitions between child and adult services have been identified as particularly problematic^{40 41} and in need of further research as to how this transition could be optimised. This raises the question whether the health system that has been developed in a way that is focused on children with CP, as if they will always remain children, and does not meet their needs as adults.

While many participants valued health professionals who had CP specific knowledge, there appeared to be tacit, if disappointed acceptance that little is known about ageing with CP. While this specific knowledge was considered ideal for best outcomes, a willingness to learn more about CP and respect of the person's knowledge of their condition on the part of the health professional provided a sufficient bridge over the knowledge gaps. While technical aspects of care were considered important, how this care was provided was more important. Positive experiences with health professionals occurred when the health professional treated the adult as a person, listened to them and respected their experiences. This is in keeping with other studies on what makes quality care for people with other conditions.^{26 42 43} In long-term conditions, making time and treating the person with respect may even matter more than isolated technical competence.

Other adults experiencing disabilities have identified being prepared and able to advocate for one's self as important skills in having one's health needs met positively.⁴⁴ While participants in this study were often proactive in voicing their experiences and indeed viewed speaking out as a strategy for meeting needs, being compelled to rely on self-advocacy places people in a vulnerable position in the health encounter if they are unable to assert their needs. This vulnerability highlights the importance and responsibility of health professionals who can work towards an ideal of health interactions that are collaborative, sharing information and respect.⁴

Key strengths of this study included the diversity in personal characteristics achieved through purposive sampling, including those with complex communication needs, a voice not often heard in research.⁴⁵ In addition, the richness of the data provided has addressed in new ways how ageing with CP is experienced and, arguably,

should impact on health services for this population. The study is limited by not attracting participants from diverse ethnic groups, people who lived in rural situations or people with a gross motor function classification system (GMFCS) classification of level I. Although a potential limitation is that the implications are not generalisable to other settings, the findings are not specific to the NZ context and focus on much deeper issues such as identity and how health professionals impact the health encounter and as such are universally applicable.

CONCLUSIONS

Findings from this study highlight new understandings of how people with CP experience ageing. It identifies how health services, health and social care professionals currently assist or obstruct positive ageing. Of particular concern, health needs were on occasion unmet and/or participants experienced threats to their sense of self and identity when interacting with health professionals. While further evidence is required to demonstrate if health outcomes would be improved, our findings suggest that the experience of care could be improved by enhancing health professionals' knowledge of ageing with CP and their respect for the knowledge produced by the lived experience.

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REFERENCES

1. Verbrugge LM, Yang L. Aging with disability and disability with aging. *J Disabil Policy Stud* 2002;12:253–67.
2. Depp C, Vahia IV, Jeste D. Successful aging: focus on cognitive and emotional health. *Annu Rev Clin Psychol* 2010;6:527–50.
3. Horsman M, Suto M, Dudgeon B, *et al.* Growing older with cerebral palsy: insiders' perspectives. *Pediatr Phys Ther* 2010;22:296–303.
4. Jones GC. Aging with cerebral palsy and other disabilities: personal reflections and recommendations. *Dev Med Child Neurol* 2009;51 (Suppl 4):12–15.
5. Rosenbaum P, Paneth N, Leviton A, *et al.* A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol* 2007;49:8–14.

6. Odding ME, Roebroek M, Stam HJ. The epidemiology of cerebral palsy: incidence, impairments and risk factors. *Disabil Rehabil* 2006;28:183–91.
7. Pharoah PO, Cooke T, Johnson MA, *et al.* Epidemiology of cerebral palsy in England and Scotland, 1984–9. *Arch Dis Child Fetal Neonatal Ed* 1998;79:F21–5.
8. Surman G, Hemming K, Platt MJ, *et al.* Children with cerebral palsy: severity and trends over time. *Paediatr Perinat Epidemiol* 2009;23:513–21.
9. Hutton JL. Outcome in cerebral palsy: life-expectancy. *Paediatr Child Health* 2008;18:419–22.
10. Ando N, Ueda S. Functional deterioration in adults with cerebral palsy. *Clin Rehabil* 2000;14:300–6.
11. Bigby C. Ageing people with a lifelong disability: challenges for the aged care and disability sectors. *Int J Dev Disabil* 2002;27:231–41.
12. Haak P, Lenski M, Hidecker MJ, *et al.* Cerebral palsy and aging. *Dev Med Child Neurol* 2009;51(Suppl 4):16–23.
13. Long T, Kavarian S. Aging with developmental disabilities: an overview. *Top Geriatr Rehabil* 2008;24:2–11.
14. Molton IR, Jensen MP. Aging and disability: biopsychosocial perspectives. *Phys Med Rehabil Clin N Am* 2010;21:253–65.
15. Sandström K, Alinder J, Öberg B. Descriptions of functioning and health and relations to a gross motor classification in adults with cerebral palsy. *Disabil Rehabil* 2004;26:1023–31.
16. Schwartz L, Engel JM, Jensen MP. Pain in persons with cerebral palsy. *Arch Phys Med Rehabil* 1999;80:1243–6.
17. Tosi LL, Maher N, Moore DW, *et al.* Adults with cerebral palsy: a workshop to define the challenges of treating and preventing secondary musculoskeletal and neuromuscular complications in this rapidly growing population. *Dev Med Child Neurol* 2009;51(Suppl 4):2–11.
18. Turk MA. Health, mortality, and wellness issues in adults with cerebral palsy. *Dev Med Child Neurol* 2009;51(Suppl 4):24–9.
19. Young NL. The transition to adulthood for children with cerebral palsy: what do we know about their health care needs? *J Pediatr Orthop* 2007;27:476–9.
20. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
21. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: implications for conducting a qualitative descriptive study. *Nurs Health Sci* 2013;15:398–405.
22. Patton M. *Qualitative research and evaluation methods*. 3rd edn. Thousand Oaks (CA): Sage Publications, 2002.
23. Lloyd V, Gatherer A, Kalsy S. Conducting qualitative interview research with people with expressive language difficulties. *Qual Health Res* 2006;16:1386–404.
24. LaDonna KA, Ravenek MJ. Challenges & strategies for conducting qualitative research with persons diagnosed with rare movement disorders. *TQR* 2014;19:1–18.
25. Keith RA, Granger CV, Hamilton BB, *et al.* The functional independence measure: a new tool for rehabilitation. *Adv Clin Rehabil* 1987;1:6–18.
26. Moll LR, Cott CA. The paradox of normalization through rehabilitation: growing up and growing older with cerebral palsy. *Disabil Rehabil* 2013;35:1276–83.
27. Morgan P, McGinley J. Gait function and decline in adults with cerebral palsy: a systematic review. *Disabil Rehabil* 2014;36:1–9.
28. Read SA, Morton TA, Ryan MK. Negotiating identity: a qualitative analysis of stigma and support seeking for individuals with cerebral palsy. *Disabil Rehabil* 2015;37:1162–9.
29. McPherson KM, Brander P, Taylor WJ, *et al.* Consequences of stroke, arthritis and chronic pain—are there important similarities? *Disabil Rehabil* 2004;26:988–99.
30. Harwood M, Weatherall M, Talemaitoga A, *et al.* Taking charge after stroke: promoting self-directed rehabilitation to improve quality of life—a randomized controlled trial. *Clin Rehabil* 2012;26:493–501.
31. Morgan P, Pogrebnoy D, McDonald R. Health service experiences to address mobility decline in ambulant adults ageing with cerebral palsy. *Int J Dev Disabil* 2014;39:282–9.
32. Sandström K, Samuelsson K, Öberg B. Prerequisites for carrying out physiotherapy and physical activity—experiences from adults with cerebral palsy. *Disabil Rehabil* 2009;31:161–9.
33. Neri MT, Kroll T. Understanding the consequences of access barriers to health care: experiences of adults with disabilities. *Disabil Rehabil* 2003;25:85–96.
34. Kayes NM, Mudge S, Bright F, *et al.* Whose behavior matters? Rethinking practitioner behavior and its influence on rehabilitation outcomes. In: McPherson KM, Gibson BE, Leplege A, eds. *Rethinking rehabilitation theory and practice*. Boca Raton (FL): CRC Press, Taylor & Francis, 2015: 249–71.
35. Taylor SJ, Pinnock H, Epiphanou E, *et al.* A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS—Practical systematic Review of Self-Management Support for long-term conditions. *Health Serv Delivery Res* 2014;2.
36. Kraut AM. Healers and strangers: immigrant attitudes toward the physician in America—a relationship in historical perspective. *JAMA* 1990;263:1807.
37. Documét PI, Sharma RK. Latinos' health care access: financial and cultural barriers. *J Immigr Health* 2004;6:5–13.
38. Thomas C, Parry A. Research on users' views about stroke services: towards an empowerment research paradigm or more of the same? *Physiotherapy* 1996;82:6–12.
39. Sandström K. The lived body—experiences from adults with cerebral palsy. *Clin Rehabil* 2007;21:432–41.
40. Björquist E, Nordmark E, Hallström I. Living in transition—experiences of health and well-being and the needs of adolescents with cerebral palsy. *Child Care Health Dev* 2015;41:258–65.
41. Wright AE, Robb J, Shearer MC. Transition from paediatric to adult health services in Scotland for young people with cerebral palsy. *J Child Health Care* 2016;20:205–13.
42. Snow R, Humphrey C, Sandall J. What happens when patients know more than their doctors? Experiences of health interactions after diabetes patient education: a qualitative patient-led study. *BMJ Open* 2013;3:e003583.
43. Fadyl JK, McPherson KM, Kayes NM. Perspectives on quality of care for people who experience disability. *BMJ Qual Saf* 2011;20:87–95.
44. Kroll T, Jones GC, Kehn M, *et al.* Barriers and strategies affecting the utilisation of primary preventive services for people with physical disabilities: a qualitative inquiry. *Health Soc Care Community* 2006;14:284–93.
45. Hemsley B, Balandin S. A metasynthesis of patient-provider communication in hospital for patients with severe communication disabilities: informing new translational research. *Augment Altern Commun* 2014;30:329–43.

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