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Gemma Cook, Elizabeth Cassidy & Cherry Kilbride

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# Understanding physiotherapy and physiotherapy services: exploring the perspectives of adults living with cerebral palsy

Gemma Cook<sup>a</sup> , Elizabeth Cassidy<sup>b</sup>  and Cherry Kilbride<sup>a</sup> 

<sup>a</sup>Department of Health Sciences, Brunel University London, Uxbridge, UK; <sup>b</sup>Freelance Academic, London, UK

## ABSTRACT

**Purpose:** To understand physiotherapy and physiotherapy services from the perspectives of adults with cerebral palsy (CP).

**Methods:** Twenty-two adults with CP (15 women, 7 men), from across the UK, aged between 23 and 51 years, Gross Motor Function Classification System I-V, were interviewed about their experiences of physiotherapy and physiotherapy services. Participants were recruited through advertisements placed with relevant national organisations. The interviews were transcribed and analysed according to principles of Reflective Lifeworld Research. A second analysis examined the findings in relation to Donabedian's structure-process-outcome framework for healthcare quality.

**Results:** Specialist services for adults with CP were described as scarce, unknowable, complex and disconnected through the life course. Specific problems included; *structural dimensions* such as access to and organisation of services, signposting to services and access to expert advice; *process dimensions* including a lack of attention to patients' perspectives, needs, priorities, experience and expertise; and *outcome dimensions* for example the negative impact of physiotherapy service configurations on health, well-being and quality of life.

**Conclusion:** Study findings support grassroots calls to radically improve and increase physiotherapy services for adults with CP. Accessible and widely available specialist services, information and advice across the life course would do much to address unmet need.

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Adults; cerebral palsy; physiotherapy; rehabilitation; service design; qualitative

## ► IMPLICATIONS FOR REHABILITATION

1. Adults with CP found it difficult to identify and access specialised physiotherapy services and to obtain information and advice to help them best manage their condition.
2. Adults with CP need physiotherapy services throughout the different phases of their lives, to meet their present needs, and to anticipate and, where possible, to prevent future needs.
3. Participants highly valued person-centred physiotherapy and we recommend this approach is adopted as the foundational philosophy guiding physiotherapy services and interventions for adults with CP.
4. More specialist physiotherapy services are urgently needed to meet the needs of adults with CP in the UK.

## Introduction


Estimates suggest that there are now three times as many adults living with cerebral palsy (CP) as there are children [1]. Steady incidence rates of 2.0–2.5 cases per 1000 live births [2] coupled with increased life expectancy for people with mild to moderate impairment [3] underline the increasing prevalence of CP in the adult population.

Recent studies have shown that adults with CP face physical, functional, and social disadvantages that contribute to activity limitations, reduced opportunities for participation, and decreased quality of life [4,5]. Impairments such as weakness, fatigue, muscle stiffness and muscle and joint pain may worsen with age and contribute to progressive functional disability in early adulthood [6]. The burden of non-communicable diseases such as diabetes,

stroke and chronic respiratory conditions is also higher amongst adults with CP compared with the general population [7]. Prompt and unrestricted open access to physiotherapy services across the lifespan should be a priority for adults with CP as poor access may impair effective management of health conditions and hamper health promotion [7,8].

Physiotherapy has not historically been offered to adults with CP [9]. Care for adults with CP living in the UK is not driven by the specialist services or care-pathways that guide physiotherapy for adults living with other neurological conditions. Patients usually require a GP referral to access physiotherapy in the UK public health system. UK physiotherapists are independent practitioners. Interventions and discharge should be jointly agreed by the patient and physiotherapist [10]. Physiotherapy services may be

CONTACT Cherry Kilbride  [cherry.kilbride@brunel.ac.uk](mailto:cherry.kilbride@brunel.ac.uk)

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provided on an outpatient basis or in the community. There are no specialist inpatient rehabilitation centres for adults with CP. Patients may seek out private physiotherapy to supplement or replace publicly funded services. Recent guidelines broadly describe high-priority areas for health service improvements for adults with CP and for children moving into adult services [11,12]. These guidelines are aspirational and the extent to which they have been met in everyday practice is yet to be determined. We are aware of one recently developed UK specialist multidisciplinary outpatient service for adults with CP.

In studies conducted almost exclusively outside the UK, adults living with CP have raised concerns about the environmental, organisational, and interpersonal contexts in which healthcare services such as physiotherapy are carried out [13–17], and have reported insufficient specialist care, inadequate services, and a lack of practical help as they grow older [15–17]. These findings have led to calls for people with CP to be given a voice in determining the way rehabilitation services are organised and delivered [16,18]. Little is known about how adults with CP access and experience physiotherapy services in the UK.

This study aimed to understand how well physiotherapy and physiotherapy services meet the needs of adults with CP in the UK through exploring personal experiences of physiotherapy. The findings offer insights to physiotherapists, policy makers, and healthcare organisations who have the potential to shape future service development.

## Methods

A qualitative lifeworld approach [19,20] provided the philosophical grounding from which participants' experiences and perspectives of physiotherapy and physiotherapy services were analysed, interpreted, and understood. Using this phenomenological perspective, we aimed to consider the relational (interpersonal), existential (the meaning of human existence), and experiential (the doing and experiencing of human life) challenges faced by adults with CP. Semi-structured interviews were used for data collection. This method affords participants latitude to talk about what is important to them whilst allowing the researcher to guide the conversation [21].

### Research ethics procedures

The research protocol and all relevant materials were approved by Brunel University Research Ethics Committee (reference number: 16829-MHR-Jul/2019-19747-2). All participants completed formal consent procedures prior to participating in the study.

### Recruitment

The study was advertised through the websites and social media of relevant independent organisations and charities across the UK, and at professional healthcare conferences. Inclusion criteria were: 1) aged 18 years or over; 2) capacity to consent; 3) any type and severity of CP; 4) experience of contemporary physiotherapy services in the previous two years in the UK. Participants were excluded if they were unable to participate in an in-depth interview in English. Lifeworld research depends on rich variation of data rather than aiming to recruit a specific number of participants (19), therefore we aimed to be maximally inclusive to achieve as broad a range of participants as possible. Purposive sampling was used to include participants with a range of socio-demographic characteristics including age, ethnicity, living

situation, gender, communication ability, employment, and mobility. Part way through data collection we identified sampling gaps related to participant characteristics and geographical location. We readvertised the study and identified new recruitment partners to address these gaps. Advertising was open for seven months from July 2019. No applicants were excluded from the study or refused to participate after receiving information about the study.

### Data collection

A semi-structured interview schedule was prepared with reference to contemporary literature and Reflective Lifeworld Research methods [19]. Iterative drafts were discussed by the three authors and shared with the study advisory group for feedback. The final schedule ([Supplementary material](#)) focused on: participants' demographic details; service provision and organisation such as referral and access to services, and length and type of treatment; perspectives on physiotherapy interventions and physiotherapists, such as relationships, communication skills and expertise. Open questions privileged participants' perspectives and priorities and encouraged them to talk at length. One-to-one interviews were conducted face-to-face and recorded by the lead researcher (GC) between August 2019 and February 2020. One participant used a communication aid and communication support workers assisted interaction during the interview. All interviews were transcribed verbatim by a professional secure transcription service.

### Patient and public involvement

The study advisory group comprised four adults with CP and five physiotherapists with experience working with children and adults with CP. The group informed the development of the interview questions, commented on emerging results, and offered advice and observations on the progress of the study and the subsequent dissemination of findings.

### Data analysis

An iterative approach was used for data analysis over a period of ten months from October 2019 to July 2020. All authors read the transcripts. The lead researcher (GC) read and re-read the transcripts from the first few interviews. Data were then grouped by identifying patterns and similarities guided by Reflective Lifeworld Research [19], and with reference to Ashworth's fragments of the lifeworld [20], such as selfhood, sociality, embodiment and temporality. Critical dialogue between GC and co-authors supported the development of the analysis through interrogation of preliminary understandings and provisional interpretations. Ongoing recruitment enabled new data gathering to fill gaps in the data and to further explore newly inferred meanings. The interview guide was not substantially changed.

The text was divided into meaning units (fragments of text such as a word, phrase or sentence that describe a specific phenomenon) through several analytical procedural elements: data immersion; reflection; back and forth comparisons between the original data and the meaning units; searching for contextual nuances, convergences and divergencies; and ongoing and evolving critical discussion between all three researchers. Data clusters (temporary patterns that can be disassembled and reassembled as the analysis progressed) were then collated. This process continued until essences of meanings (the most abstract level of

analysis) had been inferred from the entire data set from which the constituent parts (themes) were identified and named.

In a second separate phase of analysis and through discussions of the main findings with our advisory group, we mapped the findings onto Donabedian's structure-process-outcome model of healthcare quality [22]. The purpose of this second analysis was to use the framework to highlight strengths and to identify service limitations or 'friction points' that slow down or complicate access and engagement with services as perceived and described by participants in the study.

- **Structure:** factors affecting the context in which physiotherapy is delivered e.g., access, facilities, equipment, staff expertise, financial resources.
- **Process:** the application of clinical care e.g., communication, interaction, assessment, treatment, information giving.
- **Outcome:** the impact of care on the patient, including patient experience, e.g., the impact on health status, knowledge, behaviour, satisfaction, quality of life.

## Results

Twenty-two adults with CP (15 women, 7 men), from across the UK, aged between 23 and 51 years (median age 35 years) were interviewed at home ( $n=21$ ) or in a convenient location of their choice ( $n=1$ ). The mean interview time was 78 min (range 53–103 min). Sociodemographic characteristics are reported in Table 1.

Four principal but inter-dependent constituents were inferred from the data: 1) complex lives – putting out small fires everywhere; 2) the relentless search for services, support, information, and advice; 3) person-centred holistic physiotherapy and 4) physiotherapy is embedded in past, present and imagined future lives. Participants experienced physiotherapy across a wide variety of contexts. Service providers included NHS, private, and charitable organisations, and many experienced a mixture of all three. They also experienced physiotherapy across different settings including in-patient, outpatient, and domiciliary care and from generalists as well as different specialisms including community, musculoskeletal, neurological, and post-surgical/orthopaedic. Participants were, for the most part, uncertain about how much experience their physiotherapists had in working with adults with CP. Power dynamics featured implicitly and explicitly across essences and were integral to understanding the interplay between physiotherapy experiences and the personhood of adults with CP. Participants believed they lacked power, whereas systems, and some actors in those systems, were perceived to wield power through obstructing and complicating access to information and resources, and by invalidating, infantilising, labelling and stigmatising adults with CP.

### Complex Lives - Putting out small fires everywhere

Participants described living complex lives, often confronting multiple simultaneous problems related to their CP. These included acute issues that could suddenly disrupt life such as falls, trauma, injury, and exacerbations of chronic pain conditions; systemic problems that could adversely affect impairments such as spasticity and spasms; and functional problems affecting participation in the home and the community. Mental health concerns could also become unexpectedly foregrounded adding to the difficulties experienced by these participants. Living through and containing these small fires, and averting crises, emergencies and escalations in the intensity of mental or physical health conditions was

Table 1. Sociodemographic characteristics of participants.

Sociodemographic variable	Number of participants ( $n=22$ )
Age	
20–29 years	2
30–39 years	10
40–49 years	9
50–59 years	1
Ethnicity (self-described)	
White British	17
White Scottish	1
African-Caribbean	1
British Asian	1
White Jewish	1
White Irish	1
Employment	
Full time (paid)	8
Part-time (paid)	7
Student	3
Unemployed – looking for work	3
Unemployed – not seeking work	1
Living arrangements	
Lives alone	8
Lives alone with carers	3
Flat share	1
Lives with parents	4
Lives with partner/spouse	4
Lives with dependent children	2
Place of residence	
Urban	20
Rural	2
Location	
England	17
Scotland	2
Wales	1
Northern Ireland	2
GMFCS <sup>a</sup> (self-reported)	
I	2
II	6
III	5
IV	8
V	1
Limb involvement (self-described)	
Diplegia	10
Hemiplegia	3
Quadriplegia	7
Other	
Ataxia/spasticity	1
Ataxia/athetosis	1

<sup>a</sup>GMFCS: Gross Motor Function Classification System (higher score indicates more assistance required for mobility).

described as a relentless and tiring process – a constant battle to quell the flames:

*I get a physical issue, I deal with that physical issue, and then my mental health goes downhill, I deal with my mental health and then something physical happens again, so there's always something going on. [...] it can feel like a never ending battle. Alice (age 32, GMFCS IV)*

*... because sometimes it just feels like you've ended one sort of fight but one sort of challenge of trying to find something and then you're just straight onto the next one. Phoebe (age 31, GMFCS IV)*

Physical problems and physical pain were described as significant challenges that also posed a heavy psychological burden:

*So, I think my mental health and my mood has gone down in the past six months as the pain levels have cracked up again a bit. [...] everything's a struggle at the moment. [...] I just feel a bit pessimistic around, you know you've got to fight for everything, and you don't always feel like fighting. Rachel (age 48, GMFCS I)*

Participants strived to attain a steady state (in their physical/emotional/psychological worlds), but their efforts were constantly

disrupted by events out of their control and through a lack of support and poor access to services:

*... you spend a week trying to get the [GP] appointment then you get the appointment, and you wait another three weeks for that, and then you go in, then you wait another three or four months for the physio appointment, and then you find out whether or not it was the right physio or not. Rachel (age 48, GMFCS I).*

Participants looked to physiotherapists to help manage their physical body and to understand the impact of bodily problems and effective management of those problems on their sense of self, their identity, mental health, and autonomy:

*I feel a bit more supple in my legs and my arm [after physio]; my spasms decrease as well and my general wellbeing is that I have an increased mood, my mood improves. [...] doing physio makes me a bit, feel free, like I'm free to move my legs about ... Makes me feel good and makes me feel happy. I guess it makes me feel like I've got control as well. Jude (age 23, GMFCS IV)*

The sense of embodied freedom and joyfulness that may be experienced by individuals who are unable to move themselves freely but who can experience movement through skilful physiotherapy was highly valued.

All participants regretted the lack of regular and long-term physiotherapy which they viewed as an important resource in adulthood for maintaining a steady state and for working through and dealing with multiple interacting problems:

*When I first started doing the physio [as an adult] I didn't know it was going to ... I thought it would be permanent [...] I didn't know it would be just like a series of sessions and then goodbye. [...] I kind of get the idea that they're not really interested anymore; they've dealt with you and that's it. [...] We've got other people to deal with, you're not important anymore. Peter, (age 46, GMFCS II)*

### **The relentless search for services, support, information and advice**

After an initial and sometimes welcome relief from the intensity of physiotherapy in childhood, the search for physiotherapy services, often in early adulthood, was triggered when participants started experiencing new problems or a deterioration in physical capacity. Participants accustomed to wrap-around continual care in childhood found the lack of adult services or being discharged from an adult service disconcerting:

*... all these things that children had, magically disappeared in adults... But I don't magically hit 18 and get cured. Sarah (age 31 GMFCS III)*

*... you become 18 and then it all stops. But your CP doesn't disappear when you're 18, but the services seem to stop. Mary (age 35, GMFCS IV)*

Some described feeling abandoned or brushed aside, as if, on reaching adulthood, they no longer merited the type of care they were offered as children:

*... at eighteen, nineteen, [...], your case is closed, so to speak, [...] that's very hard for your brain to sort of compute that. You're not cured. You still have the condition, but everybody's closed their book on you, basically. [...] you're just pushed off a cliff. [The physios say] 'We can't do that anymore'. And then you just have to find it for yourself. Maeve (age 32, GMFCS III)*

GPs, it was felt, had little access to, or knowledge of, referral routes to relevant services or specialist clinical teams (if they existed). Available services were described as difficult to access, poorly signposted, and fragmented:

*... nobody knows where to go. Nobody can say, 'Maybe try them'. I think everyone is winging it a wee bit [...] it just sort of feels a bit, yeah just slightly messy and I feel that things could be organised a lot better. Phoebe (age 31, GMFCS IV)*

Participants described working with multiple but disconnected health and social care actors and searching for relevant specialist physiotherapy services a daunting and discombobulating prospect:

*Where do I start? ... it's like this whole big world ... it is just a real like minefield and you just kind of feel like you need someone on your side. Polly (age 30, GMFCS II)*

Where services were available, participants were often prescribed blocks of therapy in which problems were treated in isolation preventing joined-up holistic care. Strict discharge policies and re-referral processes were perceived as meeting the needs of service providers to manage waiting lists but as failing to address the ongoing needs of participants, leaving them in long-term limbo while they waited for or sought out a new referral:

*[the physiotherapists] want me to kind of come in with an issue that then gets fixed and it's not always like that, you know, I need something much more ongoing. [...] the ongoing preventative stuff just doesn't seem to exist for CP. Megan (age 49, GMFCS III).*

*... it just felt really that you were just a number in a system like, you know churn it through. Polly (age 30, GMFCS II)*

Where satisfactory services were found, they were often based on fragile foundations, such as tenuous funding systems or over-dependence on one or two exceptional individuals. The labyrinthine journey to access services was made more difficult by the lack of information and an absence of on the ground experts. Participants referred to the absence of pathway coordinators or key workers who they believed were often used to coordinate care for people with other long-term conditions.

These experiences had a profound impact on the lifeworld and personhood of adults with CP. Participants lost confidence and described feeling overwhelmed by feelings of anxiety, insecurity, and loneliness; "totally at sea" (Sarah, age 31, GMFCS III), and "left in limbo-land" (Olivia, age 29, GMFCS IV).

*... we are a forgotten condition. Tara (age 43, GMFCS III)*

*... it's almost like disability top trumps [laughter]. Because you know, it's always like people with CP are just at the bottom and they just get forgotten about. Polly (age 30, GMFCS II)*

Participants described a challenging and demanding journey through complex healthcare systems and referral processes to seek out services and support. According to participants, publicly funded services for the most part lacked the capacity to meet their needs.

### **Person-Centred holistic physiotherapy**

Participants judged the quality of physiotherapy by the degree to which physiotherapists used a person-centric approach. According to our findings, a person-centric approach had broad ranging constituents which included the environment in which therapy takes place, inter-personal relationships between staff (auxiliary as well as professional) and service-users, treatment choices, and staff expertise and knowledge of CP.

Environments were revealed to have significant interplay with personhood and self-worth. Clinical settings that engendered a sense of safety and acceptance were highly valued:

*... you kind of feel like you're in safe hands almost, it's like these people know about, you know, they know about my condition, and they know what, to some extent, what I'm experiencing. Tricia (age 34 GMFCS IV).*

Participants felt undervalued when services appeared to pay little attention to their physical, psychological and emotional comfort. Under these circumstances participants felt themselves to be



perceived as problems or objects to be dealt with rather than human beings to be understood. For example, not being able to use accessible toilets with dignity could heighten troublesome feelings of difference:

*It's quite, kind of, difficult because you obviously have to go to [physio] reception and say "Can I access this particular toilet", and normally if you just go to the toilet as a normal person, you just go, it's not like you have to tell anyone, or announce it to anyone, you just normally would just go. Tricia (age 34, GMFCS IV).*

Difficult access to treatment beds and equipment added to the sense of burden and accentuated differences when compared to other, more physically independent patients who needed less help:

*I'm wondering is, 'Is my chair going to fit in there?' [...] 'Am I going to be able to get up onto the bed?' [...] maybe they just don't see a lot of wheelchairs or disabled people but because you're slowing them down, there's no question about it, you take longer and then when you're like, 'Can you give me a wee hand?'. Phoebe (age 31, GMFCS IV)*

Some participants described being treated in a way that denied their agency and maturity. Therapy could feel dehumanising and disempowering if assessment and treatment approaches failed to validate the human being ahead of the human body:

*... it was really strange ... when I was at a session she'd clap and stuff and it just made me feel really uncomfortable and I kind of felt like I was almost like, it was like a performance in a sense, it just, just ... and I kind of remember thinking I'm a 40 odd year old woman, I'm not a child. [...] ... it was almost like she was treating me as if I was a performing seal. Stacey (age 46, GMFCS II).*

A collaborative approach demonstrated the person-centredness of the physiotherapist's approach whereas "rinse repeat" (Polly age 30, GMFCS II) treatment failed to heed to individual need. Prescribed home exercise programmes were often described as unmanageable and sometimes impossible to carry out and were recounted as examples of unsatisfactory interactions:

*I was being given exercises to do that I couldn't see the purpose of, and it wasn't explained, and I couldn't really do. I felt there that there was not much knowledge and understanding of cerebral palsy in general. [...] when you're asked to do something and you can't quite do it, it feels like judgement in a way. It feels uncomfortable because you're trying to say 'I can't'. Lucy (age 30, GMFCS II).*

Prescribed exercise programmes added to the work of living with CP, often offering no tangible improvements in physical or mental well-being, participation in life, or quality of life. Home exercise prescription gave the unfortunate impression that in every practical sense adults with CP were expected to shoulder the responsibility of their own care. This burden weighed more heavily if they were unable to exercise or to persist with exercise programmes over the long-term.

Person-centred treatment approaches acknowledged the life-world, involved meaningful projects, and conferred a sense of worthiness and value. Physiotherapists enacting these principles were described as engaged, curious and interested in exploring and understanding the lives of their patients. Mary described an example of meaningful, patient centred physiotherapy. She worked in partnership with her private physiotherapist and carers to learn how to manage her significant pain and spasticity well enough to ensure she could keep going to concerts – a great joy in her life.

*I could easily be a person that could be hoisted, but because I have regular physio, I'm still able to stand up, weight bear and balance. [...] I can go out and still access disabled toilets and things. Whereas if I was hoisted, that might not be the case. [...] I wouldn't be able to go out for long periods of time if I couldn't access [the toilet] and be able to balance*

*because I would have to come home to be able to do those things. So, I can still be out for long periods of time with friends and be able to do the things I like to do. So, it really, it means a lot to me to be able to do those things. [...] I know that the physio is going to be quite painful and not a nice experience, but I tell [my physio] that and then he's quite sympathetic and understanding of my emotions. Mary (age 35, GMFCS IV)*

Physiotherapists who connected with, understood, and looked out for patients were highly regarded by some participants, as were those few physiotherapists who sustained valued long-term professional relationships with their patients from childhood through to adulthood. The nature of these relationships was difficult to describe. Some participants referred to lifelong friendships, others talked of having a strong personal connection and rapport with their physiotherapist. Not all participants looked to develop such close ties, but all participants stressed the importance of having good interpersonal relationships with their physiotherapists and highly valued sensitivity and partnership working in the complex decision making faced by adults with CP.

*... if you get someone that's willing to help and not to give up on you, then that really makes a difference for me physically and mentally. Tricia (age 34, GMFCS IV).*

Decisions about discharge could be highly emotive, and physiotherapists were judged as failing to appreciate the impact of these decisions on psychological well-being:

*... after about four sessions she said to me, "I can't help you anymore, you just have to accept that one day you'll not be able to transfer anymore," and that really kind of knocked me for six ... uhm ... kind of mentally [...], having a health professional say to you, "I can't help you anymore," is really quite a crushing statement [...] actually you're not just affecting the outcome of the person physically, but also mentally, because they're trying to cope with the condition day to day. [...] I went into the toilet after [I was discharged] and burst into tears because I didn't know where to go from there. Tricia (age 34, GMFCS II).*

Participants pointed towards structural deficiencies in the way physiotherapy was organised, such as the lack of time available for appointments, rationing of services and appointments, frequent rotation of staff, and the lack of specialist services, to suggest that the capacity to offer person-centred care may be inextricably linked to the system in which physiotherapy is positioned rather than wholly in the hands of individual therapists. Services offering stand-alone short treatment blocks delivered by rotational therapists may further prohibit the trust and relationship building required for person-centred care:

*... [physiotherapy] was with someone who had no idea about my body, never met me before the six weeks started and wasn't planning to meet me when they finished. Angie (age 34, GMFCS II)*

*... if you're chopping and changing physiotherapists all the time or any sort of clinician you miss that [connection], you don't build up that rapport and I think that's very important. Michelle (age 48, GMFCS II)*

### **Physiotherapy is embedded in past, present and imagined future lives**

Participants' beliefs about the meaning and value of physiotherapy were influenced by childhood memories (the past), the forging of new therapeutic relationships in the context of inadequate service provision in adulthood (the present), and concerns about the impact of physical problems on future activities and abilities.

#### **The past**

Participants described some positive childhood memories of working with physiotherapists, but others recalled quite traumatic experiences that may have influenced their perception of physiotherapy in adulthood. In the following example, John recalled not

only painful encounters with physiotherapists but also his lack of agency in taking part in “corrective” interventions with barely masked overtones of perceived punishment and torture:

*I remember being put on, what would be standing frames, but felt like racks. [...] the pain was horrendous, and the muscles go numb, ... and then it'd be like going to jelly, [it was] just horrendous and you had no say in it. [...] they just told you to get on with it, suck it up, you know, even if there were tears in your eyes. John (age 30, GMFCS IV).*

Attitudes based in notions of the ‘normal body’ emanated not only from the physiotherapists encountered by participants in childhood but also people in other close support networks:

*The environment I lived with and then grew up in was all about trying to be like everyone else. [...] everyone for twenty years had told me how to do things, how to sit, how to walk, how to eat, how to drink. Brian (age 45, GMFCS II).*

Accounts suggested that some adults with CP may not have grown up in environments where positive identity formation was supported. For these participants, building new therapeutic relationships and finding a voice to talk to physiotherapists as partners and allies was something they discovered only much later in adulthood:

*You can say [to physiotherapists] that you want stuff. I never knew you could do that. I didn't know you could do that. I learnt that in my mid-thirties [...] I didn't realise you could turn around and say, no, this isn't right. [Physiotherapy] was always something that was done to me. I wasn't a participant in it. I went in, something was done to me, and I left. Ben (age 42, GMFCS III).*

Participants' accounts also suggested that advice given in childhood may need to be revisited in adulthood and positioned in the context of new evidence and the person's whole lifeworld.

*'[...] the physiotherapist when I was growing up said, "Don't do dumbbells," that had made me completely dismiss the idea of going to a gym, full-stop.' Peter (age 46, GMFCS II).*

Participants' narratives suggested that understanding the meaning and impact of childhood experiences of physiotherapy, especially the possible psychological effects of interventions based on approximating ‘normal’ function, might be an important component of a person-centred approach to working effectively with adults with CP.

### The present

A strong belief in the potential value of physiotherapy and physiotherapists appeared to survive in participants' accounts. Some interviewees had forged relationships with paediatric physiotherapists that had developed into friendships through adulthood and remained ongoing. Some participants spoke very highly of their current physiotherapists and of power and dependency dynamics that had been redefined over time:

*It's a professional relationship. [...] It's probably more of a support relationship so it's almost like putting stabilisers on the bike, where the physio is the stabilising wheel and you're the bike. I would say. John (age 30, GMFCS IV).*

In contrast to NHS provision, private physiotherapy services offered some participants the opportunity to renegotiate therapeutic relationships. Paying privately, selecting a physiotherapist, and agreeing the content and purpose of physiotherapy was felt to redistribute power more evenly:

*'As a paying customer, it kind of changed the dynamic for me in terms of we were equals. I was no longer a child. I was having something done to me. I'd actually facilitated this procedure. [...] there was a whole different dynamic. I felt more comfortable, and I felt able to explain the extent to which my cerebral palsy affects me.' Ben (age 42, GMFCS III).*

Although some participants spoke of building effective therapeutic relationships with physiotherapists on an individual level, for the most part, participants lacked confidence in physiotherapy services because specialist care in the private and public sector and long-term provision was difficult to find and to sustain.

### The future

From a relatively young age participants looked to the future with some concern. Olivia, aged 29, for example, anticipated significant physical decline by her early forties. She acknowledged the lack of information she had been given to prepare for this eventuality and perhaps regretted lost opportunities to live her life differently if she had been forewarned:

*'As I got older, I started to need to use crutches and sticks. I thought it was just a phase and that my legs were a bit tired with working. [...] It's got gradually worse as I've got older. I dread to think what I'll be like in ten years' time. [...] I think if I'd been told that it would happen, I could have prepared.' Olivia (age 29, GMFCS IV)*

A seemingly inconsequential event for someone without CP, can provoke an existential threat for someone with CP, heralding an uncertain future. For example, participants explained that a minor fall or a sprained ankle, had the potential to instigate profound knock-on effects; to other body parts, to balance, mobility levels, and ultimately to the ability to continue participating in meaningful life-projects. Encounters with physiotherapists as a result of injury or accident or small changes in mobility were described as emotionally charged events because of what participants understood was at stake in these consultations:

*My biggest fear was after this accident was that I wasn't going to be able to go to work and be independent and that was a terrible, terrible fear. And still certainly if I didn't have my physio, I'd find it very difficult to go work, and to be able to put it into perspective with things and then talk it through with the physios. Michelle (age 48, GMFCS II)*

Physiotherapists are potentially well placed to respond to the existential threats perceived by adults with CP and to sensitively discuss and mitigate the impact of injury and physical deterioration.

### Interpretation of findings against donabedian's triad of healthcare quality

To offer tangible indicators for practice we collaboratively reinterpreted our findings with our advisory group to align them with Donabedian's structure-process-outcome continuum model [22]. We identified problems throughout the continuum model which we have listed in Table 2, which may be of assistance to physiotherapists who are involved in developing and reviewing services for adults with CP.

### Discussion

We set out to understand physiotherapy and physiotherapy services from the perspective of adults with CP. Participants described dealing with often complex, ongoing, and changing health needs throughout their adult lives. Difficulty finding, accessing, and re-accessing services, rationing of services, inequitable service provision and treatment delays were widely reported. Our findings suggest participants were poorly served by a lack of specialist physiotherapy service provision, fragmentation of available services, and an inflexible assembly line approach that in their experience prioritised throughput at the expense of high quality person-centred care. Efforts to locate and be admitted to appropriate services took a toll on health and well-being and added to

Table 2. Organisation of findings about services and service delivery using the structure-process-outcome model [22].

Structure of Care
<p><b>Access to Services</b></p> <p>More specialist physiotherapy services for adults with CP are needed. Services should be fairly distributed to reduce inequalities in healthcare provision and unmet need.</p> <p>Where services exist, adults with CP should be informed about how to access services. The extended reach of websites, charities and social media may need to be harnessed.</p> <p>Where services exist, GPs should be given information about appropriate referral pathways to improve access to services and reduce treatment delays. Reach-out work by physiotherapists may facilitate this process.</p> <p>Adults with CP should have direct access to physiotherapy services to improve efficiency in the referral system and to reduce treatment delays.</p> <p><b>Human Resources and Staff Expertise</b></p> <p>Physiotherapists may need specialist training to work effectively with adults with CP.</p> <p>Adults with CP need physiotherapists to feel comfortable working with them, and not to feel a burden on the system or on individual physiotherapists.</p> <p>Physiotherapy practice that puts the patient at the centre using a collaborative and partnership model would be valued by adults with CP.</p> <p>Physiotherapists may need to consider how less experienced staff are supported to work with adults with CP, particularly those with complex needs.</p> <p>Staff on rotation should make sure that patients and newly rotated staff are prepared for transitions in care.</p> <p>Direct access to expert advice and information should be offered.</p> <p><b>Organisational Structure</b></p> <p>Long waiting lists for physiotherapy services reduce quality of care and add to treatment delays. Open access and self-referral methods would go some way to reducing this burden for adults with CP.</p> <p>Physiotherapy services should be integrated with other therapy or rehabilitation services.</p> <p>Short blocks of interventions with inadequate follow up do not meet the needs of most adults with CP.</p> <p>The frequency of reviews and the duration of interventions should be individually determined according to need.</p> <p>Central information hubs and one stop shops should be considered as a means of meeting unmet needs and to reduce fragmentation in health service provision. Talking to experts may promote wellbeing, provide a safety net for crisis situations, and may reduce the sense of isolation associated with managing complex decision making.</p> <p>Email, phone calls and electronic conferencing may facilitate timely intervention and support, the provision of information and advice, and may reduce waiting lists and treatment delays.</p> <p>Regular maintenance therapy, e.g. for those with chronic problems of stiffness and pain that cannot be managed independently, should be built into services.</p> <p><b>Process of Care</b></p> <p>Communication: precedence should be given to patient perspectives, needs and priorities.</p> <p>Interactions should elicit, recognise, and respond to patient expertise and experience.</p> <p>Interactions should take account of an individual's social, cultural, psychological, and physical contexts.</p> <p>Assessment should focus on patient priorities and should be led and defined by patients.</p> <p>Interventions should reflect patients' priorities and focus on enabling patients to live a life of their choosing.</p> <p>Information about services should be freely available and widely shared.</p> <p>Adults with CP should be prepared for the life transitions that are meaningful to them, including but not limited to the transition to adult services.</p> <p>Young people should be supported to understand the role of physiotherapy throughout their lifespan.</p> <p><b>Outcomes of Care</b></p> <p>Outcome measurement should be meaningful and relevant to adults with CP.</p> <p>Outcome should include measurement of quality of life as determined by individual patients.</p> <p>Outcomes should measure satisfaction with services and service delivery.</p> <p>Prescriptions for home exercises and self-management should be evaluated for positive and negative effects on health, well-being, and quality of life.</p>

the burden and work of living as an adult with CP. Most participants described feeling frustrated and despondent about the lack of organised services for adults with CP and disconnected from the sources of support they expected to draw on throughout their adult lives. Taken together, our findings, inferred directly from experiential accounts, strengthen the case for urgently improving physiotherapy services for adults with CP.

Our findings further support previous studies that have questioned the assumptions on which rehabilitation services for adults with CP are based and have recognised the need to create new specialised services that operate across the life course [13–17]. These studies also suggest, in line with our findings, that beneficial outcomes will be realised when healthcare professionals work in partnership with adults with CP, personalise their care and understand the impact of stigma on their everyday lives [13–17,23].

The findings add qualitative weight and urgency to the recommendations of the NICE guideline for cerebral palsy in adults [11] specifically recommendations to provide information about local services and to develop pathways that allow access to central hubs and networks of local services. The idea that physiotherapy for individuals with CP is lived through as a continuum through time, fits with taking a life course approach to the design of paediatric and adult services [17]. Mounting evidence from recent studies about the long-term health needs of adults with CP

[13,24–30] further reinforces the importance of providing uncomplicated access to healthcare, including physiotherapy services, for this population. Adults who are unable to advocate for themselves or who lack family support and those marginalised by intersectionality may need additional support to access services and to increase awareness of their eligibility for services. Many participants pointedly expressed a concern for these groups, recognising the relative privilege of their own positions, in that they were more able to get their voices heard.

The sense of injustice expressed in the interviews about the lack of specialist physiotherapy services, reflects calls to bring about changes in healthcare services for adults with CP in the UK [31] and elsewhere [9]. Disabled people should have the same rights to access healthcare as non-disabled people [32,33] and yet the experiences recounted by participants in this study suggest that these rights are not being upheld.

The findings indicate that service providers should take full account of patients' embodied selves and their psychosocial worlds, aspirations, and commitments, and should question and address practices, policies and procedures that sustain a status quo that fails to serve the needs of adults with CP. The findings of this study add to critical discourses about the moral, social, political, and cultural meanings of rehabilitation for people living with long-term neurological conditions [16,34–36], question traditions and assumptions on which services are built, and support



the NICE guideline for improving the experience of care for people using adult NHS services [37].

Physiotherapists operating with limited funds, and pressures to increase care standardisation, may feel unable to commit resources to implement the changes in practice outlined in this study. However, a shared decision making framework can help realise improved processes and outcomes, as well as individualise care, and, through its patient-centred focus, improve patient satisfaction [10]. The application of a shared decision making framework in physiotherapy practice may offer a means to structure physiotherapy services for the benefit of adults with CP.

The organisation and funding of physiotherapy may lie far upstream from the physiotherapists who deliver services, but physiotherapists have the capacity to directly address some of the friction points identified in this study, to critique taken for granted norms about service design and delivery that are often arbitrary, inherited or imported from other services, and to advocate to policy makers and funders to act on points that may require adaptations to funding configurations. Physiotherapists, policy makers, and healthcare organisations may find the points identified in table 2 useful for improving the quality of physiotherapy services for adults with CP.

In acknowledging the limitations of this study, the following points should be considered. Participants recruited from support groups and charitable organisations may feel comfortable talking about their health, have better connections to sources of support, or be particularly knowledgeable about their condition, and have something to say [38]. Despite our best efforts, we were unable to recruit significant numbers of participants with GMFCS V, older adults, or a higher proportion of participants from Black, Asian, and Minority Ethnic groups. Over eighty per cent of participants were either employed (many in professional roles) or in higher education at the time of the interview which is disproportionate to the 52.1% of disabled people aged 16–65 years in the UK in employment in 2020 [39]. However, participants from across UK with a broad range of CP severity spoke similarly about their experiences of physiotherapy and physiotherapy service provision. No new information or perspectives were advanced by participants interviewed in the latter stages of data collection which lends weight to the potential applicability of the presented findings.

All authors were white, middle class, middle-aged women with specialist neurophysiotherapy backgrounds who have worked in the National Health Service, charity, academic, and private sectors. The lead author is a novice researcher who was supported by the two other authors who are experienced qualitative researchers. Our perspectives may have narrowed the lens through which the critical analysis was undertaken, however, our familiarity with the topic may also have strengthened our ability to understand and make inferences about accounts that were highly situated in physiotherapy contexts. Discussions with the advisory group also helped to challenge our assumptions.

## Conclusion

This study has shown that adults with CP are underserved by current physiotherapy services and experience significant challenges in accessing and receiving specialist care. Physiotherapy services for adults with CP should be designed with respect to the lifelong complex needs of this patient group, which according to the findings of this study, are not being met. Considerable benefits to health and well-being could result from improving referral systems, reducing waiting times, and freeing up access to long-term

advice and support. Open access support hubs may do much to address unmet need and offer a safety net for people who feel they have nowhere to turn.

As qualitative research offers insights into what otherwise may be hidden or overlooked in day-to-day healthcare practice, physiotherapists may interrogate the findings and arguments presented here to explore assumptions about their own practice and to evaluate the evidence in relation to their existing services and experiential knowledge.

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## ORCID

Gemma Cook  <http://orcid.org/0000-0003-0868-1085>  
 Elizabeth Cassidy  <http://orcid.org/0000-0002-8628-1063>  
 Cherry Kilbride  <http://orcid.org/0000-0002-2045-1883>

## References

- [1] Rosebaum P. Cerebral palsy grows up: adulthood and the questions that remain. *Developmental Medicine and Child Neurology Virtual Issues*. [cited 2021 Sep 29]. Available from: <https://onlinelibrary.wiley.com/page/journal/14698749/homepage/virtualissuespage.html#CP>
- [2] Surman G, Hemming K, Platt MJ, et al. Children with cerebral palsy: severity and trends over time. *Paediatr Perinat Epidemiol*. 2009;23(6):513–521.
- [3] Hutton JL. Outcome in cerebral palsy: life expectancy. *Paediatr Child Health*. 2008;18(9):419–422.
- [4] McGinley JL, Pogrebnoy D, Morgan P. Mobility in ambulant adults with cerebral palsy – challenges for the future. In: Švraka E, editor. *Cerebral palsy – challenges for the future*. Available from: <http://www.intechopen.com/books/cerebral-palsy-challenges-for-the-future>. London: IntechOpen; 2014. Chapter 3.
- [5] Reddihough DS, Jiang B, Lanigan A, et al. Social outcomes of young adults with cerebral palsy. *J Intellect Dev Disabil*. 2013;38(3):215–222.

- [6] Morgan P, McGinley J. Gait function and decline in adults with cerebral palsy: a systematic review. *Disabil Rehabil.* 2014;36(1):1–9.
- [7] Ryan JM, Allen E, Gormley J, et al. The risk, burden, and management of non-communicable diseases in cerebral palsy: a scoping review. *Dev Med Child Neurol.* 2018;60(8):753–764.
- [8] Sandström K, Samuelsson K, Öberg B. Prerequisites for carrying out physiotherapy and physical activity - Experiences from adults with cerebral palsy. *Disabil Rehabil.* 2009;31(3):161–169.
- [9] Gannotti M, Frumberg D. Clinical therapy services for adults with cerebral palsy. In: Miller F, Bachrach S, Lennon N, O’Neil ME, editors. *Cerebral palsy.* Cham: Springer; 2020. [https://doi.org/10.1007/978-3-319-50592-3\\_158-2](https://doi.org/10.1007/978-3-319-50592-3_158-2)
- [10] Moore CL, Kaplan SL. A framework and resources for shared decision making: opportunities for improved physical therapy outcomes. *Phys Ther.* 2018;98(12):1022–1036.
- [11] National Institute for Health and Care Excellence. *Cerebral palsy in adults: NICE guideline, NG119.* 2019. Available from: <https://www.nice.org.uk/guidance/ng119>
- [12] National Institute for Health and Care Excellence. *Cerebral palsy in under 25s: assessment and management. NICE guideline [NG62],* 2017. Available from: <https://www.nice.org.uk/guidance/NG62/chapter/Recommendations#transition-to-adults-services>
- [13] Mudge S, Rosie J, Stott S, et al. Ageing with cerebral palsy; what are the health experiences of adults with cerebral palsy? A qualitative study. *BMJ Open.* 2016;6(10):e012551.
- [14] Morgan P, Pogrebnoy D, McDonald R. Health service experiences to address mobility decline in ambulant adults ageing with cerebral palsy. *J Intellect Dev Disabil.* 2014;39(3):282–289.
- [15] Redmond R, Parrish M. Variables influencing physiotherapy adherence among young adults with cerebral palsy. *Qual Health Res.* 2008;18(11):1501–1510.
- [16] Moll LR, Cott C. The paradox of normalization through rehabilitation: growing up and growing older with cerebral palsy. *Disabil Rehabil.* 2012;35:1–8.
- [17] Hanes JE, Hlyva O, Rosenbaum P, et al. Beyond stereotypes of cerebral palsy: exploring the lived experiences of young Canadians. *Child Care Health Dev.* 2019;45(5):613–622.
- [18] Sandström K. The lived body - experiences from adults with cerebral palsy. *Clin Rehabil.* 2007;21(5):432–441.
- [19] Dahlberg K, Dahlberg H, Nyström M. *Reflective lifeworld research.* 2nd edn. Lund: Studentlitteratur; 2008.
- [20] Ashworth PD. The lifeworld – enriching qualitative evidence. *Qual Res Psychol.* 2016;13(1):20–32.
- [21] Creswell JW. *Research design: qualitative, quantitative, and mixed methods approaches.* Los Angeles: Sage; 2014.
- [22] Donabedian A. Evaluating the quality of medical care. *Milbank Memorial Fund Quart.* 1966;44(3):166–203.
- [23] 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(13):1162–1169.
- [24] Ryan JM, Cameron MH, Liverani S, et al. Incidence of falls among adults with cerebral palsy: a cohort study using primary care data. *Dev Med Child Neurol.* 2020;62(4):477–482.
- [25] Whitney DG, Hurvitz EA, Devlin MJ, et al. Age trajectories of musculoskeletal morbidities in adults with cerebral palsy. *Bone.* 2018;114:285–291.
- [26] Whitney DG, Hurvitz EH, Ryan JM, et al. Noncommunicable disease and multimorbidity in young adults with cerebral palsy. *Clin Epidemiol.* 2018;10:511–519.
- [27] O’Connell NE, Smith KJ, Peterson MD, et al. Incidence of osteoarthritis, osteoporosis and inflammatory musculoskeletal diseases in adults with cerebral palsy: a population-based cohort study. *Bone.* 2019;125:30–35.
- [28] French ZP, Torres RV, Whitney DG. Elevated prevalence of osteoarthritis among adults with cerebral palsy. *J Rehabil Med.* 2019;51(8):575–581.
- [29] Flanigan M, Gaebler-Spira D, Kocherginsky M, et al. Spasticity and pain in adults with cerebral palsy. *Dev Med Child Neurol.* 2020;62(3):379–385.
- [30] Smith KJ, Peterson MD, O’Connell NE, et al. Risk of depression and anxiety in adults with cerebral palsy: a UK-cohort study using GP data. *JAMA Neurol.* 2019;76(3):294–300.
- [31] Adult Cerebral Palsy Hub. 2021. [cited 2021 Sep 14]. <http://adultcpub.org/latest-news/appg/>
- [32] UN Convention on the Rights of Persons with Disabilities 2007. Available from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- [33] Equality Act. 2010. Available from: <https://www.legislation.gov.uk/ukpga/2010/15/contents>
- [34] Gibson BE. *Rehabilitation a post-critical approach.* London: CRC Press Taylor Francis Group; 2016.
- [35] Aittokallio J, Rajala AI. Perspectives on ‘person-centeredness’ from neurological rehabilitation and critical theory: toward a critical constellation. *Journal of Humanities in Rehabilitation.* 2020. Available from: <https://www.jhrehab.org/2020/05/07/perspectives-on-person-centeredness-from-neurological-rehabilitation-and-critical-theory-toward-a-critical-constellation/>
- [36] Peplow UC, Carpenter C. Perceptions of parents of children with cerebral palsy about the relevance of, and adherence to, exercise programs: a qualitative study. *Phys Occup Ther Pediatr.* 2013;33(3):285–299.
- [37] National Institute for Health and Care Excellence. *Patient experience in adult NHS services: improving the experience of care for people using adult NHS services: NICE clinical guideline, CG138.* 2012. Available from: <https://www.nice.org.uk/guidance/cg138>
- [38] Kroll T, Barbour R, Harris J. Using focus groups in disability research. *Qual Health Res.* 2007;17(5):690–698.
- [39] Office for National Statistics. *Outcomes for disabled people in the UK.* 2020. Available from: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2020>