Title:

"I'm still me – I'm still here!" Understanding the person's sense of self in the provision of self-management support for people with progressive neurological long-term conditions

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Abstract:

Purpose: There is increasing interest in tailoring self-management support, but little detail is available on the relevance and impact of such approaches for people with progressive neurological conditions. The aim of this study was to draw on individuals' experiences to inform the practice of self-management support for these groups.

Method: Community rehabilitation service users were purposively recruited and took part in in-depth qualitative interviews. Interviews were audio-recorded and transcribed. Data analysis was iterative and interpretative, taking a phenomenological approach. Strategies to enhance rigour were auditability, peer review and researcher reflexivity.

Results: The sample consisted of ten adults (age 20 to 70+ years) who were living with a range of progressive neurological conditions. Individuals demonstrated resourcefulness in developing practice-based self-management strategies. Beyond practical strategies, interviewees' experiences were signified by reflecting on and upholding a sense of identity and a desire for purpose against the background of losses and gains over time. Linking with this overarching theme of 'Sense of self' were aspects of 'My body and mind', 'Time', 'Space', 'Relationships', and 'What I do'.

Conclusions: Self-management approaches for individuals with progressive neurological conditions will benefit from incorporating ways of recognising, articulating, and supporting the person's sense of identity and purpose.

Introduction

Self-management is not new, and it is now well established in health policy. The concept was first described in the 1970s, and over the past two decades it has attracted growing interest from healthcare providers and policy-makers.[1,2] Many countries are faced with an ageing population, rising prevalence of chronic illnesses, and resulting challenges for healthcare systems and resources.[3,4] It is common rhetoric to present self-management as a solution for dealing with these challenges. Against this backdrop most self-management research has focussed on health conditions that are more prevalent in older age and respond well to lifestyle modification, behaviour change, self-monitoring and self-adjustment of medication, such as arthritis, diabetes and hypertension.[1,5-7] However, there has been little research and application of self-management in groups with complex progressive conditions. These groups typically constitute a relatively small proportion of the population with comparatively high utilisation of healthcare resources. Self-management support may therefore be well-placed to benefit these groups.

Self-management interventions can include condition-specific as well as generic features. They can be delivered through techniques that are applied in one-to-one

interactions between healthcare professionals and patients,[8,9] or in group formats such as the Chronic Disease Self-Management Program, which was first developed in the United States and adopted as the Expert Patient Programme in the United Kingdom.[2,10] In the literature, definitions of self-management can overlap with related concepts of self-care, shared decision making, and patient education, but the common principle is that the person is at the centre of managing their health condition(s), not healthcare services. Many authors refer to a definition by Barlow and colleagues who described self-management as a person's "ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition".[7] In essence, the patient is considered an expert by experience. By taking a self-management approach, healthcare providers recognise, foster and enhance this patient-held expertise, thereby empowering patients to be in control.[2,11] Importantly, the conceptual starting point for most self-management approaches is the condition, not the person, with emphasis on management of the condition and disease-control.[12]

In recent years, there has been increasing interest in tailoring the self-management approach to neurological patient groups. There is a growing and encouraging evidence base for self-management after stroke,[13,14] but less so for other progressive and degenerative neurological conditions such as multiple sclerosis, Parkinson's disease and dementia. These types of conditions often present unpredictable and complex patterns of disease manifestation and progression, with trajectories of mounting care needs and increasing health service utilisation over time, rather than the relative stability and opportunity for continued improvement following acquired brain injury. There is therefore scope to re-conceptualise and develop new methods of designing and delivering self-management support for

these groups. To this purpose, it can be useful to build on qualitative work to understand what self-management means to people, how it differs for someone living with a complex and unpredictable neurological condition, and how people make sense of self-managing.[1,15]

In this paper we draw on qualitative data to explore experiences in a group of community rehabilitation clients with progressive neurological long-term conditions. The aim of this study was to develop a deeper understanding of how individuals experience life, construct personal meaning and make sense of living with neurological long-term conditions, so that these insights may inform the practice of self-management support in these patient groups.

Method

Design

In-depth interview data were generated as part of a one-year project, in which training in self-management support was implemented across a multi-agency community rehabilitation workforce in England.[16] The initial purpose of these interviews was to capture and describe service users' individual experiences of self-managing with a neurological long-term condition at a practical and factual level. This information contributed to the co-production and impact evaluation of the implemented self-management intervention.[16] The depth, richness and variability of these accounts prompted further reflection and secondary analysis, for which a phenomenological approach was chosen.[17] This methodology lends itself to inquiry into individuals' experiences and discovery of personal meaning of experiences. The

analysis focused on the experience of living with a progressive neurological long-term condition.

Setting and participants

The setting for this study was a community rehabilitation workforce in a metropolitan locality in England. Practitioners from these teams identified and invited potential participants. Individuals were eligible if they were over eighteen years old, lived with a neurological long-term condition, spoke English, and were able and willing to share their experiences in a recorded interview. We provided information sheets for distribution, outlining the purpose of the interview and further details. Practitioners then connected us with potential participants. Out of thirty-two individuals who expressed interest, twenty-one agreed to be interviewed. Data were drawn from 10 interviewees reflecting individuals with diverse progressive neurological conditions.

Data collection

The first author (SK) conducted audio-recorded semi-structured in-depth interviews between February and September 2015. Interviews were held at participants' homes and lasted between forty-five and ninety minutes. Questions aimed at eliciting participants' experiences of living with and managing their long-term conditions, and experiences and views of community rehabilitation. The interview schedule is given in table 1.

INSERT TABLE 1 ABOUT HERE

Some participants had difficulty with speech production and intelligibility. In these instances, the interviewer adopted an interview style of repeating back the interviewee's words to confirm that their words had been understood correctly and to ensure they were captured on the audio recording. Some interviewees preferred a family member to be present, in which case the interviewer adopted a style of including family members in the interview while maintaining a focus on the participant. The interviewer took field notes of relevant off-tape conversations and observations, as well as memos of thoughts and reflections on interactions with participants during and surrounding the interviews. These were added to the data corpus and incorporated in the data analysis process.

Data analysis

Interview recordings were transcribed verbatim, except for passages of talk that were off-topic or offered purely factual information, which were summarised by paraphrasing the account. Transcripts were printed in landscape orientation with a wide margin, to allow space for hand-written codes and memos. Field notes were appended to corresponding interview transcripts. Data analysis[18] was then conducted by the first author, following an iterative cycle: reading and re-reading of transcripts and field notes, and listening back to interview recordings; initial noting of codes; developing emergent themes; searching for connections across emergent themes; moving on to the next case; and searching for connections across cases. Codes, themes and researcher's memos were hand-written at first and later typed out. Data analysis gained depth through repeated reading of transcripts, contrasting

and comparing between interviewees, revisiting of codes and memos, and drafting and re-drafting of mind maps and interim analyses. Mind-maps were used to visualise the groupings of, and connections between codes and themes during the analysis process. A representation of the final mind-map is given in the results section (figure 1). In keeping with the phenomenological approach, the analysis was conducted at a latent and interpretative level, *i.e.* the analysis aimed to go beyond a description of the explicit/surface meaning of the data and identify underlying and broader meanings, assumptions and conceptualisations.[17,18] For example, one participant's statement "So, pretend as if you haven't got it [dementia]" on the surface may be interpreted as encouraging denial of the diagnosis. In context, an interpretative reading of this statement reveals that it expresses the participant's underlying attitude of "not giving in" to dementia, and "keeping going" despite the condition.

Rigour

The lead researcher (SK) has a professional background in rehabilitation physiotherapy, and a number of steps were taken to reduce unconscious bias when interpreting data. Strategies to enhance rigour were auditability, peer review and researcher reflexivity. An audit trail of data sources and researcher's working documents was maintained, to enable revisiting of analysis steps and decisions.

SK enacted researcher reflexivity through intersubjective reflexivity[19] and a conscious effort to minimise influences on data generation and analysis by bracketing prior personal knowledge and assumptions.[20] In particular, SK took care not to view data through the largely bio-medical lens that underpinned his prior

education and training. In interactions with interviewees, SK was sensitive to potential influences with respect to his personal background and possible dynamics of power due to his researcher role and affiliation with a university. It is hoped that these strategies enabled the collection and interpretation of data grounded in interviewees' experiences and intended meaning. However, it is acknowledged that the context of the project itself would have set a frame of reference for interviewees. This may have shaped the content of interviews and interactions with the researcher from the very beginning, for example through information and explanations given in the project information sheet, or through gate-keeping by rehabilitation practitioners, who had control over inviting potential participants to the project.

Ethics

Ethical approval was obtained from the United Kingdom National Research Ethics Service (NRES, Committee South East Coast – Surrey, reference 15/LO/0621). All interviewees gave written informed consent to take part in the study. To maintain confidentiality, data were anonymised and care was taken to remove any person-identifiable information from all study reports.

Results

Interviewees were five women and five men of all age groups, from the youngest participant in her mid-twenties to the oldest in her late seventies. They were from working or middle class and had diverse ethnic backgrounds. Participants had been diagnosed with: brain tumour and epilepsy, dementia, hereditary cerebellar ataxia, multiple sclerosis, muscular dystrophy, myalgic encephalopathy (chronic fatigue

syndrome), and Parkinson's disease (table 2). In the following, we provide some further information on participants' personal backgrounds, whilst retaining anonymity. Participants' names have been replaced with culturally equivalent aliases.

INSERT TABLE 2 ABOUT HERE

The overarching theme that emerged from these data was *Sense of self*. This describes how the overall experience of living with a progressive neurological long-term condition in this group of participants was signified by reflecting on and upholding a sense of identity and a desire for purpose against the background of the progressive condition. As a descriptor for *Sense of self*, we chose to use the words "I'm still me … I'm still here", taken from the following account:

> *I don't want to be treated any different, I'm still me. It's like an old picture you have on the wall, it's still your favourite picture, it's getting all cracked and, you know, but you still love it, you won't throw it away. The picture is still there, you see the picture – I'm like that, I'm still here! Okay, the framework is getting cracked or broken a bit, but, why throw me away? There's no need to throw me away.*

> Charlotte

This emotive metaphor was given by Charlotte, a middle-aged mother and former caretaker who has been living with multiple sclerosis for ten years. Bedbound and dependent on daily care support, Charlotte puts across how the condition may have damaged her body and mind, yet her sense of self endures. Her words express her sense of identity, the importance of feeling valued as a person, and how for her purpose is gained through relationships with the people around her.

We chose this quote as it depicted how the subordinate themes and codes in the data constituted strands that linked with and shaped the person's overall sense of self – their identity and purpose – in the context of living with a progressive neurological long-term condition. Five aspects that related to *I'm still me – I'm still here*, and which we describe as its sub-themes, were (1) *My body and mind*, (2) *Time*, (3) *Space*, (4) *Relationships*, and (5) *What I do*. These sub-themes did not develop as distinctly defined topics; rather, these were aspects that overlapped and interlinked in many of the narratives and examples participants gave, thereby contributing to the fabric that made up a sense of self. In figure 1 we give an overview of the theme structure with subordinate codes. In the following, rather than dissecting participants' narratives according to the five sub-themes, we present an interpretative account of the data that follows the order of these sub-themes, but maintains the interwoven nature of the data. We support our account with illustrative direct quotes.

INSERT FIGURE 1 ABOUT HERE

My body and mind

Interviewees gave comprehensive accounts of bodily impairments caused by their respective long-term conditions, and the resulting impact on daily life. Participants as a group had considerable health and social care needs. One interviewee was bedbound, three were wheelchair users, and several others relied on walking aids to move about. They often needed formal and/or informal care support in their everyday activities. All participants had utilised community rehabilitation services in the past,

some of them repeatedly and periodically. Besides physical, sensory and cognitive impairments, participants also talked about the psychological impact of their condition, for example low mood and depression. Interviewees gave many examples of practical strategies and solutions to manage or deal with the various manifestations of their conditions day-to-day. These included making use of various equipment and technologies; depending on assistance from others, either through formally arranged care or by goodwill from family members and friends; managing day-to-day life through establishing routines; utilising community services and support groups; making an effort to socialise; planning things to look forward to; eating a healthy diet; and keeping up with exercise.

A continuous thread and backdrop to participants' talk about their conditions was gradual worsening and the prospect of further deterioration in the future, which caused concern, anxiety or fear. Depending on the nature or stage of their disease, the looming threat of deterioration was experienced more prominently by some than others. Charlotte, for instance, described how with her progressive type of multiple sclerosis "it's about what you lose" and talked about performing a daily check of her movement:

> *'Cause you wake up, and you think, oh well, my eyes have opened, I'm still breathing. I can still lift my head, and you sit yourself up in the bed, and you think, right, my toes are moving, my leg's moving, my arm's moving – where the hell is the other arm, why ain't that moving. So it's sort of like that … you know, like your spot inspections with a car.*
>
> Charlotte

Some participants made the point that they purposely denied the condition to avoid consuming their identity. Sophia for example, a retired postal worker in her late

seventies, had been living with dementia for several years and described the attitude she took:

> Don't take it in, and keep on fighting. Keep on doing what you were doing, what you were doing before, you know, and speak the right words to yourself, "I haven't got dementia", you know, you don't keep on saying "I have dementia", "dementia", the more you say it, the more I think it will affect you. So, pretend as if you haven't got it [laughs], you know.
>
> Sophia

Sophia's quote can be interpreted as an expression of not internalising the diagnosis, as opposed to denial of its existence, and an attitude of "not giving in" and "keeping going", and this was apparent in many interviews. From a slightly different perspective, Ashley explained how she wanted her interests and aspirations, not her diagnosis, to define how other people saw her. An aspiring nurse in her early twenties, Ashley was recovering after a long hospital stay due to a worsening in her condition:

> I know people who have similar diagnoses to me, who it kind of becomes their identity, erm, and that's like the last thing that I want ... I don't want people to think, oh, Ashley with epilepsy, and asthma, and the brain tumour, and some balance problems, with the dodgy arm and stuff. I kind of want to be known, you know, like, someone who wants to do nursing and does all these different and interesting things.
>
> Ashley

Time

Time featured in all accounts as participants offered summaries of their biographies, and this provided some intro- and retrospective reflection on their person and life, and losses and gains over time. Within this, being given the official diagnosis of their long-term condition was a prominent life event for participants. For most it signified

the turning point and biographical disruption from a "before" to "after the diagnosis". James, for example, a middle-aged former cabinet maker and sculptor, had been educated at art school. In his twenties, he had a small and successful furniture-making business, and pursued his interests in sculpting and outdoors climbing. His active and busy lifestyle changed when he became ill and struggled with ongoing tiredness, which was eventually diagnosed as myalgic encephalopathy. Looking back, he talked about the loss of the life he had:

> *I suppose for me, there was quite a long sense of mourning, when I first got ill, because my life had gone, really, and all the things I'd worked hard to learn and become good at, I couldn't do any more. Erm, so you know, just getting over that, loss, really.*
>
> James

Talking about loss and the impact of their conditions over time, the constant threat of further deterioration was very prominent for some participants who, like Charlotte, felt in a rather vulnerable, precarious and uncertain position. As a response to that, participants often described the continuous fight, having to be ruthless in pushing one's body to "use it or lose it", in order to hold on to what abilities and independence they had. Peter for example, in his mid-sixties and living with Parkinson's disease, expressed his continuous struggle to maintain his independence as having to "keep improving":

> *I have to be very ruthless about this, that, unless I keep exercising I won't keep improving, and if I don't improve , if I don't keep improving, then I will soon dete-, degenerate, and lose my mobility, and lose my sense of independence, because I will be dependent on other people again. … And we have to keep up our determination … in order to make progress. Because if you stop making progress, then you get stuck there.*
>
> Peter

At the time, Peter was recuperating after a long hospital stay with pneumonia, and his recovery represented improvement towards his previous level of mobility and independence. At the same time, Peter's talk of improvement and progress reflects the acute threat of deterioration he experienced, and an urge to keep moving forward as a way of fending off deterioration.

Other participants felt more stable within their condition, but nevertheless thought about and feared what the future held. Vera, for example, had developed dementia in her early fifties and was now in her early sixties. Her symptoms had been relatively stable, but an elderly friend's move to a care home prompted some reflection on her own situation:

> *And it raised a lot of issues for me, in terms of what's my future with dementia, and, you know, when it comes to a time when you're no longer capable of making decisions and functioning in that respect. And, erm, you know, I don't know the timescale for that, I don't, it's something I worry about, and it's a real fear of the future, what my care needs will be in the future.*
>
> Vera

Shankara, a retired doctor in his late seventies, had a slightly different outlook for the future. Having been diagnosed with dementia for a number of years, Shankara's approach to dealing with the condition was to accept it, to be pragmatic about it, and to try to improve it as much as possible:

> *It is an ageing process, it is a disease process, I cannot overcome now, it can, I can try to slow it down, I can get it improved, I can try my best. I try, that's all it is, come to accept it.*
>
> Shankara

Explaining how he would "get it improved", Shankara talked about his general attitude in life, which was to try and learn from failure and adverse circumstance. "Improvement" to him meant learning from misfortune, thereby gaining a positive from "disaster", and he applied this same approach to difficulties he had because of dementia. Shankara accepted that the future would bring difficult situations, and he took an attitude of anticipating these inevitable situations, being prepared to learn from them as they arose, and viewing that as a positive process:

> *You see, you learn, see, even in a disaster, you derive pleasure, and also learn a lesson. So, if we're doing this day by day, you're improving all the time, you're able to learn to cope with everything.*
>
> Shankara

In interviewees' accounts there was also a contrast between changes and upset caused over time by their long-term conditions, and constants that endured over time. Constants supported participants' sense of identity and helped define them as a person, as expressed by Charlotte in the opening quote to this results section and in this further passage:

> *You know, I still got the same sense of humour I had before, I still love the same sort of music I loved before. I can't go out dancing anymore, but I enjoy a bit of company … Treat me like you used to treat me, you know.*
>
> Charlotte

In this context, many interviewees reflected, either implicitly or explicitly, on their roles within their families, communities and society over time. These passages illustrate strong themes of wishing to continue to contribute, connect with others, be valued as a person and not viewed as just a condition. Vera, who had to retire from social work due to dementia, described that for her coming to terms with the

condition was like a person re-evaluating what they should do with their life after retirement, which gives an alternative, more positive view on the loss and biographical disruption a neurological condition can cause:

> Because I've got dementia, does it mean I can't have a role, or have a function in life anymore? And that's something I haven't sorted out yet, because that's something I still feel, that I want to do something, and I want to be able to be a functioning person. And, there must be something that I can do, even if I require the support and the prompting that I might need, that it feels like you.

> Vera

Space

All participants had experienced spatial isolation to a certain extent, a shrinking of the space they could access freely and conveniently, and this linked closely with social isolation. Many accounts revolved around physical difficulties moving about, but for some participants with dementia the difficulties related to memory and orientation rather than mobility. Participants talked about the practicalities of accessing and negotiating space, and this ranged from globally, for example travelling abroad for leisure or to visit family, to the immediate surroundings, such as being confined to one's home, room or bed. Interviewees described different strategies they had developed to manage accessing space, for instance using mobility aids and wheelchairs, in-depth planning of travel routes, researching the accessibility of venues and places, utilising transportation companies' support services, or enlisting help from family and friends. In contrast to these strategies for widening space, participants also described many ways of bridging the distance or "bringing things in". Those with very restricted mobility for example often took care to keep important items within convenient reach. Others talked about getting people to come to them, or used online and telecommunications technology as a way of

maintaining social connections despite their mobility restrictions. Charlotte for example discovered and accessed digital spaces online and made new friends through a Facebook group for people with multiple sclerosis. William's account also included many of these aspects and examples. A graphic designer in his thirties, William had been diagnosed with muscular dystrophy when he was a teenager. In his late twenties, he sustained a fracture and was unable to leave his house for a year while he recovered, not knowing whether he would ever be able to walk again. William's partner separated from him during this time, which he describes as "probably the darkest time in my life". William eventually decided to begin using an electric wheelchair. Despite his mobility restriction, William was able to retain his employment, using online technology to work from home. To maintain his social life, William extended his private space to become more of a public and social space:

> *I knew that people with disabilities tend to become socially isolated … It has been quite annoying, because quite often someone will have a birthday party or something, and you can't get there on the transport, or you can get there but then you can't get in the house, this thing [wheelchair] can't handle more than a tiny step, and it's incredibly heavy, so it can't be lifted, so, it's less than ideal. So I decided to make my place more of a hub, so I've set up a projector, I got a popcorn machine, I've got lots of board games and stuff, yeah, and I'll have parties, really.*
>
> William

In a most literal example of shrinking space, Charlotte described how over several years she lost the ability to negotiate stairs. As a result she "gradually came down the house", moving her bedroom from the top to the middle floor, and later to the ground floor. Beyond the practical implications of being confined to the ground floor, Charlotte talked about how this changed her role and relationship as a mother to her teenage son, and how this affected her emotionally:

And that was heart breaking to know that I had to put the bed in here [ground floor], that really really broke my heart ... Especially with my son, 'cause when I went to the middle floor, he went up to the top floor, and so I couldn't go up and check on his room any more to make sure it was clean, so – you know what teenagers are like.

Charlotte

Relationships

Descriptions of changes in relationships, losing contact with people, and resulting social isolation featured in most participants' accounts. This was sometimes linked to stigma or lack of understanding about participants' respective health conditions, but mostly due to mobility restrictions, fatigue or other practical challenges. James, for example, talked about how fluctuations in his condition made it difficult for him to date and develop a romantic relationship:

I was gonna go out to dinner with a friend, until I got not so well, erm, a female friend, that's definitely an ambition, which I'd like to fulfil at some point when my health improves again. [pause] I mean, having a partner would be a nice thing, you know, as an ambition.

James

Peter, who had been diagnosed with Parkinson's disease in his mid-forties, explained how "everybody drew back as soon as I mentioned the Parkinson's". He was unable to keep his job as a senior manager, his wife separated from him, and he had since lived and coped on his own. Peter reflected on how "after twenty-odd years, I've deteriorated quite a bit, physically and mentally". For Peter, his mobility was crucial to meeting other people, which he saw helped him to avoid low mood:

I don't find it very uplifting to be confined to this space [home]. And after a while, people aren't so assiduous in visiting, because they've all got lives to lead, and my friends are scattered over [city], so not all come by very often. There can be some weeks when I might see very few people, except my carer.

Many interviewees talked about managing relationships by taking the initiative in explaining the impact of their condition to others, so that people could have a better understanding and adjust their behaviour and expectations. Olivia, for example, a former mental health support worker in her forties, at times struggled to continue her train of thought and the flow of her speech due to multiple sclerosis:

> *When I make phone calls, I'll always let them know that I have MS [multiple sclerosis], 'cause obviously, when they're talking to me on the phone, sometimes they're talking too fast, or my brain's not communicating with me properly. So I have to say: 'Can you please stop. I have MS, and it takes me a while to process the information.'*

> Olivia

In contrast to negative aspects around relationships, many participants also talked about positive experiences of forming new relationships, for instance meeting new people who were also living with the same or similar health conditions. Most participants gave examples of how peer support had been helpful; although some mentioned that they had deliberately avoided getting involved with peer support groups early on after diagnosis, because it would have made them feel defined by the condition. In general, interviewees found encouragement and mutual support in socialising with others. Some talked about insights they had learned from peers whose disease was further progressed, enabling them to anticipate and be prepared for future developments to a certain extent. William, for example, said:

> *A lot of them have all the tips and tricks that I wouldn't have otherwise picked up on my own. One of them has the same [type of muscular dystrophy], exactly the same thing as me, but is several years ahead. So, all the problems that he's dealt*

with already and has solutions for, I'm going to have to still deal with, so it's really useful talking to other people with similar conditions.

William

Equally, several participants themselves provided support to others, or gave back to the community in various ways, which was enjoyable and affirmed a positive self-image. For example, Olivia regularly met other people with multiple sclerosis in her area and offered advice and practical support. Together with the community nurse she planned to set up a more formal peer support network:

Supporting each other in the best way that we can, really, and so that's why we're gonna do a thing where we're gonna meet up, we'll have coffee, cakes, talk, play music, whatever anyone wants to do. So what I want to do with [community nurse] is set up a poster, so that we can start building something new … I enjoy it, and it makes me feel good inside as well.

Olivia

What I do

Participants talked much about how they occupied their time and what they could or could not do. They gave many examples of things they could still do like they always used to, or things they could continue to do if they went about it differently. Beyond many factual and practical examples, participants' accounts of "what I do" illustrate vividly how the person's sense of self is reflected in daily occupation, and, conversely, how daily practices construct and contribute to identity and purpose. Olivia, for example, talked about having to accept the help of others for chores around the house, and that it was hard for her to see other people do the things that she always used to do:

You have to get people in to come and do that. You sort of sit there, it's like being in a bubble, and everything's happening on the outside, and you're just stuck in this bubble, because you can't break it. … I'm quite an active person – I was an active person – and in some ways it's been taken away, but then I found, I'm finding other ways to be able to still help other people as well, 'cause I love helping people, which gives me a little bit of normality – if that's the correct word.

Olivia

In this quote, Olivia described how multiple sclerosis took away some of her capability and roles, but how she nevertheless found alternative ways of helping others. Olivia referred to how she offered neighbourly support to local residents who were living with disabling conditions, for example giving them a lift in her car; and to her initiative to set up a local peer support network for people with multiple sclerosis. Similarly, several other participants gave examples of how they had been able to fulfil a purpose and contribute despite living with a progressive long-term condition. This was not necessarily always phrased as overcoming limitations imposed by the condition, but sometimes opportunities also developed because of participants' diagnoses and their personal experiences of living with the condition. Peter, for example, struggled to find employment because of Parkinson's, but found a position with the local health organisation, which required "a particular perspective I can bring". Onipede, a middle-aged man who had previously worked in hospitality and marketing, found work with health charities after his hereditary cerebellar ataxia had become symptomatic. His personal experience of the condition made it possible for him to enter this line of work, and it benefited him, because he learned about different types of social and community support he could utilise later on himself: "Things get difficult, but you get by anyway … maybe some things get frustrating, but you gain other things. You lose something, but you gain something".

Interviewees also described what they would like to do in the future, accounts which again made apparent participants' desire to have a purpose, contribute, share experiences with others, and feel valued. Shankara grew up as an orphan in poverty in India. Having achieved a successful medical career in Britain, he had set up a charitable fund supporting orphans in his home village in India, and he talked about a plan to write his autobiography:

> *I have experienced, I have achieved. And that's why, even I want to write my own autobiography. Unfortunately I am poor in language, so I got some friends who have volunteered to write the book. So, and I feel proud, so that's why I'm telling the story, it may help other people, inspire other people, encourage other people.*
>
> Shankara

Some participants talked about "goals" and "achievements". Olivia, for example, recounted a goal she had discussed with her community therapist, which was to make her kitchen wheelchair-accessible and get the support of somebody to produce and market her own brand of sauces. Friends and family always praised her for her sauces, and she wanted to "see whether or not I'll be able to get my own sauces out there. … That's something, just, I suppose, just to keep *me* going". Another one of Olivia's goals was to complete the short walk to her local store, a walk she had not managed in six years:

> *But that is a goal that I'd love to complete – even if I do it once. It'd be good, because I can turn and go 'Oh my god, I walked to [supermarket]', and it'd be nice for the people, because they know me, … they all know that I got ill, they're really lovely people in our local shops, it'd be nice for them to see me actually be, 'she's standing', you know, it's gonna be difficult, but that's something I'd like to do.*
>
> Olivia

For Olivia, the importance in attempting to walk to the local store, even as a one-off achievement that may not be "functional", was to express her connection with people in the local community, who would validate her effort and give her recognition for not giving in to the illness. In a similar vein, some interviewees talked about goals or achievements as memorable experiences and moments to cherish, or as a "bucket list" of things to do before the disease progressed to a stage where it would be difficult or impossible, as in this quote from Vera:

> *[I'd like to] make the most of my life before this disease deteriorates, so I want to be able to go as many places, and spend as much time with family and friends doing things and enjoying my life, while I have my faculties.*
>
> Vera

Further examples of interviewees' plans and hopes for the future demonstrate how these relate to, and give insight into the strands that make up a person's sense of self. Sophia, for example, explained that she planned to encourage her prayer group to exercise. Her plan signifies Sophia's relationship with the local church, her love for music and movement, and the importance faith played in her life. The concluding statement in this quote reflects her attitude of not internalising the diagnosis of dementia:

> *The prayer group I have, they are old people. The pastor is going to help me, that when the prayer finishes I play some music and I exercise with them. So that's what I'm trying to do for this summer. I'm hoping that I'll have the strength and the energy to do it. It doesn't matter what dementia says – I'm going to do it.*
>
> Sophia

Charlotte used to be able to go out in an electric wheelchair, before she became unwell and took to bed, and she talked about her ambition to improve road safety for

wheelchair users. This presented an issue that was relevant for Charlotte as a wheelchair user, but it also reflected her prior training as a Health and Safety officer, which gives an almost symbolic layer of meaning to this example: The onset of Charlotte's multiple sclerosis coincided with her obtaining accreditation as a Health and Safety officer, a career progression she had looked forward to. Her illness prevented her from pursuing this career, but ten years on she continued to hold on to her interest and had a desire to contribute and improve road safety for wheelchair users:

> *When I'm up and well again, I wanna go around all the local streets. There are some dangerous spots if you're driving in a wheelchair, and I'm gonna document all that, take pictures, and raise it with the council. And I wanna make sure that something is done about it.*
>
> Charlotte

Discussion

Our findings from interviews with ten community rehabilitation service users give rich insights into experiences of managing and living with a progressive neurological long-term condition. These data need to be interpreted in the context of the project, as part of which they were generated.[16] In conducting these interviews, we initially intended to draw on the more practical and factual information from participants, *i.e.* the concrete "tips and tricks" of managing and dealing with a progressive neurological long-term condition, to inform the content and impact of a co-produced self-management intervention. However, participants' accounts went far beyond the practicalities of day-to-day management and together created a unified sense of self, their identity and purpose, which permeated aspects of body and mind, time, space,

relationships and day-to-day activity. This was generated through experiences, navigated as part of getting on with life, and not necessarily as a result of being educated by healthcare professionals. Practical examples of managing the long-term condition were embedded in talk that made apparent how interviewees reflected on their condition within the broader context of who they were as a person, and the life they wished to lead. The depth of these reflections suggests that this was a continual process and not merely prompted by the research interview. These accounts gave an insight into participants' desires to make a contribution, connect, share experiences with others, and feel valued as a person – a desire for purpose in their lives.

Qualitative evidence can be valuable to inform aspects of self-management support, such as its conceptual grounding,[21,22] the content and format of programmes,[9,23,24] the adaptation of interventions to differing implementation contexts,[25,26] and the evaluation of programmes.[1,16,27] But few studies have drawn directly on the experience of living with different progressive neurological long-term conditions to inform the practice of self-management support.[15,28,29] In this respect, our paper makes a novel contribution to the evidence base. A second original aspect to our paper is that the sample represents a group of community rehabilitation service users, as opposed to a group of people with one particular health condition who may or may not have come in contact with these services, and therefore these data relate closely to actual service provision.

How then might these findings inform our understanding, design and delivery of self-management support for this client group and in this setting? Morgan and colleagues have described how self-management can be conceptualised along a spectrum, from more narrow approaches which focus on disease control (*i.e.* managing the

condition) to broader approaches which aim at supporting people to live well (*i.e.* manage living well with the condition).[12] The former are often operationalised through more didactic programmes of education, information provision and teaching of technical skills, whereas the latter make use of paying attention to people's own perspectives and their interests in directing their own lives. At this conceptual level, the complexity in our participants' accounts and the overarching theme "sense of self" suggest to us that a broad approach suits this context and client group. While some authors may interpret self-management for people with neurological conditions mainly as a vehicle for promoting self-directed task practice and exercise,[30-32] we suggest that getting to know the person's story and discovering their sense of self through conversation can serve as a starting point for self-management interventions. This calls for an asset-based approach that has as its starting point not the deficit, but is based on values of person-centredness, shared decision-making and partnership working. Similar to the above distinction between narrow and broad approaches, self-management concepts may reflect these aspects to greater or lesser extent, and it is the more empowering and collaborative approaches that tend to explicitly articulate these values.[12,33-35]

In our own approach to self-management, which was one of the first to adapt self-management to the field of neurological rehabilitation,[9,36,37] we use bespoke client-held booklets that provide a focus to the self-management dialogue between healthcare professional and client. These co-produced booklets contain vignettes of people living with long-term conditions, and also a space for the person to reflect and note down what is important to them, their hopes and dreams, as a basis for considering and planning action. Whether using a physical tool like this or not, our findings reflect the importance of creating a space for the person to articulate their

sense of self, *i.e.* "the person I am", so that the self-management intervention may support meaningful human interactions and aspirations. Interviewees in our study expressed these aspirations in their plans and goals for the future, which – regardless of how realistic or achievable they might be perceived to be – can be understood as a way of communicating these desires. Within a self-management approach, this could be supported, for example, through genuine person-centred goal-setting conversations. Although person-centred goal-setting has been much advocated in neurological rehabilitation, in reality goals are often privileged by professionals according to financial and organisational drivers.[38] Our study emphasises the importance of creating an authentic person-centred dialogue to discover and support the person's sense of self. In this respect, our own interpretation of self-management aligns very much with other approaches that seek to support the human dimensions in rehabilitation and healthcare, such as the Life Thread Model developed by Ellis-Hill and colleagues,[39] or the humanising care philosophy.[40] It has been shown that healthcare professionals often require specific skills training to be able to realise such a collaborative, person-centred way of working.[33,41]

Our findings also give some insight into the use and interpretation of language, for example the words "improvement", "progress", "goal" and "achievement" – often used terms in rehabilitation – and how these might be understood from the perspective of people living with a progressive neurological long-term condition. These terms link with rehabilitation goal-setting, which is a common strategy for structuring rehabilitation progression and demonstrating steps of improvement towards an agreed goal. In a self-management context, goal-setting discussions can facilitate decision-making and activity, and this is also one element in our own self-

management approach. In a traditional rehabilitation environment goal-setting is often conducted based on the implicit assumption that permanent gains will be made towards a higher level of functioning.[42] In the context of a progressive degenerative condition, it may seem counter-intuitive to talk about "improvement" or "progress". And yet, some participants did use these words as they described their attitude in dealing with the condition, or their outlook for the future. Interviewees' accounts demonstrated the different ways in which they gave meaning to "improvement", "progress", "goal" and "achievement", and four distinct interpretations emerged: improvement and progress as expressions of the continuous struggle against deterioration; improvement achieved through learning from and adapting to setbacks; goals as representations of the person and what keeps them going; and achievements as experiences and "things to do" before the disease progresses, thereby making the most of life. These interpretations suggest alternative ways to think about what having a goal or making progress might mean to a person with a progressive neurological condition. Interestingly, there are similarities to how people with acquired brain injury can experience recovery, for example with respect to being determined to continue to improve, the re-construction of self, and the importance of goals as "things that make me 'me'",[43-45] and this illustrates how these are common expressions of maintaining hope, rather than indications of 'unrealistic' expectations or lack of insight. Rehabilitation practitioners may need to adapt their own conceptualisation of rehabilitation goals to accommodate these interpretations.

Participants' language may also inform the selection of relevant outcomes and measures for self-management interventions in this client group. Recent work has highlighted how different stakeholder groups may place differing emphasis on relevant outcomes, and some studies have defined outcomes that reflect our

overarching theme of sense of self.[1] Drawing on some of our interviewees' quotes, these outcomes could be evaluated through impact statements around "being me", "having things to keep me going", or "making the most of my life". In our own work, we use statements like this to evaluate our self-management service improvement projects, but items worded like this could also be included in more formally constructed psychometric patient-centred outcome measures. Outcomes are highly influential driving forces of healthcare processes, and putting person-centredness at the heart of outcome measurement is a suggested strategy for shaping healthcare delivery by measuring what really matters.[46]

We acknowledge methodological limitations to our study. We did not include a formal process of respondent validation, which would have provided an additional layer of trustworthiness to the analysis and interpretation of findings; however, several of our interviewees did participate in co-producing the self-management booklet for this project, which involved iterations of review and feedback and enabled the first author to clarify and confirm interviewees' accounts and intended meaning. Additionally, the first author's data analysis was peer reviewed by the co-authors, who reviewed one transcript each against codes and themes and offered their own summaries and interpretations. Disagreements were addressed and resolved in open discussion. Minutes and outcomes of peer review discussions were added to the audit trail.

We acknowledge that participants in our study constituted a group of service users who were engaged and willing to share from their experience. This may account for a relatively high level of self-reflection and richness in the data. It would be of interest to also capture views and experiences of individuals who are less ready to engage in research or less self-aware, although this may require an alternative approach, for example drawing on ethnographic methods. We realise that some of the diagnoses

represented in this sample do not constitute neurological conditions that are necessarily progressive *per se*, for example myalgic encephalopathy, but we used this description to distinguish from acquired brain or spinal cord injury.

In conclusion, our findings illustrate the various facets of managing and living with a progressive neurological long-term condition. Individuals demonstrated unique and personal resourcefulness, and their practice-based strategies provide valuable content for co-produced self-management interventions, giving useful advice and encouragement to others who are in a similar situation. However, going far beyond practical management strategies, individuals' experiences of these conditions are often signified by reflecting on and upholding a sense of identity and purpose against the background of living with the condition. Self-management interventions will benefit from creating a space for the person to articulate what it means "to be me". There is scope for innovative and creative ways of supporting the person's sense of self within self-management, and healthcare professionals can benefit from specific skills training to realise such an approach.

Declaration of interest

FJ is founding director and CEO of Bridges Self-Management Limited, a social enterprise conducting training, research and development in self-management support in health and social care. LH is Director of Innovation and Training at Bridges Self-Management Limited, and SK is a former employee.

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Table 1. Interview schedule

Question	Prompts
Could you tell me a little about yourself	What do you do What do you like What are you good at
Can you talk about when you first learned you had [condition]	
Can you talk about how you manage day to day at the moment	What are your main challenges What are the ways you get around things Can you tell me some of your tips and ideas that have worked for you
Some people have said that there can be ups and downs with [condition]	Can you talk about what happened to you What have you been through, some of your ups as well as your downs, or turns that your life has taken that you never would have guessed
Some people have stressed the need to get away from thinking about their health condition all the time	Is that the same for you How do you do that
Can you talk a bit about maintaining or building relationships	With family, friends and, if applicable, work colleagues
Is there anything that's really important	

to you which might take a bit of time, but you want to try and do	
What's a small thing that makes a big difference to your life with [condition]	What's the one thing you would like to tell someone in your position – a bit of advice, an idea or a tip
I would like to ask you about the [community rehabilitation service/team]	Can you talk about what happened when they met with you Is there anything you remember particularly well about the [community rehabilitation service/team] Some people feel quite confident to continue to manage under their own steam once community rehabilitation visits stop – how did you feel

Table 2. Participant characteristics

Name	Age group	Ethnicity	Diagnosis	Living situation	Professional background
Charlotte	50-59 years	White British	Multiple sclerosis	Lives with son	Caretaker, retired (due to health)
Sophia	70-79 years	Black Caribbean	Dementia	Lives alone	Postal worker, retired (not due to health)
Ashley	20-29 years	White British	Brain tumour, epilepsy	Lives with flatmates	Nursing student
James	50-59 years	White British	Myalgic encephalopathy (chronic fatigue syndrome)	Lives alone	Cabinet maker, unemployed (due to health)
Peter	60-69 years	White British	Parkinson's disease	Lives alone	Corporate manager, retired (due to health)
Vera	60-69 years	Black British	Dementia	Lives alone	Social worker, retired (due to health)
Shankara	70-79 years	Asian Indian	Dementia	Lives alone	Medical doctor, retired (not

					due to health)
William	30-39 years	White non-British	Muscular dystrophy	Lives alone	Graphic designer, self-employed
Olivia	40-49 years	Black British	Multiple sclerosis	Lives with family	Mental health support worker, unemployed (due to health)
Onipede	60-69 years	Black African	Hereditary cerebellar ataxia	Lives alone	Hospitality and marketing manager, retired (due to health)

Central: I'm still me – I'm still here

What I do
- Something to keep me going
- Being valued as a person
- Making a contribution
- Making the most of life
- Learning from setbacks
- Giving back
- Changing roles
- Practical strategies, tips and ways I manage with [condition]

My body and mind
- Denying [condition] to define me
- How [condition] affects me
- Low mood and depression
- Fending off deterioration
- Threat of further deterioration

Time
- Before and after the diagnosis
- Changes and constants over time
- Losses and gains over time
- Biography – reflecting on my life

Space
- Bringing the outside in
- Widening my space
- Spatial isolation
- Difficulty moving about
- Shrinking of the space I can access

Relationships
- Meeting others with [condition]
- Helping others understand about [condition]
- Loss of relationships
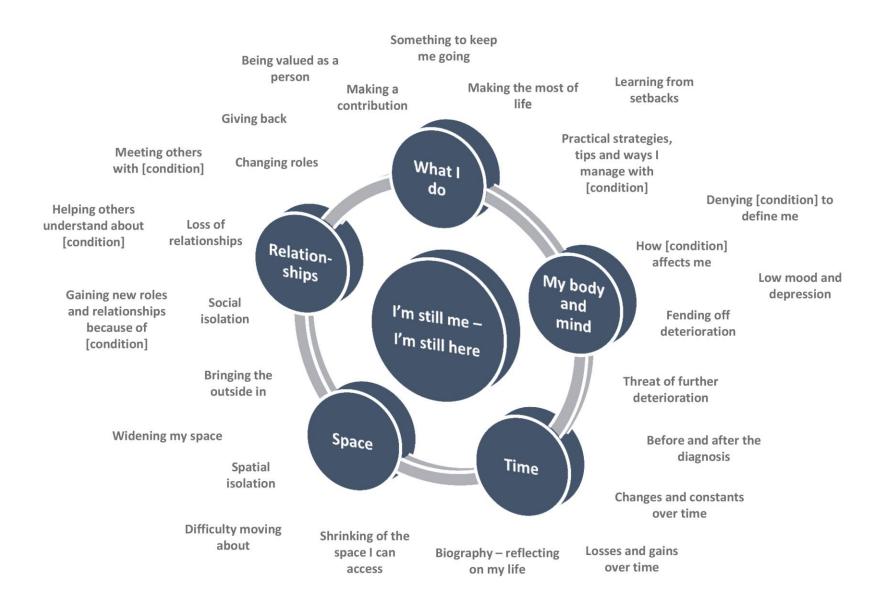- Gaining new roles and relationships because of [condition]
- Social isolation

Figure 1. Overview of theme structure and subordinate codes. The central theme, sense of self, is titled using one of the participant's words *I'm still me – I'm still here*. This describes how individuals' experiences were signified by reflecting on and upholding a sense of identity and a desire for purpose against the background of living with the progressive neurological condition. The central theme is surrounded by the five sub-themes (1) *My body and mind*, (2) *Time*, (3) *Space*, (4) *Relationships*, and (5) *What I do*. We selected a three-dimensional graphic to represent the central theme and its sub-themes. Subordinate codes are arranged loosely in proximity to the sub-theme they mostly relate to. We chose this representation to convey that this theme structure does not describe two-dimensional, linear and hierarchical relationships, or distinctly defined themes. Rather, we view this theme structure as a complex fabric of interconnected multiple strands, which constitute meaning around single aspects, but also link with all dimensions.