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RESEARCH PAPER

From dictatorship to a reluctant democracy: stroke therapists talking about self-management

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Abstract

Purpose: Self-management is being increasingly promoted within chronic conditions including stroke. Concerns have been raised regarding professional ownership of some programmes, yet little is known of the professional's experience. This paper aims to present the views of trained therapists about the utility of a specific self-management approach in stroke rehabilitation. **Method:** Eleven stroke therapists trained in the self-management approach participated in semi-structured interviews. These were audio recorded, transcribed verbatim and analysed thematically. **Results:** Two overriding themes emerged. The first was the sense that in normal practice therapists act as "benign dictators", committed to help their patients, but most comfortable when they, the professional, are in control. Following the adoption of the self-management approach therapists challenged themselves to empower stroke survivors to take control of their own recovery. However, therapists had to confront many internal and external challenges in this transition of power resulting in the promotion of a somewhat "reluctant democracy". **Conclusions:** This study illustrates that stroke therapists desire a more participatory approach to rehabilitation. However, obstacles challenged the successful delivery of this goal. If self-management is an appropriate model to develop in post stroke pathways, then serious consideration must be given to how and if these obstacles can be overcome.

Keywords

Qualitative, self-management, stroke, therapists

History

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► Implications for Rehabilitation

- Stroke therapists perceive that self-management is appropriate for encouraging ownership of rehabilitation post stroke.
- Numerous obstacles were identified as challenging the implementation of self-management post stroke. These included: professional models, practices and expectations; institutional demands and perceived wishes of stroke survivors.
- For self-management to be effectively implemented by stroke therapists, these obstacles must be considered and overcome. This should be as part of an integrated therapy service, rather than as an add-on.

Introduction

Promoting self-management, defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" [1, p. 178] is not new to western health care. Since the early 1990s and the development of the chronic disease self-management programme [2,3], subsequently adapted for the UK as the Expert Patient Programme [4] self-management has been an increasingly integral part of the management of people with long-term conditions. A recent report by de Silva on behalf of the Health Foundation [5] synthesised over 550 pieces of research in many long-term conditions covering several countries

and generally concludes that self-management approaches have a beneficial impact on quality of life as well as use of health resources, although it should be noted that extent of these benefits are debated [6–8].

It is appropriate that stroke, as the single most common cause of severe disability in adults [9], has not been overlooked in the development of self-management approaches. Despite a continuing trend for stroke research to focus on the acute phase of recovery [10], there is increasing interest in the processes of adjustment and interventions to promote successful long term outcomes [11–13]. The need for effective rehabilitation interventions beyond the acute phase is identified as one of the 10 priorities of stroke research [14] and is clearly identified in the National Stroke Strategy [15] and recent national clinical guidelines [16]. Self-management programmes could play an important role in this regard. However, although stroke has been included in some of the generic studies [3,17], it is only recently that self-management approaches have been specifically designed

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or adapted and targeted to people living with stroke (see [18] for a systematic review of most of these publications). These condition specific approaches are important as the sudden onset and range of issues that can occur as a result of stroke are quite unique to the condition and indeed some such as aphasia may exclude attendance at generic programmes [19]. These programmes have broadly fallen into either group focused or individualised and lay or profession led. This study focuses on one professionally led individualised approach which has provisional evidence on its effectiveness [20,21] and was evaluated as one of the Department of Health's Stroke Improvement Plan priority projects. Utilising an interactive workbook developed in consultation with stroke survivors and based on social cognition theory, the approach aims to assist the ongoing development and monitoring of self-management post stroke. As part of this process a key principle is the stroke survivor's control over the goal setting process.

Despite preliminary research findings which show a favourable impact of the approach, there have been some concerns raised regarding the use of self-management in stroke and more generally [19]. One of those concerns which is of specific relevance to this approach relates to the professional ownership and control of self-management programmes. The de Silva report on self-management identifies two core principles in self management support; the tools which facilitate behaviour change and "a fundamental transformation of the patient-caregiver relationship into a collaborative partnership" [5, p. vii]. This transformation has been highlighted as an area of possible disquiet. Previous studies for example have noted the paradox of medical dominance within an expert patient programme apparently designed to promote patient empowerment [8]. It is perhaps unsurprising that Kennedy et al. [22] note a tension can arise from balancing patient autonomy with the responsibilities inherent in their professional roles, resulting in boundaries being set by the professional. And Gately et al. [23, p. 943] conclude that for self-management programmes to be effective "professional practices at the interface with patients also require change". These are in addition to institutional constraints such as time which have been implicated as impeding the development and sustainment of self-management strategies [24,25].

Research in the field of stroke rehabilitation indicates that concerns about power and professional dominance in rehabilitation may have particular resonance in this regard. Suggestions have been made that therapists can be directed more by a compliance model through which patients are positively encourage to follow the wishes of the professional [8]. Further studies have examined therapeutic goal setting, a component of self-management strategies, concluding that the process is frequently professionally led, with an emphasis on professionally privileged goals [26–29].

With this background and the stated requirement for transformation in the delivery of self-management approaches, it is appropriate to investigate how the shifting balance of control is negotiated through the use of this professionally led approach, or if indeed it even occurs. Consequently, this study aimed to explore the experience of stroke therapists who are trained and currently using the professionally facilitated self-management approach. Objectives included an exploration of how self-management was understood, how its implementation differed from previous practice and the therapists experience of who controlled the process within the realities of everyday practice.

Method

In order to explore therapists held understandings and concepts as used in practice a method which facilitated in-depth discussions around specific topics was required. Qualitative methodology is best suited for such an endeavour as it both attempts to make sense

of the targeted phenomena from the perspective of the participants, and stresses the creation of experience within social and situational constraints [30]. An approach informed by interpretative phenomenology was adopted as it focuses on the specific experience under study while accepting the co-creation of knowledge through the influence of the researcher. The primary researcher (MN) is a physiotherapist and stroke specialist. While aware of the specific self-management approach, she had not been trained in it at the time of interviews and has not used it clinically. The awareness of the realities of stroke rehabilitation within the UK facilitated a shared understanding and language between researcher and participants, although it is also acknowledged that this may have influenced the questions asked and the analytical process. To ameliorate this, a reflexive diary was maintained throughout the process through which personal judgements were considered. The lack of previous experience on the approach was deemed essential in order to reduce the risk of undue personal influence.

In-depth interviews allow for an exploration of complexities in people's accounts and therefore was the method selected [31]. Following a topic guide drawn from issues raised in the general self-management literature, interviews drew on participant's experience of using the approach, examining its perceived effectiveness, facilitators and barriers.

Participants ($n=11$) were purposively sampled via email through the database of all therapists who had been trained in the approach and had experience of its use. Training consists of two workshop days – the first to introduce the underlying principles and tools (workbook) used in the approach and the second, which occurs some months after the first, to reflect on its use in practice and any issues arising. Further reflection is supported through written case-studies. The training was designed and is conducted by an organisation un-related to the research team. Preliminary efficacy for the approach including the training package is demonstrated [20,21]. As the approach is relatively new, it was expected and accepted that experience of use would be limited, consequently a minimum of 6 months was deemed appropriate. A summary of the participants is given in Table 1. Following informed consent an interview was arranged at a location and time of their convenience. This included their homes, University premises and work offices. With permission, interviews were audio recorded and further notes were taken both during and after the interviews. Interviews lasted between 53 and 87 min. All verbal data were transcribed verbatim and uploaded to an Atlas.ti software management package (ATLAS.ti Version 5.2, Scientific Software Development GmbH, Berlin, Germany). The data were analysed thematically initially by the prime author [32]. The full transcripts were all read several times, with initial ideas noted in the memo section of the Atlas.ti software. Inductive coding was then conducted at sentence level. These were collated into first level themes and the data pertaining to each theme was re-read within context to check its appropriateness. The first level themes were considered diagrammatically and the two overarching themes were developed. Transcripts were re-read at this stage to consider any contrasting views from the themes developed. Other members of the research team independently reviewed the process of coding, first theme identification and the development of the overarching themes, supporting the rigour and transparency of the process.

The study was granted ethical approval by the ethics committee at Brunel University (number 11/STF/03) and all participants have been given a pseudonym.

Results

Two over-riding themes emerged from the data. The first was the sense that in normal practice therapists act as "benign dictators".

Table 1. Participants.

Participant name	Profession	Years qualified	Years using self-management approach	Current work area
Libby	Occupational Therapist	6	1	Community
Rose	Physiotherapist	7	1	Community
Saatvick	Physiotherapist	11	2	Community
Martha	Occupational Therapist	6	1	Community
Amy	Physiotherapist	15	3	Acute/rehabilitation
Helen	Physiotherapist	36	2	Rehabilitation/community
Kathy	Physiotherapist	8	3	Acute
Lucy	Physiotherapist	14	3	Community
Gary	Occupational Therapist	16	3	Rehabilitation
Joan	Physiotherapist	15	2	Hyper and acute
Milly	Occupational Therapist	7	3	Community

This theme is drawn from an interpretation that while the therapists are committed to help their patients, they are most comfortable when they, the professional, are in control. This somewhat retrospective understanding of their “usual practice” was highlighted following reflection on their practice after completing the self-management training. The second theme, “a reluctant democracy”, symbolises the notion that therapists through adopting this approach to self-management, challenged themselves as dictators to empower the stroke survivors they worked with to take control of their own recovery. However, “giving them the vote” was not a straightforward process and it became apparent that the therapists had to confront many internal and external challenges in this transition of power. As these themes are further described and dissected, supporting quotes will be used to illustrate the points raised.

Therapists as benign dictators

Professional control

Therapists for some reason I think when they're qualified they have this unerring belief that they are now the professional, they know everything, and that from their professional standpoint they get to almost dictate if you will to clients, to patients, about what they think should be happening. (Amy)

In discussing their use of the self-management approach, therapists reflected on the position that they and their colleagues had come from prior to their specific introduction to self-management. As Amy's quote highlights, there was a concern with a professional authority that created a very uneven power structure. This issue was raised by nine of the 11 participants, all summarising a similar pattern of professional control, as illustrated by Gary.

“Predominantly because of the fact that they're in a medical environment, so you know that sort of paternalistic view of sort of like therapist knows, doctor knows everything kind of thing. So you're being done to... I used to... I used to very much believe that I had all the answers as a clinical specialist. I also should have all the answers as well to a certain extent” (Gary)

Numerous reasons were given for the emergence and sustenance of this pattern of therapeutic control. As indicated in the quotes, professional training and the expectation by the professionals that they were or should be the holder of knowledge were perceived to be central to therapy. This was shared across the professional groups represented.

Environment and culture

A further point raised, as Gary suggests, was the hospital environment and culture itself and specifically the period of acute care, in which the stroke survivor was expected to be a passive recipient of care. This point has particular relevance for stroke care as the introduction of acute and hyper-acute stroke units and guidelines that recommend hospital admission at the first sign of stroke mean that this initial acute experience will be shared by almost all stroke survivors.

In the following quote, Joan describes a sense of environmental ownership which facilitates control to remain within the therapeutic domain.

“Well you know I'd say I was guilty of it. I don't know if it's that hospital setting environment that depersonalises somebody. They're on your patch and they have to play the patient role, sick role... I don't think it is even sick role... but they're very vulnerable but also passive. And we quite like that 'cos then we can get on with our own agenda” (Joan)

In contrast, others described the lack of control patient's have because of the myriad of things that are done to them on admission and within acute care. Consequently, they described patients as not knowing what is going on and subsequently having no choice but to be passive recipients.

Agency of stroke survivors

While professional training and practice and the environment were seen as important catalysts in the dictatorship, the agency of the stroke survivors themselves was not totally absent. Three participants, again across both professional disciplines, noted that in their view at the early stages of stroke recovery, stroke survivors frequently desired the control to be in the hand of others. Kathy attributed this in part to the concept of “the expert”, in this case the therapists were considered by patients to be in the best position to make an informed decision on their behalf. Libby extends this further, drawing on recent developments within stroke medicine and the potential awareness that patients may have of advances in treatment such as thrombolysis.

“I think it's almost that people used to think that if you had a stroke that was it. And now they think with technology being what it is and things having moved on the way they are, you can fix me, you can get things back to normal again. To me, sometimes I just get this impression that it's you know, 'I've had a stroke, you're the specialist, so when and how are you going to get me back to normal?’” (Libby)

It is of course unclear from this data whether this professional control is indeed what the stroke survivors think, but does suggest a degree of perceived reciprocity/complicity in the creation of the balance of power during the process of rehabilitation. Although this was less frequently mentioned, it is important in respect to the question of power in rehabilitation as it hints at the complexity of the role creation and potentially of the nature of stroke itself. This perception that some stroke survivors are looking for professional control has significance in relation to the adoption of self-management strategies and will be revisited later.

Competing agendas

Linked with the hospital environment, were the processes of care including time and pressures for discharge which encouraged therapists to maintain control of the therapeutic agenda. Participants described how they were caught in multiple agendas where the highest priorities were often those dictated by the institutional needs: assessment, safety and meeting pre-set criteria in order to facilitate early discharge. As suggested by Rose in the following quote, these institutional agendas compete somewhat with the sense of “getting people better”, to the extent that the overall goal and time-line is pre-set and consequently the process must be controlled.

“you just need to go in and do what you have to do to get people better. And I think inpatients may be a bit like that, you kind of... if somebody's on a ward you kind of keep going don't you and you've got that aim to get them discharged, but... it's kind of on your terms, 'cos they're in hospital and you're rehabbing them to get them out of hospital” (Rose)

It is evident that much of the reference made by participants to the professional and environmental control is situated in the in-patient and specifically acute setting. This is perhaps unsurprising. Nevertheless, even in the community settings when stroke survivors are continuing their recovery in their own homes, the sense that therapy was limited, therapists were “mindful of time” and future discharge was a goal in itself was apparent. In the following quote, Helen describes how despite her desire and tendency to focus on longer term patient-led goals, the practical limitations of the service would nevertheless have influenced what she felt able to focus on.

“So I guess my tendency was always a bit to not focus in on the next 6 weeks and let's see if we can get another three seconds off your 10 metre walk, rather... and it's why I like being in the community rather ‘Well let's go out and see if you can get to the bookie's’. Um... but still I would have been constrained by... I think I would have been constrained by the SMART goals which have come on in my time as a therapist. And um... I would have said well you know yes I think that's something that you might be interested in looking at longer term but we have only got 18 weeks or 14 weeks or 6 weeks depending on the environment you're working in, and in your physio sessions we'll be working on this instead”.

This apparent paternalistic control of the therapeutic relationship, whatever its origin, was seriously challenged by training in the self-management approach. All participants described how they had become more aware of the limitations of their own practice and the importance of the stroke survivors agenda as part of a self-management strategy in the recovery process. As a consequence they endeavoured to alter their therapeutic approach to reflect the need for collaboration and facilitate the leadership of the stroke survivor in their own journey of recovery. As will

become apparent however, this re-shifting of control was complex and frequently compromised.

A reluctant democracy

Transferring control

“I think it's that old Chinese proverb about you can teach a man to fish or you give them a fish. What [this approach] does is that it encourages therapists to teach people how to fish... or give them the skills or relight the touch paper under the skills they already have. It's not about telling them how to get their arm moving” (Gary)

By teaching the stroke survivors “to fish”, or as another participant stated, giving them permission to do so, Gary was articulating that the control of where to fish, when, how and what for was no longer dictated by the professional but was in the hands of the stroke survivor themselves. Gary later added, “[this approach] is about making sure that they come up with the answers. So yeah, it is, it's the ultimate patient control”.

The participants had similar views on what self-management was in the context of stroke: that of “empowering them to maximise their potential from within themselves” (Helen), allowing them to “be in the driving seat” (Joan) and “the patient taking ownership for guiding their therapy” (Milly). They also articulated the need for that approach to be tailored to the individual. This tailoring took many forms. For the majority of participants ($n=8$) key to the success of this approach was finding out about the stroke survivor. Knowing what they used to do, activities they enjoyed prior to their stroke, became more than contextual notes of interest, but key to the process of rehabilitation itself. What was critical to this description was the intent when asking the stroke survivor about their lives. The therapists involved in this study acknowledged that they had always interacted with the patient's histories and individual stories, indeed many had used client centred goal setting strategies. But they also accepted that their self-management training had opened their eyes to a different way of listening – a difference that was highlighted when they compared their practice with others.

“I think that even though we say that we do client centred goal setting, I think that we don't. And I think this is one of the issues with [the approach] is that people say that they do everything that [this approach] does, but it's how you do it. Yeah we'll talk about listening and they'll go ‘Yeah yeah yeah yeah, goal setting's collaborative’. Is it? Is it really? Is it really collaborative? Are you really listening to what they're saying?” (Gary)

It should be noted that without exception, although the participants felt that principles of self-management should be introduced in the acute setting, all commented that the community setting was more facilitatory to engagement. A number of reasons for this were given. For example Joan suggested that in the community there was more time to explore histories, “unpick things” and talk about “what the patient really wants to do”. But, equally there is also the space and opportunity for the stroke survivors to take calculated risks, a point also voiced by Libby. Kathy reflected on the environment itself, that within their own home individuals were more likely to articulate their own attitude towards rehabilitation. For Martha, this also resulted in more flexibility within goal setting.

“everything's relevant to them... people can have whatever goal they want and now it's not like they have to have transfer goals so that they can go home”. (Martha)

Despite the increased desire and capacity to actively involve stroke survivors to engage with their own goal setting and rehabilitation strategy, a number of factors were noted as creating a tension in this approach. These highlight the potential challenges faced by therapists in transferring control away from themselves and for the stroke survivor to truly have their vote in this emerging democracy.

Fear of losing control

A significant cause of this reluctance was a perceived fear. The therapists cited three fearful factors which limited their ability to “allow” the stroke survivor to “cast their own vote”. The first was a deep concern with health and safety on behalf of their patient. Therapists queried what was acceptable risk, what was too much and who was responsible for making that decision. In one example cited, Joan had tried to use the workbook with a stroke survivor who identified many large goals, but who had been limited in their capacity to identify interim steps. Finally, the situation required more external control as she described “they ended up having lots of falls, it was very very stressful for all the therapists involved. We readmitted them [to the rehabilitation unit] ‘cos we couldn’t handle the situation”. Other participants described that one advantage of the community setting was the capacity to take more risks, seen as an essential component of self-progression and determination, but nevertheless found themselves hesitating when faced with activities they (the professionals) considered unsuitable.

In contrast to this, participants also identified their fear of doing nothing. This was a particular concern when stroke survivors were unable to clearly articulate their own goals as part of the self-management process, or alternatively stated that they did not want to work on anything, as this extended quote from Rose exemplifies.

“At the beginning I used to get quite frustrated and think ‘Oh they could be doing so much more’ . . . and you’d kind of try every way to persuade them to change their mind or . . . you know ‘What do you think about doing this?’ But then you’d kind of get to a point where there’s no point because it’s not what they want . . . but it’s what you think they should want. (laughs) . . . And I think it’s the fear . . . and we spoke about it in our team meeting yesterday . . . but it’s the fear of not doing anything, it’s the fear of like you know you should do something because you’re going there to assess them and you can’t just you know say well they haven’t got goals or they don’t really want to . . . because it feels like it’s a cop-out.” (Rose)

Rose questioned whether this need to do something is embedded in the medical model and yet creates a significant dilemma for therapists when their patients do not appropriately “join in”.

Linked with this fear of not doing anything is the potential loss of power, deemed another child of the medical model. Although the participants identified the shift from their previous controlling patterns to a more democratic position, they still recognised that they and other professionals found this an extremely challenging proposition. Kathy highlighted the specific difficulty this poses for physiotherapists.

“In physiotherapy . . . much of it is focussing on what’s measurable and - this is the impairment, this is the treatment, this is the outcome. [This approach] is quite a different concept to that, which I think physios . . . some physios struggle with . . . I think they struggle with letting go of the power

they have in the patient therapist relationship, I think that’s the crux of the issue”.

Martha, also a Physiotherapist, echoed this concern but hinted at its potential root, that of future problems which only the professional is aware and the potential fear of sharing this information.

“And for some it’s difficult to let go of that sort of ‘I’m the physio, I’m the expert. I’ve got to look at the impairments and make them better, otherwise there are going to be long term implications that this patient doesn’t even understand. So it shouldn’t be about what they functionally want to do now, it should be me as an expert saying this is what you need to do for the long term”’. (Martha)

This creates a critical tension for the therapists who have to juggle their clinical judgements, based often on years of experience along the stroke pathway, with the specific wishes and insights of individuals who are usually travelling the post stroke journey for the first time.

While some of the challenges of implementing this self-management programme may be embedded in the perceived role of the professionals themselves, they are not alone. As with the implied passivity of stroke survivors which made them complicit to the dictatorship, so the participants highlighted very real impediments with encouraging some of the stroke survivors to become active self-managers. Lucy, for example, described a patient who “just did not get it” and despite several explanations by different members of the team, the ownership of the self-management process was thrust back into professional hands. Libby, as illustrated in the following quote, re-emphasises the potential consequence of this lack of understanding of self-management and the process by which it is achieved.

“And I think self-management is not necessarily a concept that everyone working with is very familiar with. . . . we’ve had experience with a lot of people who want you to fix things for them. And talking about self-management sets them off in terms of ‘But you’re my therapist and you need to fix that for me, and it’s not my job, I’m not the expert, I don’t know how to do this”’. (Libby)

It is perhaps worth noting that both Libby and Lucy work in community settings and therefore the clients they refer to are coming to the end of their formal rehabilitation process. Furthermore participants noted that this sense of fear in taking responsibility was shared by many carers as well as the stroke survivors themselves.

In the first theme, a number of structural issues were described as promoting the profession-led approach to rehabilitation. A number of these were cited again as barriers to working effectively in a truly collaborative partnership. The most significant of these was time: “my experience is that for it to work it’s very time consuming” (Helen).

An important feature of the discussions regarding time and the use of the self-management approach was the stated action when time pressures became excessive. As Kathy states;

“I guess for me, and probably for most physios, [this self-management approach] isn’t the highest priority in terms of what we need to get done in an assessment and treatment”.

Kathy works in the acute setting and others, such as Martha noted that in this environment, the timing for promoting self-management was perhaps inappropriate given the competing

pressures. However others, such as Milly who work in the community, also found that the time to really engage with self-management created a professional tension and as such would limit her “self-management time” to focus more on movement facilitation, a more traditional professional role.

Time was also a general concern in relation to the overall resourcing of rehabilitation. The increasing focus on criteria and targets, alongside reduction in staffing levels resulted in insufficient therapy time to develop the self-management approaches. Comments such as “there’s not enough staff capacity” (Milly), “we can’t sustain and always have input” (Rose) and “you know with the current trend we can’t see the people until they reach their goal... we can’t see them” (Saatvick) were frequent and accompanied by some frustration.

Discussion

The therapists in these interviews all recognised the limitations of a stroke rehabilitation model that promotes professional dictatorship, however benign that was. They equally articulated how the self-management training and use of the resources facilitated a more inclusive and shared approach to rehabilitation and self-management in the longer term. This was an aim they both aspired to and felt was a requirement in the economics and philosophy of the modern NHS. However, there were numerous perceived obstacles in achieving this partnership which fall under three broad categories; professional models, practices and expectations; institutional demands and time; and the perceived wishes of the stroke survivors themselves.

These three categories share much with studies on self-management in general, but also highlight key differences which are perhaps specific to stroke and potentially other acute onset neurological conditions. For example, Kennedy et al. [22] discuss the need for a systems approach to self-management, one that includes the triad of patient, professional and organisation and such a framework appears appropriate in this case. There is further support for specific sections of this triad. Rogers et al. [33], for example indicate that patients may not always wish to take the responsibility of self-management, which may support the assertions of the therapists in this study. However, much more information is needed to understand the factors that facilitate or inhibit this in individuals, a point raised by Todres et al. [34] in their discussion of the humanization of healthcare. In the case of stroke it is unclear how the initial acute medicalisation of the condition, as described by the participants, potentially forces a position of dependency or passivity which later discourages the adoption of more self-generated strategies. Such information is essential if questions regarding the appropriate timing of self-management are to be addressed [35] alongside the development of effective strategies within the acute environment. Another concern is the complex nature of stroke itself and specifically the decision-making capacity of some individuals post stroke. Critiquing clinicians as wishing to maintain control, as demonstrated in both these narratives and the literature may well be appropriate [8]. But when confronted with stroke survivors who may well cause both themselves and others harm through poor decision making, as discussed by Joan, the rhetoric of “ultimate patient control” is severely tested, as noted in previous literature [36,37]. This is of course not applicable to all or indeed the majority of stroke survivors. However, it does pose the question of who controls the initiating, monitoring and ownership of self-management approaches when this potential is inherent in the diagnostic category itself. A further discussion on the complex nature of stroke as a condition is developed elsewhere [19].

With regards to the professional models, practices and expectations, much was echoed from the previous research on

goal setting [28,38]. Similarly, Bury [39] is forthright in his sentiment on how professionals consider partnership working stating that “whilst it is clear that such language is more than just superficial rhetoric, how much more is less clear” (p. 53). This research would indicate that the stroke therapists involved have a clear understanding of the limitations of their previous dictatorial position and also the means by which a more equal and democratic system could develop. However, the complex discussions regarding balancing of risks; real or perceived, to the individual or professional standing, touch on fertile ground for further research on clinical decision making and the distribution of control. A further complexity suggested in this study is the differing interprofessional positions. Some factors, such as the fear of too much risk and equally being seen to be “copping out” were shared amongst the professional groups interviewed. However, other influences appeared to be more specifically related to individual professions. Of note, here was the stated requirement to maintain professional control over current and potential future impairments, as expressed by the physiotherapists. These differences highlight the need to investigate how self-management strategies are integrated into specific professional models of practice which may or may not be shared by other team members. If self-management is designed and promoted as most effective within a team approach, the differences within the team and their genesis need to be considered alongside the shared experiences.

The final part of the triad, that of time and organisational needs, is a complex category. It was apparent that institutional demands for measurements, discharge outcomes and time restrictions on therapy sessions were constraints to the delivery of self-management strategies. Such limitations have been noted elsewhere [33]. However, what is less clear is whether these are fixed organisational constraints or more factors which encourage a slippage back into traditional models of practice. As such, the interplay between professional models and organisational constraints needs some unpicking. For example, when discussing their response to the time constraints participants referred to therapy time and self-management time, the latter of which was sacrificed when time conflicts arose. Such language may indicate that self-management is still conceived as an additional extra rather than an integrated and essential aspect of successful therapy. Such an observation should not undermine the considerable pressures that are placed on therapists to “deliver” by their employing institution. Rather, it raises the point that attribution of constraints in practice change need to be carefully dissected and considered. This and the other areas identified indicate fruitful areas of future research which would further enhance our understanding of the utility of self-management approaches in practice.

It is accepted that the data presented in this paper draws from the expressed experience of therapists rather than their observed use of this self-management approach and therefore has a number of resultant limitations. Furthermore, as indicated earlier, it in no way reflects the experiences of the stroke survivors themselves. However, rich narratives from experienced therapists facilitate an insight into the complexities of utilising self-management post stroke which has been previously undeveloped in the literature. As such, the themes presented add to the current debates on professional roles within self-management approaches and highlight several areas of further research needs.

Conclusion

This exploration of the experience and views of stroke therapists in using a self-management approach post stroke has illustrated both the desire for a more participatory approach to rehabilitation,

but also the complexities in delivering it effectively highlighting several obstacles. If self-management is an appropriate model to develop in post-stroke pathways, and if therapists who work in the stroke pathway are suitable facilitators in this process, then serious consideration must be given to how and if these obstacles can be overcome.

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Declaration of interest

The authors report no declarations of interest.

References

- Barlow J, Wright C, Sheasby J, et al. Self-management approaches for people with chronic conditions: a review. *Patient Educ Counselling* 2002;48:177–87.
- Lorig K. Self-management in chronic illness. A model for the future. *Generations* 1993;17:11–15.
- Lorig K, Sobel D, Stewart A, et al. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized controlled trial. *Med Care* 1999;37:5–14.
- Griffiths C, Foster G, Ramsay J, et al. How effective are expert patient (lay led) education programmes for chronic disease? *BMJ* 2007;334:1254–6.
- De Silva D. *Helping People help themselves*. London: The Health Foundation; 2011.
- Taylor S, Bury M. Chronic Illness, expert patients and care transition. *Sociol Health Illness* 2007;29:27–45.
- Ch'Ng A, French D, Maclean N. Coping with the challenges of recovery from stroke. *J Health Psychol* 2008;13:1136–46.
- Wilson P, Kendall S, Brook F. The expert patients programme: a paradox of patient empowerment: medical dominance. *Health Social Care Commun* 2007;15:426–38.
- National Audit Office. *Reducing brain damage: faster access to better stroke care*. London: Stationary Office; 2005.
- Cott C, Wiles R, Devitt R. Continuity, transition and participation: preparing clients for life in the community post stroke. *Disabil Rehabil* 2007;29:1566–74.
- Ellis-Hill C, Robison J, Wiles R, et al. Going home to get on with life: patients and carers experiences of being discharged from hospital following a stroke. *Disabil Rehabil* 2009;31:61–72.
- Kendall E, Catalano T, Kuipers P, et al. Recovery following stroke: the role of self-management education. *Social Sci Med* 2007;64:735–46.
- Jones F. Strategies to enhance chronic disease self-management: how can we apply this to stroke? *Disabil Rehabil* 2006;28:841–7.
- Wolfe C. *Top ten priorities for stroke services research*. London: Kings College; 2008.
- Department of Health. *A new ambition for stroke: a consultation on a national strategy*. London: The Stationary Office; 2007.
- Intercollegiate Stroke Working Party. *National clinical guideline for stroke*. London: Royal College of Physicians; 2012.
- Hirsch R, Williams B, Jones A, Manns P. Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury. *Disabil Rehabil* 2011;33:1136–46.
- Jones F, Riazi A. Self-efficacy and self-management after stroke: a systematic review. *Disabil Rehabil* 2011;33:797–810.
- Jones F, Riazi A, Norris M. Self-management after stroke: time for some more questions? *Disabil Rehabil* 2013;35:257–64.
- Jones F, Lennon S. A new stroke self-management programme: preliminary analysis of training for practitioners. *Int J Stroke* 2009;4(s2):23.
- Jones F, Mandy A, Partridge C. Changing self-efficacy in individuals following a first time stroke: a preliminary study of novel self-management intervention. *Clin Rehabil* 2009;23:522–33.
- Kennedy A, Rogers A, Bower P. Support for self care for patients with chronic disease. *BMJ* 2007;335:968–70.
- Gately C, Rogers A, Sanders C. Re-thinking the relationship between long-term condition self-management education and the utilisation of health services. *Social Sci Med* 2007;66:934–45.
- Kennedy A, Gask L, Rogers A. Training professionals to engage with and promote self-management. *Health Educ Res* 2005;20:567–78.
- Wetzels R, Geest T, Wensing M. GP's views on involvement of older patients: an European qualitative study. *Patient Educ Counselling* 2004;53:183–8.
- Barnard R, Cruice M, Playford E. Strategies used in the pursuit of achievability during goal setting in rehabilitation. *Qual Health Res* 2010;20:239–50.
- Bloom L, Lapierre N, Wilson K, et al. Concordance in Goal setting between patients with multiple sclerosis and their rehabilitation team. *Am J Phys Med Rehabil* 2006;85:807–13.
- Levack W, Dean S, Siegert R, McPherson K. Navigating patient-centred goal setting in inpatient stroke rehabilitation: how clinicians control the process to meet perceived professional responsibilities. *Patient Educ Counseling* 2011;85:206–13.
- Parry R. Communication during goal-setting in physiotherapy treatment sessions. *Clin Rehabil* 2004;18:668–82.
- Denzin N, Lincoln Y. Introduction: the discipline: practice of qualitative research. In: Denzin N, Lincoln Y, eds. *Collecting and interpreting qualitative materials*. 2nd ed. California: Sage Publications; 2003.
- Miller W, Crabtree B. Depth interviewing. In: Crabtree B, Miller W, eds. *Doing qualitative research*. 2nd ed. CA: Sage Publications Inc.; 1999.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Res Psychol* 2006;3:77–101.
- Rogers A, Kennedy A, Nelson E, Robinson A. Uncovering the limits of patient-centredness: implementing a self-management trial for chronic illness. *Qual Health Res* 2005;15:224–39.
- Todres L, Galvin K, Holloway I. The humanization of healthcare: a value framework for qualitative research. *Int J Qual Studies Health Well-being* 2009;4:68–77.
- Jones F, Livingstone E, Hawkes L. 'Getting the balance between encouragement and taking over' – reflections on using a new stroke self-management programme. *Physiother Res Int* 2012; doi:10.1002/pri.1531. Accepted in press.
- Calne R, Calne J, Calne S. Patient choice or patient abandoned? *J Eval Clin Practice* 2009;15:996–9.
- Kilbride C, Allison R, Evans P. What do stroke survivors think about the evidence based stroke care they receive? Learning from insights at the 'periphery'. *Int J Person Centred Med* 2011;1:254–9.
- Rosewilliam S, Roskell C, Pandyan A. A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation. *Clin Rehabil* 2011;25:501–14.
- Bury M. Researching patient-professional interactions. *J Health Serv Res Policy* 2004;9:48–54.