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Dilemmas of identity: A qualitative analysis of stigma and support seeking for individuals with cerebral palsy.

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Negotiating identity: A qualitative analysis of stigma and support seeking for individuals with cerebral palsy.

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Abstract

Purpose

The current research investigates how adults with cerebral palsy construct their personal and social identities in the face of stigma when support seeking, and considers the dilemmas they might face when doing so.

Method

Participants were 28 adults with cerebral palsy who completed an online survey reporting on their identity as a person with cerebral palsy and their experiences of stigma when seeking and accessing support.

Results

Qualitative analyses indicated that the majority of participants sought support to help manage their cerebral palsy. Of these, half reported experiencing stigma in these environments, although they largely continued seeking support despite this. The majority viewed both their personal identity (i.e., as a unique individual) and their social identity (i.e., as a person with cerebral palsy) as important to their sense of self. However, how participants constructed their identity also appeared to vary according to context. While they appeared to value being seen as an individual to receive support that was unique to their needs (their personal identity), they also reported valuing the group to facilitate coping with stigma (their social identity). Yet, despite

their utilities, enacting their identity in each of these ways was associated with costs. In order to access desired support, they had to incorporate their social identity as similar to other disabled people, which led to stigmatisation through feelings of difference to the non-disabled. Conversely emphasising individuality and difference from the disabled stereotype was associated with concerns about the degree to which their suitability for support might be questioned by their care provider.

Conclusions

As has been observed in many fields, stigma can complicate identity. In this domain, people with cerebral palsy face a number of threats in how they construe their identity, both in navigating stigma and maintaining access to needed support.

Implications for treatment

1. Stigma in help and support settings remains a signficant problem for adults with cerebral palsy (CP).

2. Participants generally view their CP positively, with their condition being central to their personal and social identities.

3. However, many dilemmas are experienced in how they view and construct this identity in the context of stigma and support-seeking.

Introduction

Cerebral palsy (CP) is a primarily physical disability that is believed to arise from prenatal or early childhood brain damage [1]. Adults with CP typically rely on formal and informal support throughout their lives to assist with their care needs [2,3]. There are, however, many barriers to receiving support in adulthood, including limited contact with rehabilitation services [4] and treatment availability [5]. Consequently, many adults with CP may experience difficulties accessing support as readily as they might wish.

In addition to these practical barriers, there are psychological barriers to accessing support. Needing the support of others reinforces notions of dependency and is, therefore, stigmatising [6]. As such, support is something that people with CP might be reluctant to seek. This presents the individual with a dilemma that requires them to reach a balance between accessing needed support and maintaining a positive, non-stigmatised identity. Although there is a wide literature that highlights the barriers to support seeking in CP, to our knowledge, the specific role of stigma as a barrier, and the identity dilemmas this creates for individuals with CP, has not been thoroughly addressed. The present research draws on an identity perspective to explore, and to better understand, the dilemma of support-seeking.

Stigma and CP

An individual experiences stigmatisation when their individual identity, or the social group to which they belong, is somehow 'marked' and negatively evaluated within broader society or within a specific social context [7,8,9]. CP, like many other physical disabilities, is highly stigmatised. To varying degrees, CP is a marked condition and people with CP face negative attitudes within the general community, but also, ironically, in healthcare and support situations. For example, general

practitioners, gynaecologists and medical students have all been shown to have limited knowledge about CP, which promotes misunderstanding, negative attitudes and stereotyping of patients [10,11,12]. Even away from these more formal healthcare settings, such as in the context of family and friends, there is evidence of misunderstanding or inappropriate knowledge that feeds into peoples' negative attitudes and evaluations. For example, relatives of adults with CP often view the disability as having a more severe impact on important physical tasks – for example eating, drinking, personal care and movement – than do the adults themselves [13].

To date, research into the stigma of disability has tended to focus on non-disabled observers (e.g., family, health professionals, the general public), and quantifying the attitudes they have about disabled others. Whilst this is an important strategy for working towards alleviating stigma, disability and stigma researchers have highlighted the simultaneous need to better understand stigmatising experiences from the perspective of disabled people [14]. Indeed, growing evidence suggests that adults with CP are very much aware of the attitudes and stereotypes through which they are perceived in society, and because of this, consider stigma to be a major barrier to social participation [15,16]. For example, adults with CP report that nurses treat them differently from other patients, such as speaking to them in a patronising way, or assuming they have intellectual difficulties [17]. Moreover, as a consequence of the limited knowledge and negative attitudes of care providers and society at large, adults with CP often report experiencing embarrassment created through unwanted attention and report that their needs are not sufficiently met when support is needed or required [18,19,20,21].

In sum, adults with CP contend with a variety of difficult and stigmatising experiences, even in the context of accessing needed support. As a consequence of

these experiences, individuals with CP may feel less willing to seek desired support [10]. If stigma does cause adults to withdraw from valued support, this is likely to prove costly to their overall health and wellbeing. It is therefore important to address how people with CP experience stigma when support-seeking and how they cope with, or overcome, this particular barrier to receiving support.

One way in which to understand how disabled individuals experience stigma is in reference to identity [7]. Specifically, personal stigmatisation is experienced because their disability assigns them to an identity that is negatively viewed by society [7]. If the individual feels stigmatised by others because of their disability, this challenges the possibility of a positive sense of identity, and is therefore something that they may want to manage [22]. From this perspective, we believe that it is important to consider how people with CP who are potentially stigmatised construct their identity and how this helps them to deal with such experiences.

Identity and stigma

Theoretical approaches to identity such as the social identity approach state that rather being viewed as a singular entity, identity is multi-faceted and incorporates both personal and social components (e.g., [23,24]). Personal identity reflects how people see themselves as unique individuals (and in comparison to other individuals), whereas social identity refers to how people view themselves as members of meaningful social groups (and in comparison to other groups [24,25]). Importantly, recognising the social dimension of identity allows for the possibility that others can be incorporated into the individual's self-concept, and that the individual can be affected by the experiences of their social group rather than simply their own unique experiences. Along these lines, although CP can greatly influence one's personal identity (e.g., "I have CP"), it can also become an important part of their social

identity, and be the basis through which people connect to others who share this disability (e.g., "I belong to the group 'people with CP'" [26,27]).

The distinction between personal and social identity is not just theoretical, it has practical relevance to the experience of stigma in support environments. The experience of stigma is likely to be threatening both to one's personal identity (e.g., by reducing a sense of individual competence or uniqueness as a consequence of their CP) and one's social identity (e.g., by casting negative aspersions people with CP more generally [6]). It is therefore important to consider how individuals might navigate these threats to their identities and what this might say about the balance between personal and social aspects of the self.

A common way in which individuals might manage a stigmatised identity is to adopt individualistic strategies such as leaving the group or of concealing group membership from others [28]. Such strategies prioritise the personal self at the expense of the social identity, which allows the individual to distance themselves from their negatively valued group, and therefore protect the self from the associated stigma (e.g., [29]). Alternatively, an individual may enact group-based strategies in order to collectively challenge the stigma [22,23,30]. Such an approach may indeed be the only option if group membership is fixed or visible [31,32], as in the case of CP, because leaving the group or concealing group membership may not be possible [33]. These strategies, however, require connecting the individual self to a stigmatised group, which may be costly in terms of wellbeing, as it may reinforce the salience of the collective stigma and the devaluation from which they wish to disengage [29,34].

Nonetheless, there is also a growing body of research suggesting that being a member of a stigmatised group does not always negatively affect wellbeing [35] and that identifying with the stigmatised identity itself might sometimes be protective

against stigma [33,36,37,38]. For example, studies have demonstrated that a sense of a shared identity with other stigmatised people allows the individual to benefit from the actual or perceived support that comes with group membership [22,34]. Shared identity also gives the individual access to collective resources that help combat stigma [26], such as the knowledge and emotional support to challenge negativity that they may face [39]. Through engaging collectively, individuals can reinterpret the meanings of their stigma (e.g., as something more positive) that are applied to them by others (social creativity [23,40]) in ways that allow for the maintenance of positive self-esteem [34]. They can also work with the group to bring about social change through collective action [23,40].

As a consequence of these many benefits, embracing a disabled social identity may facilitate support-seeking in stigmatising environments [41]. This is because a shared social identity can empower the individual to potentially cope with the negative attitudes that care providers might hold when they provide support [38,39], and can also act as an informational resource regarding the availability of appropriate treatment [42]. It may also encourage the individual to participate in collective support-seeking (e.g., helping other disabled people to advocate for positive change). As noted previously, however, the many possible benefits of social identity sometimes come at the cost of personal identity. Specifically, accessing the material or psychological support of similar others requires that the individual connects themselves and their identity to a devalued group, thereby potentially stigmatising the self. This presents a dilemma to those who personally wish to avoid such negative connections [39]. People who wish to protect themselves from negative stereotypes, may instead emphasise their individuality (i.e., personal identity), and thus distance from the social identity. However, enacting identity in this way may impact on their

willingness and ability to access desired support and the benefits they can receive from this.

The present research

In accordance with the ideas discussed above, the current study seeks to understand the way in which adults with CP experience support-related stigma and to elucidate the implications of this for their personal and social identity. More specifically, we aimed to qualitatively investigate three main research questions:

1. What support-related stigmas do participants feel are directed at people with CP in general? (RQ 1)

2. What support-related stigmas do participants personally experience and does this impact on their willingness to access desired support? (RQ 2)

3. How do participants view their identity as an individual with CP, and how does this influence the way in which they cope with stigma and how they seek support? (RQ 3)

Method

Participants

A total of 28 White adults with CP (5 male, 22 female, 1 not reported) aged 17-58 years ($M = 31.68$, $SD = 13.05$) were recruited to participate in the study. The majority of participants were from the UK ($n = 15$), with the remainder from the USA ($n = 6$), Australia ($n = 6$) and New Zealand ($n = 1$). The sample had a broad range of educational attainment (high school or lower $n = 8$, college/higher education level $n = 7$, undergraduate degree $n = 8$, postgraduate degree $n = 5$) and severity of CP (see below). Table 1 outlines each participant's characteristics.

Procedure and Materials

Participants were asked to provide written responses to open-ended questions within an online survey that was advertised through a number of social networking pages aimed at people with CP. A survey method was decided upon in order to address associated mobility and communication difficulties [43] that may restrict access for traditional interview techniques. Using this method of recruiting therefore allows access to, and responses from, a larger selection of adults with CP than might have otherwise been available.

The survey was anticipated to take between 30-45 minutes to complete. Participants were first asked to specify demographic information (i.e., gender, age, education, and nationality) and the perceived severity of their CP using the *Gross Motor Function Classification System* (*GMFCS* [44,45])*.* The GMFCS is a measure of severity of gross motor functioning disability for children and adults with CP through five levels (I-V), with higher levels representing greater impairment [46]. Participants reported their GMFCS levels between I-IV (I $n = 6$, II $n = 13$, III $n = 6$, IV $n = 3$). Finally, participants were asked to list the support they access to assist with management of their condition. The supports they listed (if any) were then fed into later questions in the survey.

Participants were then asked to describe their experiences with stigma. More specifically, they were asked to report whether or not they believed CP in general is a stigmatised condition in support settings, and if so, how they thought adults were stigmatised, regardless of whether they believed such stigma to be personally relevant. Then participants were asked to describe whether they had personal experiences of stigma when using each of the supports they listed earlier in the survey, and if so, whether this impacted on their willingness to seek support.

Participants were then asked to describe the personal importance of their identity as an adult with CP, and the extent to which they saw themselves primarily as an individual or in more social terms. Developing on from this question, to delve further into the features of their possible social identity, participants were asked to describe how important the CP community was to how they constructed their identity, and the connection and emotion they associated with fellow group members. Finally, participants were asked to describe whether this social identity influenced their personal support-seeking behaviour or how they coped with stigmatising support experiences. The Psychology Ethics Committee at the University of Exeter, UK, granted ethical approval for the research.

Analysis

The qualitative data generated from the survey were analysed by reading the written answers provided by participants and identifying content that addressed the three research questions. Themes were then constructed or modified whenever a new viewpoint emerged from the written responses, and an example quote describing this theme was recorded. When similar content was observed from different participants, additional quotes were assigned to the relevant theme. Once all 28 surveys were analysed, a final coding frame was created, which summarised all the constructed themes, including a brief description of their meaning, as well as the entire list of example quotes assigned to each theme. From here, the data was independently coded and checked by a second researcher.

Results

In presenting the results of this investigation, we consider each of the research questions in turn and provide indicative quotes that exemplify each of the themes that emerged from the analysis. These quotes are attributed to specific participants, as indicated by the number in brackets connected to each quote (see Table 1).

RQ1: What support-related stigmas do participants feel are directed at people with CP in general?

The majority of participants (71%) were aware of the stigma associated with their condition and believed stigma to be a fundamental reason why adults with CP may not seek the support they need.

(8)*"stigma has always been a barrier to many of us because of our CP."*

Participants gave several examples of the stigma that adults with CP are likely to face. The most commonly reported example was that the disability promotes an automatic stereotype of a severely impaired person who is entirely reliant on others for assistance, or of an individual with a speech or intellectual disability. As a consequence of these stereotypes, many believed that support providers engaged in patronising communication or offered inappropriate care to adults with CP who need support.

(7)*"Yes, people with CP do experience problems due to stigma. We are often seen as unable to talk for ourselves and we are not given the opportunity to orchestrate our own care needs."*

(5)*"People tend to see those with cerebral palsy as mentally handicapped, even if they are not. This reaction can cause them to treat the person with CP*

not as an adult but a young adult or child. Being talked down to restricts how much help the supporter is willing and able to provide."

In addition, participants felt that the majority of adults with CP do not fit the rigid and extreme stereotype held by some care providers. As a result, some were concerned that individuals responsible for providing care may not believe that those who do not fit this stereotype, such as those with milder forms of CP, actually have the disability, or may not provide necessary support to meet their needs.

(4)*"People don't seem to be able to comprehend that CP can mean a mild or major disability and that it's individual to each person who has it."*

(19)*"I think there's a stigma that society believes if you don't look 'that disabled' you can't need any extra support."*

(10)*"People expect us to always be 'severely disabled' in some respects bedridden. When they realise that is not always the case they tend to overlook the difficulties we do have."*

RQ2: What support-related stigmas do participants personally experience and does this impact on their willingness to access desired support?

A large majority of participants indicated that they accessed some form of support (93%). Of these, when asked about the stigma they encountered when accessing support, over half (58%) reported feeling stigmatised. Personal experiences often reflected the stigmas that adults' believed were common in support situations for those with CP more generally, as described above. However, respondents also gave other examples of how they felt stigmatised. The most commonly reported

stigma was simply acknowledging they needed to access desired support, something which amplified feelings of difference from the non-disabled community.

(24)*"I feel the fact that I need so much support marks me out as different from other people"*

Many participants also experienced stigma in relation to the rigid CP stereotype outlined in the previous section. Specifically, some participants indicated that while they accepted that they needed a particular support, they often felt that those responsible for providing such support and the wider community did not share this view because they did not appear 'sufficiently disabled'. Where disagreements around this occurred, participants felt they had to justify their need as a disabled person, something that created additional burdens on the self. However, this also caused some participants to reflect on their actual need for this support, resulting in feelings of guilt that they may be preventing adults with more severe impairments from accessing necessary assistance.

(22)*"I feel that we have to battle to receive this support…because each time I try to access support I have to justify myself"*

(9)*"I do not look like I have '[Cerebral] Palsy'. It's a very [unhelpful] label in my case because people don't think I should have a blue badge* [disabled car parking permit] *or use a disabled toilet and they sometimes wonder why I get any help at all."*

(19)*"If I'm made to feel like I don't deserve it or I'm ripping off the system because I'm not as much of a severe case as someone with full blown CP, it makes me feel like I shouldn't even ask for the support, despite needing it just as much."*

(20)*"As a lot of my friends with disabilities have conditions that are more severe than my own, I tend to feel guilty accessing the same services they use. Even though I do need them!"*

Finally, several participants reported that care providers had a general lack of awareness of the problems associated with CP, which created uncomfortable situations for them. As a consequence, they had to acknowledge inappropriate attitudes towards them and their ability. Such experiences occurred both in, and away from, support situations.

(9)*"I hate [how] people have to be explained to about my [disability]"*

(12)*"I [find] people's attitudes towards CP frustrating"*

(3)*"GP's do not understand what hemiplegia* [a specific type of CP] *is - there is not enough awareness of it - I find myself having to explain it to medical professionals who look at me confused"* (sic)

(24)*"[a] colleague has been very discriminatory towards me…For example, she once said I take a while. I may be slower than others at some tasks due to my hemi[plegia] arm but having it pointed out in this way made me feel dreadful"*

However, despite the numerous experiences of stigma, very few participants believed that this had any detrimental impact on their support seeking. The main reason for this was due to their perception of need. Specifically, that the benefits provided by the support outweighed the possible negativity associated with accessing this help.

(20)*"I do recognise how important and positive all the support that I do get is. In this area of my life, the fact that I may be viewed differently by others or discriminated against because of it, does not affect my willingness to attend."*

RQ3: How do participants view their identity as an individual with CP?

When participants reflected on how they constructed their identity in terms of whether they preferred to see themselves as individuals first and foremost or as part of a shared, social identity centred around being an adult with CP, responses were mixed. Some participants reported not feeling a sense of common identity with others sharing their condition, and instead viewed their diagnosis and life with CP in individualistic terms and as unique and personal to them.

(18)*"Every CP person is…different."*

Conversely, others felt that their diagnosis was a reason to identify as part of a larger CP group.

(10)*"We all share a very common interest that relates to each of us everyday."*

However, a large number of participants highlighted that their constructed identity contained both personal and social components, and discussed their awareness of how they 'shifted' their identity depending on the situational requirements.

(17)*"we are all individual but have common ground also"*

(23) *"I'm just me, everyone is different, an individual. I know that there are others with cerebral palsy but the only time I consider myself as part of a group is at an event for people with cerebral palsy"*

With respect to participants' personal identity, the vast majority viewed their diagnosis and life as an adult with CP as unique and important to them. Many participants explained this importance through the highly salient nature of their CP status and the constant impact of this on their lives. Although the salience of this identity also made participants aware, to varying degrees, of their impairment, the majority were also very positive about their CP, through feeling that they have personally overcome challenges they have faced and will continue to face throughout their lives.

(5) *"I'm constantly aware of my CP. It affects everything I do in every part of my life."*

(4) *"I'm proud to have success [despite] having a disability"*

Consequently, for many participants, being an adult with CP has shaped, and continues to greatly influence, their constructed personal and social identities.

(7) *"My CP has helped to form my identity. I wouldn't be the person I am today if I didn't have CP. I probably wouldn't be working as a disability support worker or have the friends that I have."*

Indeed, adopting a social identity was also positive for many participants. In particular, participants wanted to display a strong sense of community to other people with CP, and sought out interactions and relationships with them because of *"a*

shared history and an understanding" (1). From disclosing and listening to experiences of other adults with CP, participants gained a better understanding of their condition and gained the feeling that they were not alone.

> (7)*"I have a great deal of respect for the other folk I have recently met with CP. We are all doing great things in our lives."*
>
> (18)*"It is nice to talk with other CP adults."*
>
> (21)*"I feel I can relate to others with CP, where the majority of people around me cannot, and I also feel…some advantage of knowing to some extent how they may be feeling."*
>
> (7)*"It has been very liberating discovering that many of my experiences have been very similar to other adults with cerebral palsy"*
>
> (25)*"it's nice to know I'm not the only one with the condition"*

In addition, this sense of shared social identity appeared to provide a meaningful strategy for dealing with experienced stigma or other difficulties. In particular, many reported that discussing these experiences with other social network and forum group members was positive.

> (19)*"Venting and sharing similar stories of discrimination with people that understand you is a wonderful thing"*
>
> (3)*"Chatting to other [people] on the hemi[plegia] Facebook pages is very comforting, as there are people with the same issues, problems and fears as me"*

With respect to how they viewed their identity in relation to their support-seeking behaviour, all participants very much viewed their own support-seeking as

entirely personal to them, and thus prioritised their personal identity in order to ensure that their received care was individualised to their own unique needs.

(14)*"I seek support because of my individual needs and requirements independently and not because I identify with other adults with CP."*

However, some did value the social group, but only as an informational resource whereby they could learn from the support experiences of others. By doing so, this allowed participants to incorporate this acquired knowledge into their own support-seeking behaviours.

(1)*"If I learn of a potential health issue from an old friend with CP, I ask my service providers about it."*

In other words, participants again expressed motivations to portray themselves both in terms of their personal and their social identities emphasising both desired individuality for support, and also similarity to others to assist support requests.

(15)*"If a method of support has been useful to a friend with CP, I would be more likely to try it, but a lot of the support I receive is individualised and necessary for me to perform basic daily tasks."*

Nevertheless, regardless of whether participants felt that their social identity facilitated their own support seeking, they commonly felt the need to support others who needed assistance with their seeking support and experiences of stigma.

(7)*"I find myself in an advocate/advisor role - informing other younger people about types of services they may be able to access."*

(6)*"it is important to me to share my struggles with the hope of saving others from struggles as well."*

Discussion

The aim of this research was to investigate the way in which adults with CP recognise and experience support-related stigma, and whether this influences their willingness to access such support. Moreover, we aimed to investigate how adults with CP construct their identity, how they incorporate both personal and social aspects into their identity, and how this identity construction influences how they cope with stigma and the support they seek.

When asked to describe the overall stigma associated with CP, the majority of participants indicated that this was a significant concern. Participants reported that they believed that care providers held rigid ideas about how an adult with CP is supposed to 'look' and 'act'. They also noted that the majority of adults with CP do not fit this stereotype. The lack of fit between stereotypes and reality was seen to promote care provider scepticism regarding the legitimacy of milder (or less-stereotypical) forms of the disability, and thus lead to difficulties in accessing desired support [47].

The described experiences of stigma largely reflected this view, although participants also offered additional, unique experiences. Many acknowledged that they needed support, and were legitimately entitled to it. However, accepting needed assistance heightened feelings of 'being different' from the majority of society who do not need support [48,49]. In addition, accessing support resulted in their perceived need being scrutinised. Consistent with the above, this feeling of scrutiny was especially pronounced when participants believed that they did not fit the stereotype

of CP held by those providing care. Participants reported that this scrutiny also extended to the wider community beyond the support environment. As a consequence, participants continually felt the need to defend and justify their use of support services to society. This, in turn, triggered feelings of guilt about their apparent deservingness, because their own use of support might adversely affect the access of others who also need assistance, and who are perhaps 'more deserving'. Interestingly though, despite a common awareness of these negative experiences, the majority of participants indicated that they continued to access support. This was largely because they expected that the benefits of the desired support would outweigh the costs of any negativity experienced.

When discussing identity, participants did not view their identity as primarily personal *or* social, but rather as something that displayed elements of both these aspects of self-definition. This is in line with the social identity approach, which suggests that both personal and social aspects can be important bases of self-definition [24,50]. Unpacking this further, many participants believed that their diagnosis was unique to them, and as such, only they can experience living with *their* disability and the associated life choices and challenges (i.e., personal identity was emphasised). However, participants were also generally positive about identifying as a member of a CP social group. In particular, participants felt a strong desire to create and maintain meaningful and positive relationships with other adults with CP [27]. Moreover, recognising oneself as part of a larger CP group offered potential benefits based on mutual experience, and the feeling that others are experiencing similar difficulties [49].

Although both personal and social aspects of identity were important, each of these bases of self-definition may bring potential costs in terms of stigmatisation,

something that needed to be negotiated. More specifically, participants appeared to be continually balancing the need to protect their sense of individual self in relation to the CP social group, while simultaneously ensuring access to desired support. Reflecting on the priority and value placed on individuality in this sample, many preferred to distance themselves from the group in order to ensure that they were seen and treated as unique, rather than on the basis of their disability [38,51]. Yet, viewing themselves solely in personal terms may also prove costly, as they may nonetheless be associated with their disability group by others and stereotyped on that basis [38]. Perceiving themselves only in individual terms could also restrict access to the social support provided by other disabled people, as in order to use these resources, individuals need to identify as similar to this group [22,38]. The social support received from others via this shared social identity may be of particular importance for personal coping, through providing mutual understanding of the individual's experience [49].

Similar issues are also raised when attempting to navigate the stigma of support from care providers. Specifically, because the majority recognised that support was needed, this created possible pressures to demonstrate their disability social identity in a stereotypical way to their care provider [47,52]. Yet, demonstrating their CP social identity can also be costly, as care may become focused on the needs of the CP community as a whole rather than their personal requirements. It also may elicit dual concerns regarding feelings of difference from those who are non-disabled, but also about being "insufficiently disabled" to legitimately receive support in the eyes of their care provider [48,49]. Through being negatively associated with their social group in this way, participants discussed additional costs

in terms of awareness of their impairment and feelings of guilt over their support access.

Thus, we infer from the data that there is likely to be a continual back-and-forth between different bases of self-definition (i.e., as a unique individual versus a member of the CP group) as individuals try and manage the implications of maintaining a positive view of the self and for accessing required care. This apparent shifting between personal and social identity may reflect not just the demands of the immediate contexts, but also the on-going process through which the individual attempts to balance the relative costs and benefits of each aspect of identity.

In sum, we believe that this research provides insight into two parallel identity concerns: one of ensuring a positive personal view of the individual self in relation to the group, and one of navigating identity when stigmatisation from care providers is experienced. Within the support environment, these two concerns intersect. In order to navigate stigma, as well as ensuring support access, participants may have to construct a desirable identity that incorporates both a positive sense of individual self in relation to others, whilst also maintaining their social identity [53]. These two aspects of identity potentially conflict with the needs of the self and the requirements of the support situation (e.g., advocating their uniqueness to ensure that support is individualised to their own needs, whilst at the same time, highlighting their similarity to others to assist the support process). In attempting to address these potentially conflicting concerns, individuals may experience difficult identity dilemmas in terms of how and whether they align themselves with the CP community.

These parallel concerns raise important practical implications for both people with CP as well as the individuals providing support. From the perspective of individuals with CP, our data suggest that recognising and demonstrating their

individuality was highly important, both in life and when accessing support. But, in certain contexts (e.g., support), highlighting similarity to others (i.e., their social identity over the personal identity) may be both necessary and important for overcoming potential stigma and negativity. Being similar to the "disability stereotype" marks them as the legitimate recipient of support, whereas desired uniqueness in this context may potentially preclude them from this. A sense of social identity with others was also an important basis for accessing disabled support networks, and benefiting from the sharing of knowledge and experiences. Accordingly, from the healthcare perspective, it is important to see patients as both individuals with unique needs, as well as part of a shared collective CP group. To do this, we recommend encouraging a view of CP as a highly heterogeneous disability, both in its visibility and severity, and that care should be personalised to suit individual needs and experiences, while at the same time also recognising the common concerns around need for support and understanding of CP [54]. Allowing for both these views of identity, and promoting awareness of the importance of each to successful coping, might help to alleviate some of the tension between personal and social aspects of identity faced by individuals with a disability, and some of the stigma associated with accessing necessary support services.

Because of chosen design and analytic strategy, we are limited in our ability to infer causally from this data. Specifically, we cannot say whether stigma was instrumental in guiding how participants negotiated their identity, nor whether the various identity constructions causally impact on support-seeking. Because of this, the interpretations of the data offered here should be treated with caution. While we believe we are correct in inferring that stigma, identity construction, and support seeking go together in interesting ways in the context of physical disability, to build

on this insight, and to elucidate our claims, further research is clearly necessary. Specifically, additional qualitative work could delve deeper into the contrast between the desire to maintain individual identity and the need to engage with, and even perform, collective identity, and the dilemmas this might create for maintaining the individual's sense of self. Quantitative investigations could also explore identity navigation more closely by examining the impact of different salient concerns, or the different audiences related to these, on how individuals with CP communicate their identity to others and the psychological processes behind these choices.

An additional weakness of this research is the sample used. This was heavily biased towards women, and research suggests that physically disabled women may be more aware of stigma than men (e.g., [55]). This may have amplified the overall prevalence of stigma-related concerns within the current investigation. There was also a slight skew to participants of lower GMFCS levels to that of societal distribution [56]. Due to the nature of the study and the depth of answers required, the emphasis on having sufficient motor skills may have prevented adults with the most severe impairments from participating. This is important to highlight considering previous research has demonstrated that people with more severe CP may be more at risk of stigmatisation [57,58]. Therefore, the study may have not successfully recruited adults who experience the greatest stigmatisation. However, our results suggest that stigma experience was consistent regardless of reported GMFCS level, potentially questionning this as a limitation. Nevertheless, we recognise that although the findings provide rich data on the selected participants, they cannot be generalised to the wider CP or support populations. Future research should continue to explore the influence of identity, stigma and support seeking to a wider and more representative sample of adults with CP.

Conclusion

Our research demonstrates that the experience of stigma remains an issue for many people with CP, especially within the context of seeking and receiving support. In response to this stigma, individuals face a number of difficult dilemmas in how they view and portray their identity both in terms of maintaining a positive sense of self in relation to the wider CP community, but also ensuring that they are able to access desired support from their care provider.

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Declarations of Interest

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Table 1. Characteristics of participants

Participant	Gender	Age	Nationality	Education	GMFCS
1	Male	45	Australia	Postgraduate degree	4
2	Male	56	USA	Postgraduate degree	2
3	Female	26	Britain	College/Higher education level	2
4	Female	27	Britain	Undergraduate degree	2
5	Female	18	USA	No/High school level	1
6	Female	58	USA	No/High school level	2
7	Female	48	Australia	College/Higher education level	3
8	Male	52	New Zealand	No/High school level	4
9	Female	26	Britain	No/High school level	3
10	Female	22	Britain	Undergraduate degree	3
11	Male	38	Britain	Undergraduate degree	2
12	Female	22	Britain	Undergraduate degree	1
13	Female	20	Britain	College/Higher education level	1
14	Female	29	Britain	Undergraduate degree	2
15	Female	24	Britain	Postgraduate degree	4
16	Female	20	USA	Undergraduate degree	3
17	Female	39	Britain	No/High school level	2
18	Female	54	USA	Postgraduate degree	3
19	Female	25	Australia	Postgraduate degree	1
20	Female	29	Australia	Undergraduate degree	2
21	Female	17	Britain	College/Higher education level	2
22	Female	46	Britain	College/Higher education level	2
23	Female	21	Britain	College/Higher education level	2
24	Female	20	Britain	College/Higher education level	1
25	Female	20	Britain	Undergraduate degree	1
26	Female	18	USA	No/High school level	2
27	Missing	31	Australia	No/High school level	2
28	Male	36	Australia	No/High school level	3