This is the peer reviewed author accepted manuscript (post print) version of a published work that appeared in final form in:

Luker, Julie, Lynch, Elizabeth, Bernhardsson, Susanne, Bennett, Leanne, Bernhardt, Julie 2015 'Stroke Survivors' Experiences of Physical Rehabilitation: A Systematic Review of Qualitative Studies', *Archives of Physical Medicine and Rehabilitation*, vol. 96, no. 9, pp. 1698-1708

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Accepted Manuscript



Stroke survivors' experiences of physical rehabilitation: a systematic review of qualitative studies

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PII: S0003-9993(15)00290-7

DOI: 10.1016/j.apmr.2015.03.017

Reference: YAPMR 56155

To appear in: *ARCHIVES OF PHYSICAL MEDICINE AND REHABILITATION*

Received Date: 16 December 2014

Revised Date: 17 March 2015

Accepted Date: 28 March 2015

Please cite this article as: Luker J, Lynch E, Bernhardsson S, Bennett L, Bernhardt J, Stroke survivors' experiences of physical rehabilitation: a systematic review of qualitative studies, *ARCHIVES OF PHYSICAL MEDICINE AND REHABILITATION* (2015), doi: 10.1016/j.apmr.2015.03.017.

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Title page

Title: Stroke survivors' experiences of physical rehabilitation: a systematic review of qualitative studies

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Acknowledgements

The authors thank and acknowledge Ross Kennett for his assistance with data extraction for this study.

Funding acknowledgements: Julie Luker holds an NHMRC Early Career Fellowship; Elizabeth Lynch is undertaking a PhD funded by an Australian Postgraduates Award; Julie Bernhardt holds an NHMRC Established Career Fellowship.

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Presentation acknowledgments: Part of this material was presented at the Australasian

Nursing & Allied Health Stroke Conference, Sydney in 2014

Conflicts of interest: The work of one author (Leanne Bennett) is an included primary study in this review.

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Title: Stroke survivors' experiences of physical rehabilitation: a systematic review of qualitative studies

ABSTRACT

Objective: The objective of this systematic review of qualitative studies was to report and synthesise the perspectives, experiences and preferences of stroke survivors undertaking inpatient physical rehabilitation.

Data Sources: MEDLINE, CINAHL, Embase and PsycINFO were searched from database inception to 2014. Reference lists of relevant publications were searched. All languages were included.

Study Selection and Appraisal: Qualitative studies reporting stroke survivors' experiences of inpatient stroke rehabilitation were selected independently by two reviewers. The search yielded 3039 records; 95 full text publications were assessed for eligibility and 32 documents (31 studies) were finally included. Comprehensiveness and explicit reporting were assessed independently by two reviewers using the COREQ framework. Discrepancies were resolved by consensus.

Data Extraction: Data regarding characteristics of the included studies were extracted by one reviewer, tabled, and checked for accuracy by another reviewer. All text reported in studies' results sections were entered into qualitative data management software for analysis.

Data Synthesis: Extracted texts were inductively coded and analysed in three phases using thematic synthesis. Nine interrelated analytical themes, with descriptive subthemes, were identified that related to issues of importance to stroke survivors: physical activity is valued; bored and alone; patient-centred therapy; recreation is also rehabilitation; dependency and

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lack of control; fostering autonomy; power of communication and information; motivation needs nurturing; fatigue can overwhelm.

Conclusions: The thematic synthesis provides new insights into stroke survivors' experiences of inpatient rehabilitation. Negative experiences were reported in all studies and include disempowerment, boredom, and frustration. Rehabilitation could be improved by increasing activity within formal therapy and in free time, fostering patients' autonomy through genuinely patient-centred care, and more effective communication and information. Future stroke rehabilitation research should take into account the experiences and preferences of stroke survivors.

Key words: stroke, rehabilitation, qualitative research, activity, patient preference

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INTRODUCTION

Evidence from high-quality research has shown positive effects of physical rehabilitation on the recovery of function and mobility after stroke (1), but the superiority of one approach or intervention over another is not clear. In cases where several approaches or treatment methods of similar effectiveness exist, patient preferences should be integral to clinical decision making and the development of rehabilitation interventions (2, 3).

Clinical guidelines in Australia direct stroke rehabilitation to be 'a proactive, person-centred and goal oriented process' and place patients and their families at the core of the process (4). Currently however, there is little collective knowledge about stroke survivors' experiences of, and preferences for, different models of physical activity and rehabilitation. This is a concern because a central tenet of evidence-based practice is the consideration of patient preferences, together with best evidence treatment (5).

Stroke survivors participating in inpatient rehabilitation currently spend large proportions of their day alone and inactive (6, 7). Many researchers are interested in increasing physical rehabilitation and activity for these people through different models of care and therapy formats such as 7-day services (8, 9), circuit exercise groups (10), enriched environments (11), and via adjunct therapies such as robotics (12), virtual reality and games (13). Many of these initiatives are driven by clinicians and researchers who aim to improve post-stroke recovery by providing greater opportunity for task practice and patient engagement (8-11, 14), however the patients' voice is not currently well represented.

All authors in this systematic review are physiotherapists and researchers interested in evidence-based practices that meet the needs of healthcare consumers. The group has particular interests in stroke care and models of rehabilitation to optimise functional recovery.

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The aim of this systematic review was to synthesise and report the perspectives, experiences and preferences of stroke survivors undergoing physical rehabilitation in inpatient settings with a view to generating new insights for practice improvements and to suggest new research directions. Given the complex nature of the rehabilitation process, we elected to focus our review on physical rehabilitation. We particularly wanted to understand what was important to stroke survivors regarding:

- Person-centred and/or goal orientated rehabilitation
- Physical activity during therapy and in their free time

METHODS

We followed the ENTREQ statement to enhance transparency in reporting the stages of our qualitative synthesis (15). Thematic synthesis methodology, as described by Thomas and Harden (2008) (16) was employed, providing the additional benefit of analytical theme development beyond the primary studies, to potentially inform initiatives to improve stroke rehabilitation. The review protocol was not registered with PROSPERO.

Criteria for considering studies for this review

Types of studies: Qualitative studies were included, where data had been collected via interviews, focus groups, or questionnaires that allowed free text. No language or publication date constraints were applied.

Types of participants: Studies were included if data were obtained directly from adults (18 years and older) with stroke who underwent physical rehabilitation in acute or post-acute

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inpatient settings. There were no other age, gender, comorbidity or discharge destination restrictions. Included studies gave some consideration to physical rehabilitation or physical activity either on its own, or included within a rehabilitation package of care.

Exclusion criteria:

- Mixed methods studies where the qualitative data could not be separated out.
- Studies with mixed participant groups or various settings, where inpatient stroke survivor data could not be separated out.

In this review stroke rehabilitation was defined as:

…a dynamic, progressive, goal orientated process aimed at enabling a person with impairment to reach their optimal physical, cognitive, emotional, communicative and/or social functional level (17).

Physical stroke rehabilitation was defined by the authors as:

Interventions, rehabilitation environments, programs or devices that promote bodily activity with the aim of improving a person's independence in mobility or activities of daily living.

Search methods

A pre-planned, comprehensive systematic search of the literature sought to identify all relevant studies. Electronic database searches were conducted in MEDLINE, CINAHL, PsycINFO, and Embase from the inception of the databases to February 2014. We consulted a research librarian to help develop a search string on MEDLINE. This was adapted for the other databases and included text words and Subject Headings terms for stroke, rehabilitation, physical activity and qualitative methodologies (example MEDLINE search in Online Appendix 1). Reference lists of relevant studies and reviews were hand searched (pearled) to identify additional potential studies. Grey literature sources were not searched, however two

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105 potentially relevant, freely available theses that were known to the authors were added to the
106 theses found during database searches, and considered for inclusion.

107 **Identification of studies**

108 One reviewer (JL) screened out obviously irrelevant titles. Two authors (JL, EL) reviewed
109 the titles and abstracts and rejected those that they agreed did not meet the inclusion criteria.
110 Full articles of potentially relevant studies were retrieved for detailed two-person review and
111 final selection (JL, EL, LB).

112 **Critical appraisal of selected papers**

113 Two reviewers (JL, EL, LB, SB) independently assessed each study for comprehensive and
114 explicit reporting, discussed differences and reached consensus on scoring.

115 *Exclusion based on quality:* To assist the internal validity of this review, included studies had
116 to meet at least two of the four quality reporting criteria developed by Carroll and colleagues
117 regarding study design, selection of participants, methods of data collection and analysis (18).

118 *Assessing comprehensiveness of reporting*: To provide details of quality, included studies
119 were assessed against the COREQ criteria (19). Findings were presented in a table for easy
120 comparison between studies.

121 **Data extraction**

122 Data on the characteristics of included studies were extracted by one researcher (JL) and
123 checked for accuracy by a research assistant. Extracted fields, considered to be most relevant
124 to the review's aims, were tabled and included reference details, aim of study, sample size,
125 participant characteristics, methodological approach, participants other than patients, data

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collection method, time since stroke, and country (Table 1). Data were also extracted for all text presented as 'results' or 'findings'.

Thematic synthesis analysis

Using the thematic synthesis approach coding and thematic development were conducted in three stages, each involving independent consideration by two or more researchers, discussions and consensus (16). Extracted data from the results of all included studies were entered verbatim into NVivo 10 (QRS International Pty Ltd) for coding and data management. In the first stage of analysis, codes were inductively derived from the data in an iterative process of attributing codes to small sections of meaning within the text, moving back and forward across studies and constantly comparing data and codes. In the second stage, codes were grouped into logical and meaningful clusters in a hierarchical tree structure, forming descriptive themes and sub-themes. Finally, analytical themes relating to the aims of the review were developed to provide a larger meaning, extending beyond the original individual studies, and delivering evidence-informed recommendations for inpatient stroke rehabilitation. The descriptive and analytical themes were tabulated and their labels revised by two researchers (JL, SB), reviewed by the other researchers, and a final version was agreed.

RESULTS

Study selection results

The systematic search yielded 3039 records after removal of duplicates. The selection process resulted in the inclusion of 32 documents representing 31 separate studies (see Figure 1).

<< Figure 1 about here >>

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150 **Characteristics of included studies**

151 The 32 documents were comprised of 27 published journal articles, one article in press, and
152 four freely available theses. One article (20) was published in Swedish and was translated
153 prior to analysis. Study details are shown in Table 1. Of note, qualitative data were
154 contributed by 560 stroke survivors in ten different countries, enhancing the transferability
155 and applicability of the review's findings. Studies were published between 1994 and 2014,
156 with most (26/32) published after 2000. The number of participants varied between 3 and 79
157 patients, and most (23/32) had less than 20 participants. Included studies had a primary focus
158 on one or more topics, including stroke survivors' overall experience of stroke (n=8), their
159 experience and preferences for rehabilitation (n=12), innovative rehabilitation models or
160 interventions (n=4), self-care or autonomy during rehabilitation (n=5), recreation during
161 rehabilitation (n=2), goal setting (n=2), motivation (n=1), and stroke service development
162 (n=1).

163 << Table 1 about here >>

164

165 **Comprehensiveness of reporting**

166 No papers were excluded on the basis of insufficient quality, when assessed against the four
167 core quality reporting criteria (18).

168 Reporting of methods, contextual details and findings in included articles was of variable
169 quality, with authors reporting between 8 and 31 of the total 32 items on the COREQ
170 checklist. A third of the studies met less than 50% of the COREQ criteria. Most frequently
171 reported items were sample size (described in 32 studies/100%), sample description
172 (29/91%), consistent data and findings (28/88%), and clarity of major themes (28/88%).

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Least reported items were interviewer characteristics and return of transcripts to participants, described by 3 (9%) of the studies. Details are reported in Online Appendix 2.

Synthesis

Coding of the primary studies resulted in 94 preliminary codes, reflecting the meaning and content of the underlying text. The codes were grouped into 34 descriptive themes (shown in italics below), from which nine interrelated analytical themes were developed: Physical activity is valued; bored and alone; patient-centred therapy; recreation is also rehabilitation; dependency and lack of control; fostering autonomy; power of communication and information; motivation needs nurturing; fatigue can overwhelm. The source studies for the analytical themes are cited in the results text, and in Online Appendix 3 for the descriptive themes. Selected illustrative quotations from the reviewed studies are listed in Online Appendix 4.

Overlapping themes and relationships between themes were noted, painting a complex picture of participants' experiences of inpatient rehabilitation.

Physical activity is valued

The first analytical theme was derived from 26 primary studies and comprised nine descriptive themes and sub-themes (20-26, 28, 30-33, 36-46, 48-50).

Physical activity was highly valued by participants undertaking inpatient rehabilitation and there was a belief that *'more is better'* for their recovery. *Walking and mobility were especially important* forms of physical activity for participants. To maximise recovery, participants *wanted more training and intensity* in their physical rehabilitation sessions. Physical activities and functional recovery were so important to many participants that they

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wanted to *practice outside formal therapy* sessions. Rehabilitation environments were often unable to accommodate this, and participants perceived a *lack of practice opportunities*. Several participants spoke of *practicing with non-clinicians* in their free time, such as with visiting family members or with other patients.

When to work and rest was a descriptive theme underpinned by three studies. Participants were able to accept *innovative dosage models* of rehabilitation designed to increase their therapy time (such as circuit classes, or 7 day services). However, they expressed personal preferences regarding timing and format of therapies, and several participants recognised that they also *needed a break*.

Bored and alone

One reason for wanting more activity was that participants commonly reported *feeling bored* and/or *feeling alone* during their inpatient stay (20, 23, 28, 31, 38-42, 46, 48). Patients' free time was described as 'depressingly unstimulating' (39) , difficult for them to deal with and had the potential to negatively impact on mood and motivation (themes below). In 10 studies, participants spoke of *needing more things to do* in their free time. Although most participants raised concerns of boredom, in two studies single participants *denied boredom* problems.

Patient-centred therapy

Unsurprisingly patient-centred therapy was a strong theme in included studies (20-26, 29-39, 43-47, 49-51), and it was contributed to by 18 descriptive sub-themes. *Meaningful rehabilitation* was an important sub-theme encompassing participants' desire to understand the purpose of therapy and how it would help them achieve their goals. Participants wanted to work on *meaningful tasks* in therapy, and appreciated practicing 'real proper life chores' (23). Walking and mobility were central issues for many participants who reported the *importance*

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of mobility therapy for them. *Boring or meaningless therapy* was described in seven studies, with participants particularly critical of practicing *menial tasks* which seemed irrelevant to their recovery. Participants wanted *enjoyment in therapy*, and *variety and innovations* such as Wii computer games or circuit classes, which suited many participants, but not all.

An important theme that contributed to engagement in therapy was the *importance of goal setting*. *Patient-generated goals* were important to participants and they were particularly happy when *collaborative goal setting* took place between themselves and members of the clinical team. Participants often needed to *set their goals high*, and these frequently *needed to be participatory goals*, such as 'to play golf again' (33). Participants reported that *individualised therapy plans* should be closely linked to their personal goals. Participants enjoyed active involvement in translating goals into therapy plans, which directly facilitated engagement in therapy and also motivation. Unfortunately, numerous studies reported that *goals were not directing therapy* for participants, potentially causing *conflict* between participants and the clinical team and impacting negatively on autonomy and motivation.

Physical rehabilitation therapy could be *difficult or stressful* for some participants, including reports of pain and difficulty attending to task. Participants were willing to tolerate difficulties when they perceived therapy as a *means to an end*. Two studies reported *family involvement was lacking* in therapy.

Recreation is also rehabilitation

In 15 studies participants reported wanting more recreational and social activity in their free time (20, 23, 25, 28, 31, 36-39, 41, 42, 44, 45, 48, 49). This is linked closely to the theme of *bored and alone* above. A desire for *more recreational activities* was expressed, and specific examples included access to reading materials, electronic games, exercise equipment, and crafts. Participants considered that *recreation is therapeutic*, and not only counteracted the

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boredom of the rehabilitation environment, but also actively contributed to stroke recovery. *Social opportunities* were considered important to lessen the burden of loneliness, and participants valued social activities with other patients, staff and family visitors.

Dependency and lack of control

Experiencing a stroke suddenly moved people to a state of dependency, where they lacked control over their daily lives (21-25, 27-31, 33, 34, 37-41, 44-46, 48-50). Seven studies reported the *value of independence* and autonomy to participants. *Fear, anxiety and frustration* were experienced by many during rehabilitation, and in particular, *frustration came from a lack of control*. *Fearing activity* was reported in two studies, due to the lack of physical control some people had over their bodies, who then feared injury. Five studies reported participants' extreme distress at losing control over their lives, coupled with boredom and examples of disrespectful and dehumanising treatment, describing *rehabilitation as purgatory*. Patients with poor English proficiency experienced additional levels of disadvantage and dependency.

Disempowering staff attitudes had a strong negative influence for many. These included authoritarian attitudes and decision making processes, restrictions on participants' acts of independence or access to information, and dismissive responses to participants' goals. *Organisational barriers to autonomy*, such as inflexible rules and a lack of opportunities for participants to make choices, also contributed to participants' dependency.

Fostering autonomy

Participants reported that rehabilitation settings could assist them to regain control of their lives (20, 23, 24, 27, 29-34, 37-46, 48-50). For many, *reclaiming autonomy marks recovery*, because the recovery of functional abilities facilitated recovery of some aspects of control.

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Just as staff attitudes could be disempowering, many studies reported that participants could have *empowering relationships with staff* that helped to foster their autonomy. This could involve the development of *trust in staff*, but did not necessarily mean a one-sided power relationship. An increasingly *collaborative and collegial relationship* and communication style between the treating team and patients was associated with stroke recovery.

To reduce dependency and encourage independence, staff needed to be mindful to *balance the help provided*. Participants varied in the amount of help they wanted from staff, and this could change over time. Many wanted *more room for trial and error* while others wanted *more supervision and help* to develop confidence, highlighting the importance of individualised physical activity planning.

Power of communication and information

Good information and communication between participants and the treating team was essential to a good rehabilitation experience (22, 24-27, 29-31, 33-41, 43-46, 49, 50) These interactions could directly *foster autonomy*. *Good communication was empowering* if there was a timely, consistent flow of two-way communication between the treating team and the patients and their families. Participants especially wanted information to help them understand stroke recovery and the rehabilitation process.

Poor communication is disempowering and had the potential to diminish autonomy, confidence and motivation. *Mixed messages* or conflicting information from staff were particularly confusing and distressing to participants. Avoidable *misunderstandings* commonly reported included participants' beliefs that functional recovery would occur if they just waited and rested, and not understanding that practicing self-care was part of rehabilitation. *Frustration from a lack of understanding* was common and particularly overwhelming for participants with poor English proficiency.

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Motivation needs nurturing

Rather than a static quality, participants considered that their motivation toward physical rehabilitation was a fluid condition that required nurturing and could be affected positively or negatively by the treating team (20-34, 37-39, 41-44, 46, 48-50). *Hope* was also a fragile feature of stroke recovery, and contributed to motivation during rehabilitation. Motivation could be nurtured by *encouragement and support* and this could either come from staff, from other patients and/ or from family. *Humour* was important to many participants, and was recognised as a way of maintaining a positive outlook during difficult times. Participants did not mind *being pushed* to work harder during rehabilitation and recognised that this was sometimes helpful when their motivation was lagging. *Noticing progress* and recognising the links between rehabilitation and progress towards goal achievement were very motivating.

Participants recognised that *motivation can be undermined* and that periods of *low motivation can happen* during rehabilitation. Patients experiencing low motivation were often those who felt they were making slow progress or those experiencing low mood.

Fatigue can overwhelm

Stroke-related fatigue, reported by many participants, could overwhelm their ambitions to be more active or independent (20, 22, 23, 25, 28, 30, 34, 42, 46). This was a dominant experience for some participants: '…it was exhausting for me to just think' (34). For those affected by it, fatigue influenced every other analytical theme in this review. Its impact highlights the importance of individualising physical activity during rehabilitation, to effectively work within and around the limitations of fatigue and to provide suitable education and support about the phenomenon.

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DISCUSSION

While other qualitative systematic reviews have focused on the experience of living with stroke (52) and psychosocial processes in stroke rehabilitation (53), this is the first known study to synthesise the perspectives, experiences and preferences of stroke survivors undertaking physical rehabilitation.

Global efforts to find new evidence-based treatments to improve stroke recovery are considerable. Three recent stroke Cochrane reviews of physical interventions (1), exercise (54) and treadmill training (55), which together include over 185 randomised controlled trials of 15,247 patients, illustrate the extent of interest in this field. Despite these efforts, the best interventions to enhance the physical recovery of patients remain unclear. The results of this systematic review, which includes views from 560 stroke survivors, highlights the need for deeper consideration of how we engage with stroke survivors in developing and implementing treatment programs, and the importance of partnership. The review results emphasise the need to consider not just face-to-face time spent with patients in inpatient rehabilitation, but the broader potential impact of the physical and regulatory environment of hospitals on recovery.

Complexity in person-centred rehabilitation

The difficulties for people recovering from stroke are reflected in the findings of this review. Many of the analytical themes that emerged in the synthesis are closely interrelated or overlapping, emphasizing the complexity of the stroke recovery process. For example, *motivation* is a theme that was linked to many others, such as *bored and alone*, *fatigue*, *dependency and lack of control*, the *power of communication and information*, and most of the sub-themes within *patient-centred therapy.* This illustrates the complexity of concepts

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such as motivation during rehabilitation and helps to explain why it can be challenging for staff to assist patients who appear to be poorly motivated.

Activity during rehabilitation

The findings related to physical activity demonstrate that stroke survivors are frequently bored and would like more activity and more intense training and practice, both within and outside of formal therapy sessions. Quantitative systematic reviews in which different types of physical stroke interventions are pooled, clearly show that more is better (56, 57), just as the patients in this study believe. Therapists have a responsibility to promote greater practice and need to find ways to achieve this with often limited resources. Our review found that this additional activity could potentially be with non-clinicians such as visiting family or other patients. These preferences raise a number of issues.

Autonomy versus risk

Promoting out of therapy practice with the non-expert requires some fundamental changes to the current risk-averse hospital policies, professionals' attitudes and possibly the physical environment itself. The concept of allowing patients the autonomy to practice without the supervision of a trained professional requires a shift in thinking to a position that patients have the right to take risks. Falls in hospital are common (58) and falls with injury can slow the recovery process. However, for some patients and their families, the inability to exercise choice and experience autonomy negatively influences their recovery, as this review highlights. Increasingly, attention is being paid to models of informed consent and shared decision making that respect patients' choice, values and preferences (3). Decision making can be shared, even for patients with cognitive or communication difficulties, through engaging with families and carers.

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However, even if we could overcome the legal and procedural concerns associated with independent training for those at risk of injury, it remains to address the attitudinal barriers from the therapists themselves. The frequently held belief that training without a professional may jeopardise recovery has no scientific basis, and can be detrimental to not only activity levels but also to patients' self-efficacy and confidence. In contrast, allowing patients the option of practicing independently could result in more training, less boredom, more engaged patients, and possibly shorter lengths of hospital stay.

Patient-centred rehabilitation

According to the stroke survivors in this review, the additional practice they seek must be meaningful. In some cases the problem may simply be tasks for which the explanation of the biological basis of the therapy or the training intent is inadequate. In these cases simple, repetitive tasks may be viewed as *menial* but may have therapeutic value. It is here that good and consistent information, communication and collaborative goal setting, as identified in this review, play important roles.

Goal setting in stroke rehabilitation has been identified in this review and in previous research (59), as being important for recovery and a positive influence on patients' perceptions of self-care ability and engagement in rehabilitation. Despite almost universal approval for the concept of collaborative goal setting, the practice is not widespread (60). There are a number of poorly understood barriers to goal setting, such as ineffective collaboration and communication between patients and professionals that need further

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research (59). Collaborative goal setting takes time, but it also requires therapists to be willing to allow patient choice and autonomy.

The physical environment of rehabilitation hospitals has a role to play in a number of themes that emerged from this review, and yet it has received limited attention in the literature. Access to communal spaces, such as lounge and dining rooms, may help reduce boredom and feelings of 'aloneness'. Improved social engagement and opportunity for cognitive stimulation may facilitate recovery, as demonstrated in animal stroke models of 'environmental enrichment' (61). The ward and therapy area layout will also impact on the opportunity for patient autonomy and independent practice.

Study strengths and limitations

Strengths of this review include the rigorous methodology and comprehensive sampling used, the large combined sample (560 stroke survivors) and the international spread of studies (10 countries). The use of thematic synthesis enabled us to stay close to the data from the primary studies and thereby be empirically faithful to the included cases (16), providing explicit and transparent links between our conclusions and the text of the primary studies.

We highlight the variable quality of reporting in the included studies, and show that a third of studies met less than half of the COREQ criteria. Although no studies needed to be excluded based on our chosen minimum quality criteria (18), poor reporting in the primary studies may affect the credibility and dependability of our findings. The inclusion criteria of the primary studies also varied and there is a gap in primary data collected from stroke survivors who

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suffer from significant cognitive or communication impairments. This may introduce a bias of the findings in favour of survivors in the less severe stroke category, which may affect the transferability of the findings.

Areas for future research

In addition to identifying issues of importance to stroke survivors during rehabilitation, this review uncovered several areas where evidence gaps exist. Research is required to better understand:

- Interventions to facilitate additional activity and practice that do not rely on direct professional supervision
- Barriers to collaborative goal setting during stroke rehabilitation
- How hospital policies and practices, models of care, and hospital environments could be modified to improve the rehabilitation experience for stroke survivors.

Conclusions

The thematic synthesis in this review provides new and compelling insights into stroke survivors' experiences of inpatient physical rehabilitation. Negative experiences are reported in all 31 studies and include disempowerment, boredom, frustration and personal goals not reflected in therapy. Stroke rehabilitation could be improved by increasing activity both within formal therapy and in free time, fostering patients' autonomy through genuinely patient-centred care, and more effective communication and information. Future stroke rehabilitation research should take into account the experiences and preferences of stroke survivors.

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Table 1 Characteristics of included studies

First author, year, country	Participants n= [ages]	Methodological approach	Data collection	Other participants	Time of data collection	Aim
Alaszewski 2004 (21) UK	31 [38–89 yrs]	Naturalistic	Interviews, focus groups, diaries	Health professionals	1 yr post-stroke	To explore with stroke survivors, carers and professionals, the impact of stroke and the process of recovery and rehabilitation.
Bendz 2003 (22) Sweden	15 [<65yrs]	Phenomenography	Interviews, health professionals records	Health professionals	3,6 & 12 mths post-stroke	To highlight divergent ways in which a group of people hit by a stroke and their health care professionals understand the implications of having a stroke.
Bennett 2013 (23) Australia	11 [51–89yrs]	not stated	Semi-structured interviews	nil	<6 mths post-stroke	To explore stroke survivors' perspectives of two novel models of inpatient physiotherapy which provide increased therapy dosage: circuit class therapy and

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						7 day a week usual care. (Thesis)
Briggs 2012 (24) USA	10 [49–66yrs]	Phenomenology	Semi-structured interviews	nil	2 & 6 wks into outpatient rehabilitation program	To examine participants perspectives on the lived experience of stroke and the effectiveness of inpatient rehabilitation. (Thesis)
Celinder 2012 (25) Denmark	9 [51–95yrs]	Not stated	Semi-structured interviews, field notes, observations	nil	<46 days post-stroke	To explore stroke patients' experiences with Wii Sports as a supplement to conventional occupational therapy in a controlled hospital setting.
Clark 2000 (26) Australia	60 [mean 70.9 SD 10.1yrs]	Ethnography	Structured interviews	spouses	Acute admission, rehab admission & discharge, 6mth & 12mths post-discharge	To examine, in a group of stroke patients and their spouses, their perceptions of stroke, information received about it, its management and its rehabilitation
Clark 2005 (27)	13 [mean 75yrs	Symbolic interactionism	Semi-structured interviews	Occupational therapists	Acute admission	To determine the views of stroke survivors and their occupational

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UK	SD 12.2]					therapists regarding the importance of independence in toileting
Cowdell 2003 (28) UK	8 [NA]	Grounded theory	Interviews	nil	Acute admission	To investigate whether patients perceive a need for recreation while undergoing stroke rehabilitation in an acute hospital setting.
Dixon 2007 (29) UK	8 [NA for stroke]	Not stated	Semi-structured interviews	Non-stroke neurological rehabilitation patients	unclear	To explore constructs relevant to self-efficacy in neurological rehabilitation
Folden 1994 (30) USA	20 [65 – 78yrs]	Grounded theory	Structured interviews	nil	2 wks post-stroke & 2-3 wks post-discharge	To explore how stroke survivors manage the multiple deficits produced by a stroke event during the first months after the event
Fryer 2012 (31)	14 [66 – 88yrs]	Constructivist grounded theory	Semi-structured, in-depth interviews	Family members	Average 8wks & 21wks post-	To explore the healthcare experience after stroke for older people with limited

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Australia					discharge	English proficiency. (Thesis)
Galvin 2009 (32) Ireland	10 [56–88 yrs]	Not stated	Semi-structured interviews	physiotherapists	31–89 days post-stroke	To examine the experience of inpatient physiotherapy intervention delivered after stroke from perspectives of the person with stroke and the physiotherapist
Gallagher 2011 (33) Canada	9 [40– 80yrs]	Grounded theory	Semi-structured interviews	nil	After inpatient rehab (3 mths – 4 yrs post-stroke)	To examine the emotional process of stroke recovery, personally experienced by stroke survivors. (Thesis)
Guidetti 2007 (34) USA	5 [< 65yrs]	Phenomenology	Semi-structured interviews	spinal cord injury patients	1-3 mths post-stroke	To identify the characteristics of the lived experience of recapturing self-care after a stroke or a spinal cord injury
Gustafsson 2009 (35) Australia	16 [mean 70yrs]	Not stated	Semi-structured interviews	nil	mean 61 days post-stroke	To explore the goal setting of patients with stroke during inpatient and outpatient rehabilitation

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Jones 2008 (36) UK	28 [age unclear]	Not stated	Semi-structured interviews, focus groups	informal carers	acute admission & post-discharge	To develop local stroke services by involving, in a meaningful way, those affected by stroke
Lewinter 1995 (37) Denmark	19 [36–77yrs]	Not stated	Semi-structured interviews	nil	3 mths – 1 yr post-stroke	To explore patients' experience of rehabilitation in an experimental stroke unit
Lui 1999 (38) Hong Kong	15 [>60yrs]	Ethnography	Semi-structured interviews	nil	1 wk post-stroke, hospital discharge, 1mth post-discharge	To identify the rehabilitation needs of Chinese elderly patients following a stroke
Maclean 2000 (39) UK	22 [38–86 yrs]	Not stated	Semi-structured interviews	nil	inpatient rehab (mean 6 wks post-stroke)	To explore the attitudes and beliefs of stroke patients identified by professionals as having either ‘high’ or ‘low’

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						motivation for rehabilitation
Mangset 2008 (40) Norway	12 [60–87 yrs]	Phenomenology	Semi-structured interviews	nil	1-6 wks and 11-23 wks post-stroke	To identify factors contributing to elderly stroke patients' satisfaction with rehabilitation following stroke
Morris 2007 (41) UK	10 [59–81 yrs]	Not stated	Semi-structured focus groups	Informal carers, health professionals	4 – 18 mths post-stroke	To study the experiences of patients, carers and staff throughout a hospital stroke care pathway
Peiris 2012 (42) Australia	3 [64–78 yrs]	Not stated	In-depth interviews	nil	1 – 3 mths post-stroke	To explore how patients receiving inpatient rehabilitation experience physiotherapy and extra Saturday physiotherapy
Pound 1994 (43) UK	40 [40–87yrs, mean 71.5]		Semi-structured interviews	nil	Mean 10 mths post-stroke	To describe the components of physiotherapy valued by survivors of a stroke

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Proot 2000 (44) Netherlands	17 [50–85yrs]	Grounded theory	Semi-structured interviews, field notes	nil	8 wks after admission to rehab ward	To determine facilitating or constraining factors regarding patient autonomy during inpatient rehabilitation
Proot 2007 (45) Netherlands	22 [50–85yrs]	Grounded theory	Semi-structured interviews, field notes	nil	admission to rehab, during rehab & at discharge	To explore stroke patients' experiences of health professionals' approach towards autonomy in a longitudinal way
Rejno 2007 (20) Sweden	5 [66–87yrs]	Not stated	Semi-structured interviews	nil	16-40 days post-stroke	To study patients' experiences of being cared for in a combined acute and rehabilitative stroke unit (Translated from Swedish)
Roding 2003 (46) Sweden	5 [37–54yrs]	Grounded Theory	Semi-structured interviews	nil	1 – 1.5 yrs post-stroke	To describe how young stroke patients experience the rehabilitation process

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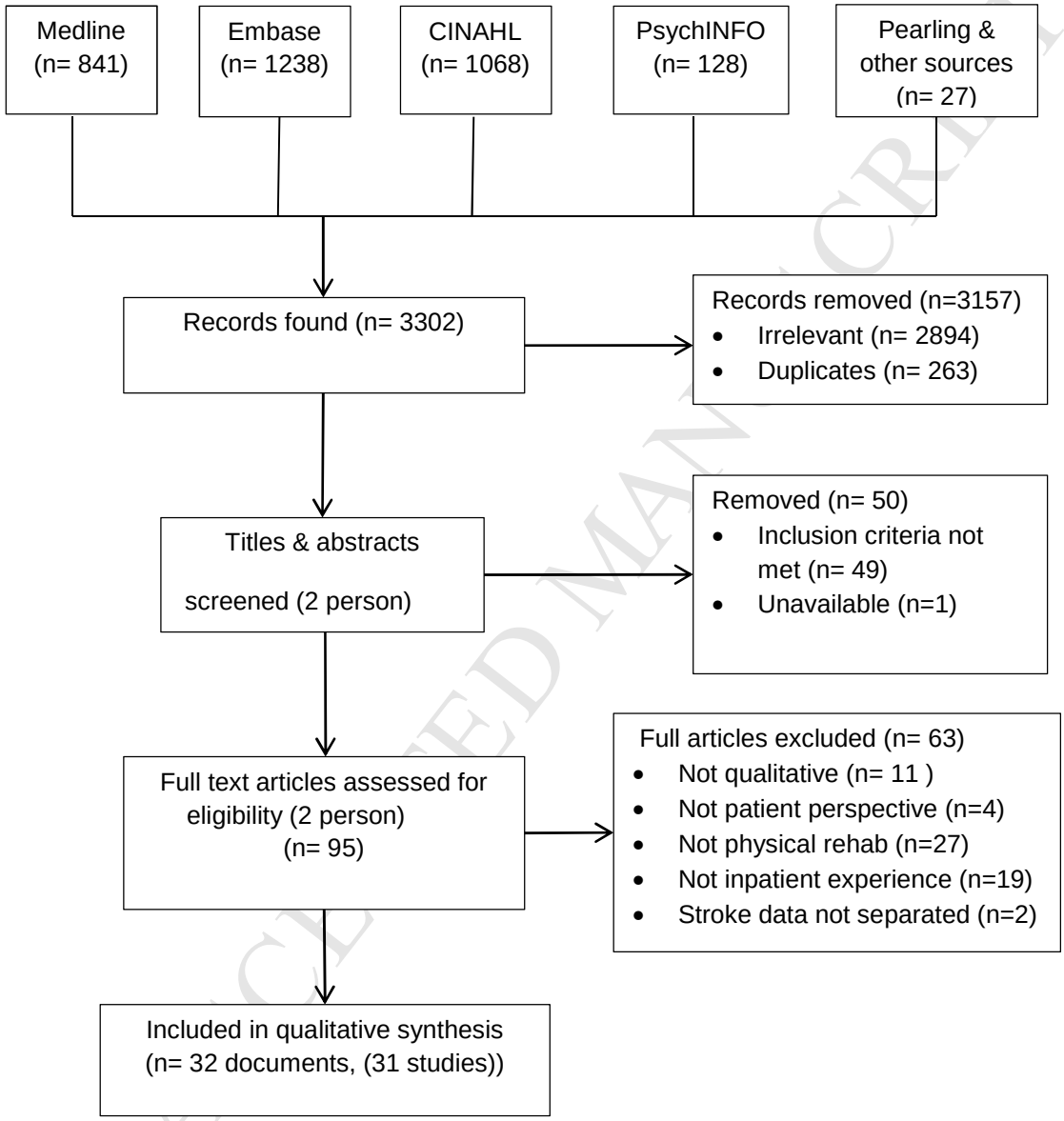
Timmermans 2009 (47) Netherlands	20 [28–79yrs]	Not stated	Semi-structured interviews	nil	mean 3.12 mths (SD 1.21) post-stroke	To examine skill preferences of persons after stroke regarding arm–hand training and patient's training preferences
White (in press 2014) (48) Australia	10 [41– 83yrs]	Qualitative	Semi-structured interviews	nil	Post-acute rehabilitation admission	To qualitatively explore stroke survivors' experience of participation in environmental enrichment within a rehabilitation setting, to identify benefits and limitations to implementation. (In press)
Wohlin Wottrich 1999 (49) Sweden	9 [45–88yrs]	Not stated	Semi-structured interviews, field notes, observations	chronic stroke survivors, physiotherapists	Mean 3.5 (0.5 – 48) mths post-stroke	To explore and compare physiotherapy sessions after stroke from perspectives of the patients' and the physiotherapists', in relation to observed behaviour

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Wressle 1999 (50) Sweden	5 [age unclear]	Grounded theory	Semi-structured interviews, diaries	nil	during inpatient rehab & post-discharge	To describe and analyse stroke rehabilitation goals expressed by the staff and the patient, and the treatment interventions chosen by therapists
Wressle 2002 (51)	79 [45–97yrs]	Not stated	Semi-structured interviews	nil	2-4 wks after rehab discharge	To evaluate whether a client-centred instrument affects the patients' perception of active participation in the rehabilitation process

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Figure 1 Flowchart of search and selection process



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Online Appendix 1

Example Medline database search

#	Search terms	Hits
1	Exp cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp intracranial arterial diseases/ or exp "intracranial embolism and thrombosis"/ or exp intracranial hemorrhages/ or exp stroke/ or exp brain infarction/ or exp vasospasm, intracranial/ or exp vertebral artery dissection/	268737
2	(stroke or poststroke or post-stroke or cerebrovasc* or cva* or SAH)t. ab.	174948
3	Exp hemiplegia/ or exp paresis/	15729
4	(hemipleg$ or hemipar$ or paresis or paretic).t.ab..	26034
5	OR 1-4	367784
6	Exp Qualitative research/	17985
7	Exp Interviews as topic/ or exp focus group/ or exp questionnaires/ or exp self report/	335756
8	(interview* OR focus group* or question$air*).t.ab.	225139
9	Exp Patient-centered care/ OR exp patient satisfaction/ OR exp consumer satisfaction/	84650
10	(Patient centered OR patient centred OR Patient-centered OR patient-centred OR patient satisfaction).t.ab.	26677
11	OR 6-10	566555
12	Exp Rehabilitation/ OR exp activities of daily living/ OR exp early ambulation/ OR exp exercise therapy/ OR exp occupational therapy/ OR exp rehabilitation of speech and language/	790
13	Exp rehabilitation centers/	11742
14	Exp Recovery of function/	29255
15	(rehabilitat* OR therap* OR exercise* OR “physical activity”)t.ab.	677283
16	OR 12-15	706948
17	5 AND 11 AND 16	841

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Online Appendix 2 Quality appraisal of comprehensive reporting

	Core quality criteria (Carroll et al 2004)	COREQ (Tong et al 2007)			
First author/year	**Inclusion score ≥ 2/4**	**Domain 1 (8 items) Research team & reflexivity**	**Domain 2 (15 items) Study design**	**Domain 3 (9 items) Analysis and findings**	**Total (32)**
Alaszewski 2004 (21)	2	0	5	6	11
Bendz 2003 (22)	3	3	11	5	19
Bennett 2013 (23)	4	5	13	7	25
Briggs 2012 (24)	4	6	8	6	20
Celinder 2012 (25)	4	3	8	6	17
Clark 2000 (26)	2	0	6	2	8
Clark 2005 (27)	4	4	7	5	16
Cowdell 2003 (28)	4	4	9	5	17
Dixon 2007 (29)	4	1	8	6	15
Folden 1994 (30)	3	4	8	7	19
Fryer 2012 (31)	4	8	14	9	31
Galvin 2009 (32)	4	2	7	3	12
Gallagher 2011 (33)	4	6	12	8	26
Guidetti 2007 (34)	4	5	6	6	17
Gustafsson 2009 (35)	3	3	5	5	13
Jones 2008 (36)	4	3	8	6	17
LeWinter 1995 (37)	3	0	8	3	11
Lui 1999 (38)	4	2	8	7	17
MacLean 2000 (39)	4	3	7	7	17
Mangset 2008 (40)	4	2	10	7	19

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Morris 2007 (41)	3	2	6	5	13
Peiris 2012 (42)	4	5	9	8	22
Pound 1994 (43)	4	3	8	4	15
Proot 2000 (44)	4	1	12	7	20
Proot 2007 (45)	4	1	10	6	17
Rejno 2007 (20)	2	4	4	5	13
Roding 2003 (46)	4	1	8	6	15
Timmermans 2009 (47)	3	3	2	3	8
White (in press 2014) (48)	4	4	8	6	18
Wohlin Wottrich 2004 (49)	3	2	8	5	15
Wressle 1999 (50)	4	1	8	2	11
Wressle 2002 (51)	3	1	7	0	8

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Online Appendix 3 Themes and source documents

	ANALYTICAL THEMES	DESCRIPTIVE THEMES	SOURCE DOCUMENTS
1	**Physical activity is valued**		(20-26, 28, 30-33, 36-46, 48-50)
		More is better	(23, 25, 28, 31, 32, 37-46, 48, 49)
		More training & intensity	(23, 25, 28, 32, 37, 38, 40-46, 49)
		Importance of walking & mobility	(21, 24, 26, 30, 37-39, 45, 49, 50)
		Practice outside therapy	(20, 21, 23, 25, 28, 32, 33, 36, 37, 39, 40, 44, 48)
		Lack of practice opportunities	(23, 39, 48)
		Practicing with non-clinicians	(21, 32, 37, 44, 48)
		When to work & rest	(23, 38, 42)
		New rehab dosage models	(23, 42)
		Need a break too	(23, 38, 42)
2	**Bored and alone**		(20, 23, 28, 31, 38-42, 46, 48)
		Need more things to do	(20, 23, 28, 31, 38-42, 48)
		Feeling alone	(23, 46)
		Not bored	(28, 48)
3	**Patient-centred therapy**		(20-26, 29-39, 43-47, 49-51)
		Meaningful rehabilitation	(20, 21, 23-26, 32, 34, 36-39, 43, 45)
		Meaningful tasks	(23-25, 34, 36, 39)

		Importance of mobility therapy	(20, 21, 23, 26, 32, 37-39, 43, 45)
		Enjoyment in therapy	(20, 23, 25)
		Variety & innovation	(20, 23, 25)
		Boring, meaningless therapy	(23-25, 30, 36, 44, 45)
		Menial tasks	(24, 30, 36, 44, 45)
		Goal setting importance	(20-24, 26, 29-31, 33-37, 39, 43-47, 49-51)
		Patient generated goals	(21, 29, 30, 33, 39, 47, 51)
		Collaborative goal setting	(21, 29, 33, 36, 44, 46)
		Needing to set goals high	(21, 22, 24, 26, 29-31, 33-35, 37, 44, 47, 50, 51)
		Needing participatory goals	(21, 22, 24, 30, 33, 35, 47, 50, 51)
		Individualised therapy plans	(20, 21, 23, 24, 29, 33, 44, 49, 51)
		Goals not directing therapy	(21, 23, 24, 31, 33, 35, 39, 43-46, 49)
		Conflict over goals	(21, 22, 24, 30, 31, 33, 34, 39, 45, 46, 49)
		Therapy difficult or stressful	(22, 23, 25, 30, 39, 43-45)
		Means to an end	(22, 23, 30, 39, 43-45)
		Family involvement lacking	(33, 49)
4	**Recreation is also rehab**		(20, 23, 25, 28, 31, 36-39, 41, 42, 44, 45, 48, 49)
		Recreation is therapeutic	(25, 28, 36, 48)
		More recreational activity	(20, 25, 28, 31, 41, 44, 48)

		Social opportunities	(20, 23, 31, 36-38, 41, 42, 48)
		Barriers to recreational activity	(20, 28, 38, 39, 48, 49)
		Organisational and environmental barriers	(28, 39, 45, 48, 49)
		Needing help to participate	(38, 48)
5	**Dependency & lack of control**		(21-25, 27-31, 33, 34, 37-41, 44-46, 48-50)
		Valuing independence & autonomy	(24, 27, 29, 34, 40, 44, 45)
		Rehab as purgatory	(28, 30, 38, 40, 41)
		Fear, anxiety & frustration	(21-23, 25, 27, 30, 31, 33, 37-39, 44-46, 48, 50)
		Frustration from lack of control	(21-23, 25, 31, 33, 37, 38, 44-46)
		Fearing activity	(22, 27)
		Disempowering staff attitudes	(24, 27, 31, 33, 38, 40, 41, 44-46, 49)
		Organisational barriers to autonomy	(28, 31, 33, 39, 48-50)
6	**Fostering autonomy**		(20, 23, 24, 27, 29-34, 37-46, 48-50)
		Reclaiming autonomy marks recovery	(29-31, 33, 34, 37, 44, 45)
		Empowering relationships	(20, 27, 29, 31-33, 38, 40-45, 49)

		with staff	
		Collegial, collaborative relationships	(29, 33, 49)
		Trust in staff	(20, 31, 33, 40, 42-45, 49)
		Balancing the help provided	(20, 23, 24, 27, 29, 33, 37, 39, 45, 50)
		Room for trial & error	(23, 24, 27, 37, 39, 50)
		More supervision & help	(23, 24, 29, 45)
7	**Power of communication & information**		(22, 24-27, 29-31, 33-41, 43-46, 49, 50)
		Good communication empowers	(24, 26, 29, 31, 33, 36, 38-41, 43-46, 49)
		Good communication fosters autonomy	(40, 44, 49)
		Understanding the rehab process	(26, 29, 36, 38, 39, 41, 43-46, 49)
		Poor communication disempowers	(22, 24-27, 29-31, 33-41, 44-46, 49, 50)
		Misunderstandings	(22, 27, 31, 33, 34, 39, 40, 45)
		Waiting for recovery	(22, 27, 33, 34, 39)
		Self-care not seen as rehab	(34, 39, 40, 45)
		Frustration from lack of understanding	(29, 31, 36-39, 41, 44-46, 50)
		Mixed messages	(29, 31, 36, 39, 44, 45, 50)

8	**Motivation needs nurturing**		(20-34, 37-39, 41-44, 46, 48-50)
		Hope	(20, 24, 30, 33, 39, 43, 49)
		Encouragement and support	(20, 21, 23-27, 29, 31-33, 37-43, 46, 48, 49)
		Encouragement and support - staff	(23, 24, 26, 27, 31-33, 38-43, 49)
		Encouragement and support - patients	(20, 23, 25, 29, 31, 33, 37, 42, 46, 48)
		Encouragement and support - family	(21, 25, 29, 33, 37, 48, 49)
		Being pushed	(21, 23, 29, 33, 44, 48)
		Humour is important	(20, 33, 37)
		Noticing progress	(20, 23, 25, 29-31, 37, 44, 49)
		Undermining motivation	(21, 28, 33, 34, 37, 39, 40, 44, 49, 50)
		Low motivation can happen	(34, 39, 50)
		Slow progress	(21, 37, 40, 44, 49)
		Low mood	(28, 33)
9	**Fatigue can overwhelm**		(20, 22, 23, 25, 28, 30, 34, 42, 46)

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Online Appendix 4 Themes and Illustrative Quotes

	Analytical & descriptive themes	Examples from included documents
1	**Physical activity is valued**	
	More is better	"The belief that more therapy meant better outcome was both implicitly and explicitly expressed in many participant responses. Functional improvement and psychological benefits were identified as being associated with increased dosage. Some participants believed increased dosage could contribute to earlier and greater independence; 'The more I did the better it was for me because this leg never worked. Now it is working.' (Bennett 2012)(23)
	More training & intensity	"None of the patients felt that they had received enough training. A typical comment was that 'one can- not have too much training'." (leWinter 1995)(37)
	Importance of walking & mobility	"The main concern for all respondents was functional improvement. Mobility was most commonly noted, but speech, balance and limb function were also cited." (Clarke 2000)(26)
	Practice outside therapy *Lack of practice opportunities*	"'The help was good downstairs [in the physiotherapy gym] but when I come up here, I go to bed again so what can I do? ... So I don't know what is good or bad ... I just don't know ... you can't bother people just because you want to learn how to walk'" (MacLean 2000)(39)
	Practicing with non-clinicians	"Mr Jones, who had previously led an outdoor life, was supported by his family in his goal of learning to walk again but was not entirely satisfied with his progress. When walking, supported by his wife and daughter, he did not feel that this was 'real walking', and therefore did not value it." (Alaszewski 2004)(21) "Three men who shared a room practised walking in the room when no-one was watching them. They had a moment of panic when one of them fell and the others had to help him up (from their wheelchairs) before any of the nursing staff discovered them. (LeWinter 1995)(37)
	When to work & rest *New rehab dosage models*	"'...they're only half hour sessions, it didn't take a lot out of you' (Participant 11, 7 day week usual care) Ideal therapy duration varied between participants. Responses generally indicated that despite the previously mentioned belief that more is better, overall, participants perceived there was an upper limit to one's own physical capacity with respect to endurance." (Bennett 2012)(23)

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	Need a break too	"These patients said they were concerned that they would not get enough rest if they received additional physiotherapy: 'That's enough for me at the moment. I couldn't cope with any more because I get so very tired.' (P4)" (Peiris 2012)(42)
2	**Bored and alone** Need more things to do	"The participants spoke of the overwhelming boredom they experienced in the rehabilitation setting. When asked what he did during the day, one participant replied: 'Nothing. It's boring, very boring.' " (Cowdell 2003) (28) "Not much happens here, [it would be] nice with more activities" (Birgitte). This desire for meaningful activities and the perception that not much happened on the ward was common. 'In the beginning [of my hospitalization], nothing happened. I thought it was odd'" (Celinder 2012)(25) "There was little to distract participants from boredom. Having LEP [limited English proficiency] in a predominantly English-speaking inpatient context limited their ability not only to communicate with health professionals but also to socialise with others in healthcare." (Fryer 2012)(31)
	Feeling alone (2)	"Later in the rehabilitation process the informants also expressed a need to be able to talk to others in the same age that also had been affected by stroke and shared experiences. 'Well, I felt like there was no one that I could share my experiences with at the ward. I was only 38 years old and I had to be together with those who were 70 – 80 years.'" (Roding 2003)(46)
	Not bored (2)	"'There is probably only a few minutes of the day that I am bored and then I think well it is up to you to do something. You can be bored or you can be busy, you make the choice.' (Participant 3)" (White in press)(48)
3	**Patient-centred therapy (26)** Meaningful rehabilitation (14) *Meaningful tasks (6)*	"Another participant voiced his appreciation for the 'down to earth' functional content of his program; 'Real proper life chores and everything, nothing like you know ballet dancing or ballroom dancing, whatever. Just normal, ordinary things, balance, attention and stability. That was good. I enjoyed that'" (Bennett 2012)(23) "Practical advice given by therapists was appreciated, including for example, guidance given by physiotherapists about how to get up if they had a fall: 'How to get up if I fall. Very useful, hold onto this chair and pull myself if I can.'" (Jones 2008)(36)
	Importance of mobility therapy (10)	"Participants were asked what component of their physiotherapy programme they liked the most.

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		Walking was the most frequent response (n=6) followed by lower-extremity exercises (n=4). (Galvin 2009)(32)
	Enjoyment in therapy (3)	"Group physiotherapy was a fun and easy-going activity where each person participated on their own terms. The whole body and soul were active." (Rejno 2007)(20)
	Variety & innovation (3)	"Several patients expressed a desire to play Wii again, as the excitement of playing was motivating." (Celinder 2012)(25)
	Boring, meaningless therapy (7)	"One circuit participant described becoming bored with her program and reported that staff responded by providing her with new challenges; 'I was getting bored with what I was doing. I'd gotten to the stage where I was that mobile that I was getting bored with the same repetitive and so they had to come up with new things for me to get myself stimulated'"(Bennett 2012)(23)
	Menial tasks (5)	"Participant 5 stated that at first he didn't understand some of the 'menial' tasks he was given, and was 'frustrated' but later understood the purpose of how the interventions were beneficial to his recovery. Overall participant responses in relation to specific interventions were vague and indicated little patient-centeredness." (Briggs 2012)(24)
	Goal setting importance (23)	"A key dimension of determining what is important is goal setting. The degree of congruence of priorities and expectations between rehabilitation teams and stroke survivors is important to achieving the goal of becoming normal" (Gallahger 2011)(33)
	Patient generated goals (7)	"Participants' goals were related to improving functional ability and returning to some of their former activities. All participants wanted to walk independently; many ex-pressed the desire to drive again." (Folden 1994)(30)
	Collaborative goal setting (6) *Needing to set goals high (15)*	"Recall of discussing meaningful activities with inpatient therapists. Participants' responses identified what they wanted to return to after discharge. They identified personally meaningful activities such as, walking, getting dressed, being able to take care of themselves, driving, participation in social activities (e.g., community organizations), recreational sports (e.g., kayaking, jogging, golfing), and work." (Briggs 2012)(24)
	Needing participatory goals (9)	"The goals were more likely to be at the activity and participation level (n=18, 78%) than the body

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		functions and structures level (n=5, 22%). Goals at the activity and participation level centred on attending to tasks and activities within the home (n=5), spending time with their family (n=4), returning to work or leisure activities (n=4)…" (Gustafsson 2007)(35)
	Individualised therapy plans (9)	"Although decision-making about their own treatment is difficult for most patients, they valued shared decision-making" (Proot 2000)(44)
	Goals not directing therapy (12)	"Nearly all participants recalled dialogue with their therapists about activities that were important to them. None of the participant's recalled working on these tasks during inpatient therapy. … 'they'll make a stab at it for a couple days and then it kinda falls by the wayside, until I mention it again, which I'm gonna keep mentioning it to them'" (Briggs 2012)(24) "Although not explicitly expressed, the goals differed between the persons who had had a stroke and the health care professionals. While the goal for the health care professionals was to recapture lost functions, this was merely the means for those who had had a stroke. The goal for them was either to recapture their former social position or to adapt to another life situation." (Bendz 2003)(22)
	Conflict over goals (11)	"Participant 1 had a goal of returning to driving and stated his therapist told him he would 'not be able to drive again.' He stated that at this point he had 'fired' that therapist." (Briggs 2012)(24) "Progress within rehabilitation is often measured through the use of goals and achievement of such targets assists the relationship between the practitioner and client. However, when goals are considered to be unrealistic by the professional, the relationship becomes more difficult to maintain" (Alaszewski 2004)(21)
	Therapy difficult or stressful (8)	"Physical discomfort and difficulty during therapy was reported by some participants, who struggled with the intensity of their program; 'My worst was they put those heavy weights on the legs, my legs were, they felt heavy you know, but I put up with it, but I knew I had done it when I was finished'" (Bennett 2012)(23)
	Means to an end (7)	"The training was often perceived to be the only way to recover, irrespective of what kind of problems the stroke had caused. The quotation below illustrates the meaning of training for the patients. 'I'm going to train … feel that you mustn't give up. 'Cos I don't think that's any good … but I … I do it to be able to … carry on existing … 'cos its no good … no good giving up … oh, no.'" (Bendz 2003)(22)

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	Family involvement lacking (2)	"Seven participants reported that their family members were not invited to attend physiotherapy but would be happy to do so. 'They would like to know what help they could give me' [TCD 02]. 'They would be interested in finding out what I do and doing it with me' [TCD 03]." (Galvin 2009)(32)
4	**Recreation is also rehab (15)** Recreation is therapeutic (4)	"Those participants that did yearn for more activity clearly expressed that such activity was for the purpose of recovery rather than for pleasure….They gave a clear message that recreation was of value in enhancing and speeding their recovery: 'I would love to do something physical…I would like that instead of being just like a cabbage, sat there waiting to go home or waiting to die.' (participant 1)" (Cowdell 2003)(28)
	More recreational activity (7)	"'Something is needed to keep us occupied. It's badly needed…last Sunday I sat by that window all afternoon.' (participant 2)… When discussing recreation, the participants expressed quite broad ideas on what would be included in a definition of such activities. They suggested some of the activities that may have been predicted: "'Bowls and things like that" (participant 1) 'Something like draughts or snakes and ladders' (participant 2) The majority of participants expressed a strong desire to have an increase in activity." (Cowdell 2003)(28) "In the rehabilitation stage patients were bored and some welcomed the chance to play the Chinese game of Mahjong, seeing this as therapeutic." (Liu 1999)(38)
	Social opportunities (9)	"A number of participants felt that their need for family contact should be given greater consideration: ' ... [because of] how awful it was and on the wards, the children did not want to come in .. . , when they did come in there was nowhere for us to go, .. . and he missed the children so much,' " (Morris 2007)(41)
	Barriers to recreational activity (6) Organisational and environmental barriers (5)	"Both PTs and patients stressed that the environment in the rehabilitation unit as a whole did not promote activities. The surroundings in the rehabilitation unit were also said to make it difficult for the patients to regain activities that they previously had been able to do." (Wohlin Wottrich 2004)(49)
	Needing help to participate (2)	"Overall participants' indicated that assistance to access the communal area was dependent on staff availability. Some participants' expressed access to more assistance from staff would have reduced feelings of frustration and difficulty related to accessing environmental enrichment activities. 'Maybe it would be useful if there was more [staff to help you], but the staff are stretched out pretty, pretty thin.' (Participant 8)" (White in press)(48)

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5	**Dependency & lack of control (23)**	'Several statements, however, revealed incidents of inhuman treatment and degrading behaviour by the staff, which made the patient feel deprived of value and personality: 'It has something to do with being ... with human dignity, which in itself is a problem since you're lying there and need help with everything, that you don't get sent around like a package from one examination to another. You can't say 'No, sorry, it's a bit inconvenient right now.' You don't know what you're doing, where you're going. You really don't know a thing, which proves the point that you don't have any dignity at all, because 'we [the hospital staff] do as we like.' And that's that.'" (Mangset 2008)(40)
	Valuing independence & autonomy (7)	"Being able to manage even small, seemingly trivial tasks on their own was of great significance to patients: 'I can thread a needle and I was made up with that because I did not have to ask anyone to do it so it gave me a boost because I had a bit of independence." (Dixon 2007)(29)
	Rehab as purgatory (5)	The construct of purgatory paints a picture of patients catapulted into a situation in which they have relatively low capacity to control their own activity."(Cowdell 2003) (28) "They often felt the lack of control over their body. They described these periods of time as lonely and humiliating. These feelings were most often expressed in relation to needing assistance with toileting, as one participant discussed: 'I rang for help, no one came, so I tried to get up by myself and I sat on the floor. I don't know how they knew I was on the floor, but they all came running in here. .. . Well, they got me up and into the chair, and they tied me down. They tied me to the chair. They tied me to the bed." (Folden 1994)(30)
	Fear, anxiety & frustration (16) *Frustration from lack of control (11)*	"'In the beginning I had some difficulty with that (waiting periods). And I said: You girls have to take into account that it is not my fault either, that I have to pee. My doctor tells me to drink lots. I do, and then I have to pee more. …I am already punished enough by this disease. They have taken much of your freedom'" (Proot 2000)(44)
	Fearing activity (2)	"The perceived risk of a relapse seemed to be ever present for many of them. They did not know if they dared to do something even if they were capable of doing it." (Bendz 2003)(22)
	Disempowering staff attitudes (11)	"Most participants experienced health professionals giving information about their condition and treatment to their children instead of to them. …Participants were not always given a reason why they were bypassed by health professionals but they assumed it was because their family would understand the information better than they would…" (Fryer 2012)(31)

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		"The manner in which professionals treat stroke survivors is also vital. When professionals address care and helping in a matter-of-fact way, survivor's feelings of helplessness and being demeaned by stroke are lessened. Conversely, when professionals restrict or limit stroke survivors' acts of independence, they feel helpless and demeaned." (Gallagher 2011)(33)
	Organisational barriers to autonomy (7)	"The rehabilitation ward studied is situated in a large general hospital providing acute care and, by necessity, tends to focus on medical and nursing interventions. It seems plausible to assume that the 'medical model' culture has permeated the rehabilitation ward, despite the inappropriateness in this type of setting. A significant factor of this model is that patients become passive recipients of care." (Cowdell 2003)(28) "Another low motivation patient described feeling obliged to let the nurses wash him as this was the 'law' in the hospital." (Maclean 2000)(39)
6	**Fostering autonomy (23)**	
	Reclaiming autonomy marks recovery (8)	"As participants progressed toward their goals, they perceived themselves as seizing control of their recovery." (Folden 1994)(30) "Reclaiming Control. All participants expressed the desire to become less dependent on others and to have more opportunities to make choices for their actions in daily life at the clinic. They described how they sought to reclaim control of their bodies and doing in their daily life. In particular, they expressed that becoming independent in self-care was important for their self-perceived sense of agency (i.e., the sense that they are the owner of their own actions)." (Guidette 2007)(34)
	Empowering relationships with staff (14) *Collegial, collaborative relationships (3)*	"The ability to collaborate is essential. Collaboration is the comfort with and ability to seek help, accept advice, and work with others who can help survivors achieve their goal of becoming normal. … Stroke survivors in this study sought collaboration with therapists, nurses, physicians, and other stroke survivors" (Gallagher 2011)(33) "Working with professionals. Many patients talked about their own role in the rehabilitation process and how they worked with the therapists: 'I think they work on the fact that you've got to meet them at least half-way and put just as much effort in.' (Dixon 2007)(29)
	Trust in staff (9)	"Having confidence and trust in professionals The patients' trust in the professionals' competence strongly influenced their satisfaction." (Mangset 2008)(40) "The act of trusting was itself a risk for participants. In the unfamiliar context of healthcare after stroke, they did not know the majority of health professionals whom they were required to interact

		with. The trust was then accorded to the expert role rather than the individual … ' I trust them because they are a doctor, what else can I do?' (Emanuele, Italian)" (Fryer 2012)(31)
	Balancing the help provided (10) *Room for trial & error (6)*	"There was broad agreement among both groups of participants that staff who were friendly, encouraging, helpful, timely and reassuring and who provided explanations generally promoted independence: 'It's important that you should just be watched and not helped too much.'" (Clark 2005)(27) "The second part of this question asked for participant perspectives on what therapists could do less of during inpatient therapy. Typical responses included 'talk less about themselves', 'leave you alone a little less', 'less holding on, you don't give a person room for trial and error'…" (Briggs 2012)(24)
	More supervision & help (4)	"Participant concerns included feeling unsafe, tiring without support and exercising correctly; 'Sometimes they left me too much by myself' (Participant 8, 5 day week circuit therapy.)… The treadmill provided particular concern for some circuit participants who were fearful of being left alone on it." (Bennett 2012)(23)
7	**Power of Communication & information (23)** Good communication empowers (15)	"Moreover, gaining knowledge helps as a means of controlling their feelings of powerlessness." (Liu 1999)(38)
	Good communication fosters autonomy (3)	"In order to empower the patient, to make the patient take a more active part in the rehabilitation process, the PTs attached great importance to informing and teaching the patient about theories regarding different options in training procedures and chances of regaining motor capacity after stroke." (Wohlin Wottrich 2004)(49)
	Understanding the rehab process (11)	Though walking was the most commonly reported goal of rehabilitation, some patients reported not understanding the therapeutic process leading towards that goal: 'The ultimate aim is to get me walking ... I don't understand the steps. How they [the physiotherapists] plan it'" (Maclean 2000) "A substantial minority of patients hoped for improvement, but were unable to specify what form it would take or how rehabilitation would achieve it." (Clarke 2000)(26)
	Poor communication disempowers (22)	"A number of patients experience lack of information, deliberation and evaluation about treatment plans and discharge planning which constrains the dimensions independence and self-determination: 'When they told me: 'It is written down here, that you have to take care of yourself', I said: 'Nobody has ever told me that, but I appreciate it', I can see that I have to'".(Proot 2000)(44)

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	Misunderstandings (8) *Waiting for recovery' (5)*	"Some of them regarded the stroke a passing disease. They trusted that the stroke would go away and that they would regain their former social position. 'Well, they've said that the healing process takes a year and a half so I've got plenty of time.'" (Bendz 2003)(22)
	Self-care not seen as rehab'(4))	"The participants who had had a stroke said that self-care activities were something that they had to do, 'a must', and therefore they did not experience self-care as training." (Guidette 2007)(34)
	Frustration from lack of understanding (12)	"Frustrations and feelings of anger are reported by some of the informants in this study when the staff cannot meet their informational need." (Liu 1999)(38) "The lack of information and the need of knowledge made the informants frustrated."(Roding 2003)(46)
	Mixed messages (7)	"A few low motivation patients described some of the stroke unit professionals as giving out unhelpful 'mixed messages.' One patient reported that physiotherapists encouraged her to work at rehabilitation. On returning to the ward, however, she thought the nurses discouraged such effort by putting her to bed." (Maclean 2000)(39)
8	**Motivation needs nurturing (26)**	"However, participant motivation levels towards recovery fluctuated throughout their rehabilitation stay, influencing uptake of activities and equipment offered through environmental enrichment." (White in press)(48)
	Hope (7)	"Hope is the knowledge and feeling that the negative effects of stroke can be overcome. Hope is described as something that comes from within; however, receiving hopeful messages from others is important and sought." (Gallagher 2011)(33)
	Encouragement and support (21) *From staff (14)*	"Health professionals limiting the information they gave to participants also had the potential to limit what was an important source of motivation and reassurance for people in their recovery from stroke. Krystyna explained how powerful the words of health professionals could be in a person's recovery, 'All the good words together, they collect themselves and they help sick people' (Polish)"(Fryer 2012)(31)
	From other patients (10)	"The circuit therapy group provided the opportunity for participants to experience mutual support and encouragement. 'I was happy just having that group...being there to support others as well as getting the support that I needed... based on the encouragement of others and you know, keep going. That

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		was something that we all thrived on and we all took that, grabbed that when someone said you're doing well or, she's a show off, or sort of mucking around, we just absorbed it and we took it and it was precious to us'" (Bennett 2012)(23)
	From family (7)	"Hans pointed out the significance of sharing the experience with his family. '[While]my wife watched [me playing Wii], she said, 'Oh yes, it looks like a lot of fun. We should probably have one like that at home, also for our grandchildren.'" (Celinder 2012)(25)
	Being pushed (6)	Mr Tucker a 76-year-old man explained, he did not mind being pushed: Mr Tucker: She was very good. She was an Australian girl and . . . She said 'you can do it, you can do it, go, go, go'. Int: What do you think it was about her that made you feel she was good? Mr Tucker: I think she knew where she wanted me to go and she certainly pushed that and that alone you know." (Aleszewski 2004)(21)
	Humour is important (3)	"'Then someone came and made a joke and chatted a little which cheered up.' The informants think that as patients, they had a great need to think about something other than the disease and their new situation." (Rejno 2007)(20)
	Noticing progress (9)	"Recognizing one's own improvements is a vital source of encouragement for patients. Making the connection between rehabilitation and progress provides both incentive and reward to persevere with repetitive tasks and prevents the development of despondence" (Dixon 2007)(29)
	Undermining motivation (10) *Low motivation can happen (3)*	"Another low motivation patient doubted the point of physiotherapy as her leg had been injured when nurses were putting her in a wheelchair. This patient also reported feeling less inclined to attend rehabilitation when she discovered that her goal of returning home was deemed unrealistically high." (Maclean 2000)(39)
	Slow progress (5)	"A few of the patients admitted to being 'impatient' with the rehabilitation process, and with reconciling themselves both to the hospital routines and life at home after stroke. In retrospect they felt that this impatience was a negative factor in their rehabilitation, but felt that it was due to the fact that they had counted on being 'up and about' again relatively rapidly after the stroke" (LeWinter1995)(37)
	Low mood (2)	"This concept of 'learned helplessness' is in line with the feelings of worthlessness expressed by some

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		patients: 'I feel that I'm useless, as if I'm incapable, I can do nothing … It's soul destroying, you feel 'what am I here for'' (participant 1)" (Cowdell 2003)(28)
9	**Fatigue can overwhelm (9)**	"Preserving energy: The most prevailing obstacle to get- ting better was the often overwhelming feeling of fatigue. Because of constant fatigue, stroke survivors protected the use of their time." (Folden 1994)(30) "Participants believed that they were unable to influence this fatigue, and activities such as self-care were at times perceived as unreachable. One participant (recovering from stroke) said, 'In the beginning it was exhausting for me to just think; that in itself was more than enough.'" (Guidette 2007)(34)

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