

THE EXPERIENCE OF AGEING WITH CEREBRAL PALSY



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Introduction

- Cerebral palsy (CP) is the most common lifelong physical disability worldwide.
- Despite most people with CP living into late adulthood most research and healthcare focus on childhood and adolescence.
- This study was designed to gain an in-depth understanding of the experience of ageing with CP and what people felt helped and hindered them in ageing well.

Methods

- Twenty-two people who were aged 40 or older living in London were recruited through the NHS and community organisations. The sample included five participants with co-occurring learning disabilities (LD) and three non-verbal participants.
- Participants took part in a semi-structured interview and data were analysed using reflexive thematic analysis [1].

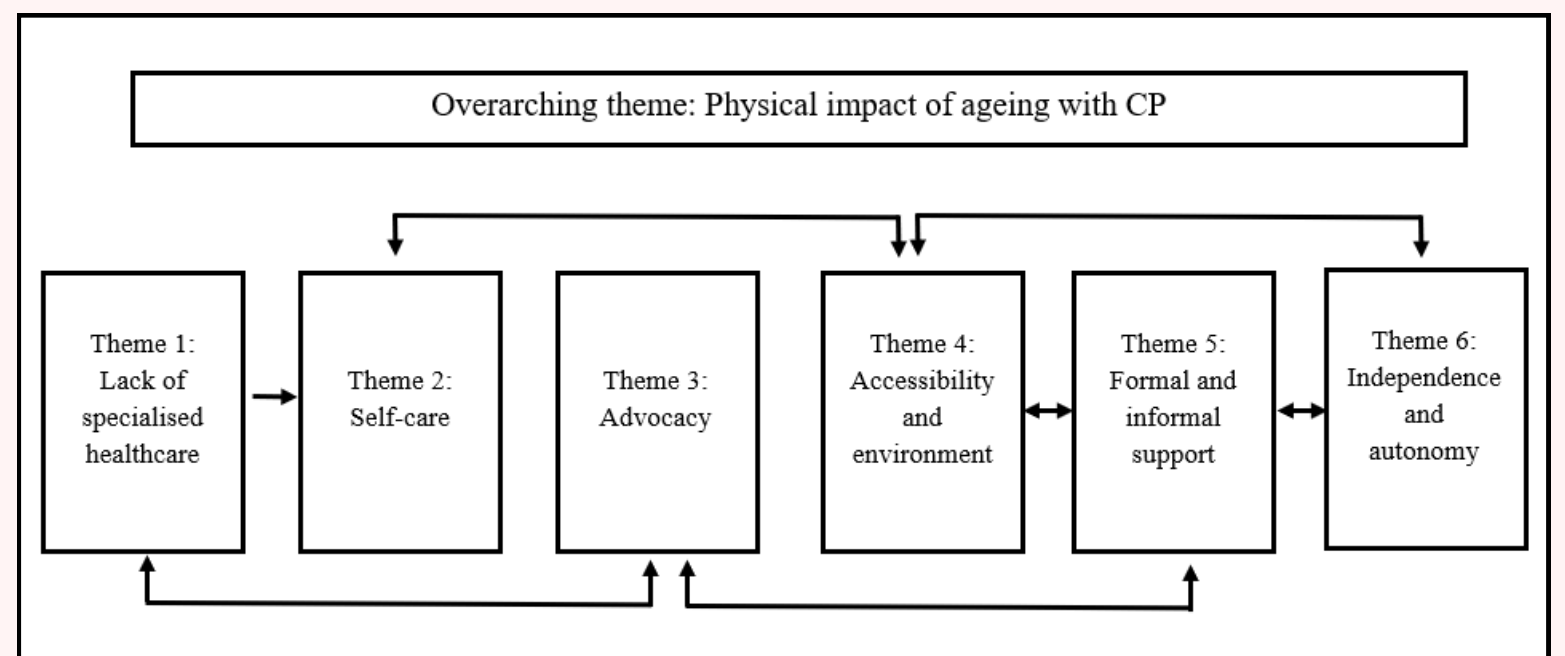
Findings

- The **physical impact** was central to participants' experience of ageing with CP. Participants spoke about their decline in mobility and function, worsening speech, loss of bladder control, and difficulty swallowing. They also spoke about issues related to pain, fatigue, and medication side effects.
- **Lack of specialised care** was the most salient theme amongst participants without LD and those living in the community and highlighted how the absence of specialised healthcare and physiotherapy in adulthood impacted negatively on ageing.
- **Self-care** was linked to theme 1 and described the different ways in which people with CP looked after their health and wellbeing in the absence of specialised healthcare. This included exercise, symptom management, and physiotherapy, accessed privately by those able to afford it.
- **Advocacy** captured the ways people used their expertise in their own condition to advocate in healthcare, work, and community settings and the ways that others acted as advocate to support ageing well.
- **Accessibility and environment** highlighted barriers to access and transports, which were described as a source of distress and could lead to isolation.
- **Formal and informal support** captured how sources of support helped people with CP to age well. Informal support was reported by most participants and was linked to Theme 3. Formal support was the most salient theme amongst people living with LD and those living in supported housing.
- **Independence and autonomy** were described as key goals to aging well. The need to ask for help, use additional support, or rely on mobility aids was linked to complex feelings.

I fall over much more now, I get tired much more, it hurts more when I walk. And I think all of those things are related to my body becoming more stiff and less agile.
(Alice, 50-59, GMFCS 1-3)

I've learnt a lot about myself. I definitely know more compared to when I was a teenager, I definitely know more about my condition than some professionals I do believe.
(Maisie, 40-49, GMFCS 4-5)

Well as you get older, you slow down. It takes me longer to get ready or to do things.
(Mark, 60-69, GMFCS 1-3)



Discussion

- For most participants, the physical impact of ageing with CP was the most salient aspect, affecting participation, daily life, and autonomy, and was therefore identified as their main support need for ageing well. This is in line with existing research [2].
- The lack of access to physiotherapy was perceived to be the greatest unmet need amongst adults with CP to age well, consistent with current literature [3].
- Social and psychological wellbeing were less explicitly emphasised, but were evident across themes and remained important for ageing well, particularly through relationships, support, and mental wellbeing.
- Participants described tensions with healthcare professionals regarding who held expertise, which were linked to narratives highlighting limited specialised healthcare and a lack of clinician understanding about the impact of ageing with CP, in line with previous research [3; 4].
- Many participants felt abandoned by health services and pointed to limited investment in their health and wellbeing. Some internalised this as a sense of being less valued.

I'm finding... because I don't have hands on physiotherapy like the physio physically helping me stretch, I can't access, there's ranges of motion in my muscles that I can't access without someone physically helping me stretch. I think that's part of the stiffness.
(Maisie, 40-49, GMFCS 4-5)

One of the things I'm constantly saying is that my life is just full of constantly fighting for something. Full of constantly fighting for my needs in a way they should be there in the community and they're not. And that's quite an exhausting existence at the same time.
(Rebecca, 40-49, GMFCS 4-5)

