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## Barriers and facilitators to engagement in rehabilitation for people with stroke: a review of the literature

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### ABSTRACT

While there is a growing acknowledgement of the significant role that engagement plays in rehabilitation, there is limited knowledge of the factors that may help or hinder engagement in stroke rehabilitation. This review drew on systematic principles and aimed to explore what is currently known about the perceived barriers and facilitators to engagement in stroke rehabilitation. EBSCO, SCOPUS and Google Scholar databases and reference lists were searched for papers that provided insight into the process of engagement or disengagement in stroke rehabilitation. Data were extracted and synthesised thematically from 17 papers. Themes included goal setting, therapeutic connection, personalised rehabilitation, paternalism versus independence, patient centred practice, knowledge is power, and feedback and achievement. None of the papers identified however, explicitly sought to investigate the complexities of engagement in rehabilitation specifically within the stroke population. Future research is needed to explore this topic in more depth from the perspective of all the key stakeholders. A more comprehensive understanding of engagement in stroke rehabilitation may inform the development of interventions to better equip rehabilitation providers with the clinical skills to facilitate engagement and effectively deliver rehabilitation modalities.

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Key Words: stroke, rehabilitation, engagement, facilitator, barrier, experience

### INTRODUCTION

Strokes are a major source of disability in the New Zealand adult population, with around 7600 people experiencing a stroke each year (Stroke Foundation 2012). In 2007 there were estimated to be 57,700 stroke survivors living in New Zealand, many severely disabled and needing significant daily assistance (Ministry of Health 2008). This number is likely to have increased since. It is suggested that these individuals, many who often have multiple impairments affecting physical, cognitive and/or communicative functioning, may benefit from an intensive multidisciplinary rehabilitation approach (Bonita et al 1993, Horton et al 2011). Rehabilitation is advocated as best practice following stroke (Stroke Foundation of New Zealand 2010); however, the positive outcomes observed in response to rehabilitation strategies in research frequently fail to translate to effective strategies in real world practice. A person's engagement within the rehabilitation process has been suggested as one variable that may impact on rehabilitation outcomes (Lequerica et al 2009, Lequerica and Kortte 2010, Medley and Powell 2010).

Lequerica and Kortte (2010) define engagement as "a deliberate effort and commitment to working toward the goals of rehabilitation interventions, typically demonstrated through

active, effortful participation in therapies and cooperation with treatment providers" (p.416) in which individuals incorporate "high levels of vested interest" (p.416). It is suggested that engagement is demonstrated through body language and non-verbal actions (Simmons-Mackie and Kovarsky 2009), as well as attendance, compliance, working alliance, disclosure and active participation within rehabilitation sessions (Lequerica and Kortte 2010, Staudt et al 2012, Tetley et al 2011). Increased levels of engagement within the rehabilitation process have been associated with enhanced adherence and attendance, functional improvements during inpatient rehabilitation, reduced levels of depression and improved function after discharge (Kortte et al 2007, Lequerica and Kortte 2010). Absence of patient engagement within rehabilitation can impede an individual's functional recovery of cognitive and motor functioning and increase their time in hospital (Lequerica et al 2009, Lequerica and Kortte 2010).

Despite the increasing acknowledgment of the significant role that engagement plays in rehabilitation, there is less known about what constitutes engagement, influencing factors, and how it is best applied in a clinical setting. Rehabilitation is a lifelong process for many people following stroke. As such a more comprehensive understanding of the factors that may help or hinder their engagement in that process is needed.

This may inform the development of interventions to better equip rehabilitation providers with the clinical skills to facilitate engagement and effectively deliver rehabilitation modalities. The aim of this review was to explore what is currently known about the perceived barriers and facilitators to engagement in stroke rehabilitation.

## METHOD

A literature review drawing on principles of systematic review and using thematic analysis was undertaken.

### Search Strategy

Key search terms are stated in Table 1. Databases searched included EBSCO health databases (CINAHL, MEDLINE, SPORTDiscus, Health Source: Nursing/Academic Edition & Psychology and Behavioral Sciences) and Scopus. In addition, a hand search of the reference lists from all included articles and two review articles was completed in order to capture any additional papers relevant to the topic. Finally, a Google Scholar search was administered using the terms; "stroke", "engagement" and "rehabilitation" and the first 50 citations reviewed.

**Table 1: Key search terms for the literature search**

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stroke OR cva OR "cerebrovascular accident\*" OR "cerebrovascular disease"  
AND  
rehabilit\* OR "physical therap\*" OR physiotherap\* OR "occupational therap\*" OR therap\*  
AND  
participat\* OR engage\* OR involvement  
AND  
success\* OR fail\* OR help OR hinder OR facilitat\* OR barrier\* OR experience\*

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### Inclusion and exclusion criteria

Papers were included if they reported empirical studies that provided insight into the process of engagement or disengagement in stroke rehabilitation. They were included if they were: a) published in an English-language peer-reviewed journal; b) set in the context of active stroke rehabilitation, and c) either explicitly explored engagement-related issues, reported engagement-related issues as a key finding, or if they explored experiences of stroke rehabilitation such that they might offer insight into engagement-related issues. Papers were considered to be set in the context of active stroke rehabilitation if there was evidence of, or reference to, a therapeutic encounter between a person with stroke and rehabilitation professional. Papers which met these criteria were included regardless of whose perspectives of engagement were being explored, including but not limited to people with stroke, their caregivers, family/whānau and/or health professionals working in the context of stroke rehabilitation. Papers were excluded if they were not exclusive to stroke rehabilitation, for example, where participants with impairments not related to stroke were included in the study sample.

## Procedures

The titles and abstracts of all papers yielded in the search were screened for relevance independently by two researchers (GM and FB). Full text copies of papers were obtained when papers were identified to possibly or probably meet the inclusion criteria, or if this could not be determined by reviewing the title and abstract. The full text was then reviewed to confirm eligibility. Disagreements regarding eligibility for inclusion were initially discussed by GM and FB to see if a consensus could be reached. If agreement was not reached, a third researcher (NK) was called upon to arbitrate. Included articles were read multiple times to gain an in-depth understanding of the selected topic. Analysis identified key ideas relating to the process of engagement in stroke rehabilitation and factors that were perceived to help or hinder this process. These were coded initially by the lead author; these codes were then grouped to generate themes. Meetings were held to discuss codes, themes and supporting data to check for consistency of interpretation.

### Data extraction and critical appraisal

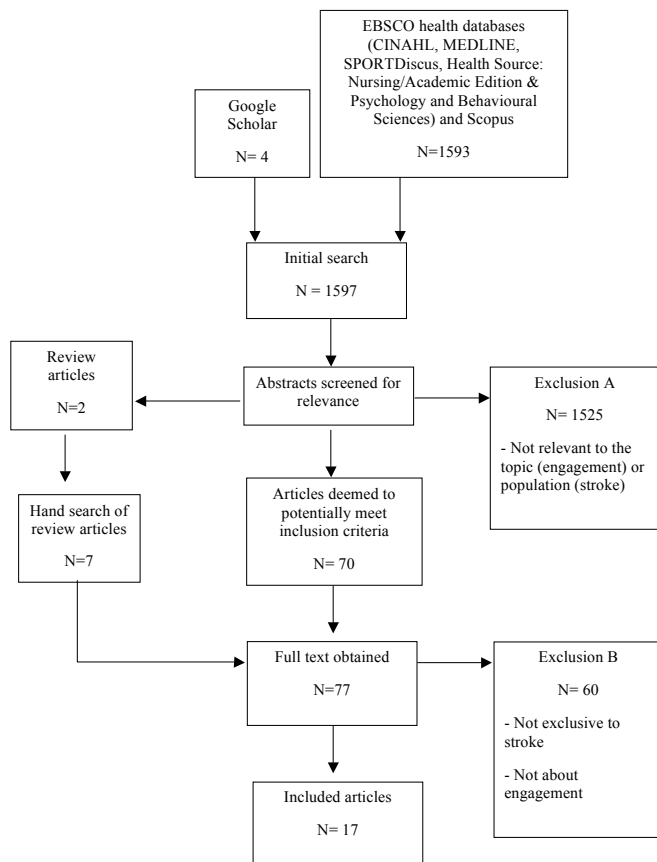
The included articles were read and relevant data extracted including study aim, design, data collection methods, study perspective, participants and key findings relevant to engagement. The methodological quality of qualitative studies was determined using the Critical Appraisal Skills Programme (CASP) framework. This tool uses ten questions to critique theoretical perspectives and quality of qualitative research evidence (Public Health Resource Unit 2007). The mixed method studies were critiqued using the mixed method appraisal tool, a tool designed to concomitantly appraise and describe the methodological quality for three methodological domains of studies: mixed, qualitative and quantitative (Pluye et al 2011). Critical appraisal was undertaken by the lead author with oversight by NK regarding the appropriateness and relevance of the study design, explicitness and generalisability of the reported findings and relevance to practice. Papers were included in the review regardless of methodological quality as per recommendations for this type of review where the aim is to gain a better conceptual understanding of a phenomenon of interest (Morse 2000). Methodological quality was reported so the findings might be interpreted within that context.

## RESULTS

The search results are outlined in Figure 1. In total, 1597 articles were identified using the original search terms and were screened for applicability. Of these, 70 were identified as probably or possibly meeting the inclusion criteria. Two review articles were identified and although they were not directly relevant to engagement in stroke rehabilitation, their reference lists were hand searched identifying a further seven potentially relevant articles. The full texts of these 77 papers were retrieved. After reviewing the full text, 17 were identified to meet the inclusion criteria for this review.

Table 2 refers to the characteristics of the included studies. None of the included articles explicitly explored engagement within a stroke rehabilitation setting. The majority explored experiences of stroke rehabilitation such that they might

**Figure 1: Search result**



offer insight into engagement-related issues. Of the 17 studies that explored patient and therapist experiences of stroke rehabilitation, 14 were qualitative and three used a mixed method design. Several papers used semi-structured interviews whilst some also used observation and a range of questionnaires.

The quality of included studies varied widely with findings of the quality appraisal presented in Tables 3 and 4. Several of the studies met the majority of the appraisal tool criteria whilst others only met a few. It was unclear in a number of studies whether certain criteria were met due to the insufficient detail provided. Common weaknesses within the studies included: little or no critical examination of the relationship between researcher and participant (e.g. critically examining their own pre-conceptions and potential for that to influence the formulation of research questions, data collection and interpretation of findings) and the failure to mention whether saturation was met in the qualitative research. Strengths included clear description of aims, consideration of ethical issues and clear statement of study findings.

Thematic analysis of the included papers identified several factors perceived to help or hinder engagement in stroke rehabilitation. These included goal setting, therapeutic connection, personalised rehabilitation, paternalism versus independence, patient centred practice, knowledge is power and feedback and achievement. These themes are described in more detail below.

## Goal Setting

Goal setting was considered an essential component of an effective rehabilitation programme by those who suffered from stroke and their therapists offering an opportunity to motivate and engage a person in their rehabilitation (Bendz 2003, Maclean et al 2000, Marklund et al 2010, Wottrich et al 2004). A patient centred approach was perceived to be the most effective form of goal setting; an example of this was demonstrated by Bendz (2003). This paper looked at the perspectives of patients with stroke and their therapists within the first year of their rehabilitation and found that goals set within the rehabilitation setting can differ between the patient and therapist. A key finding of Bendz (2003) was the importance of personally relevant goals that are based on mutual understanding, negotiation and interaction.

Further studies have observed enhanced patient motivation towards their rehabilitation when clear goals are established prior to treatment (Bendz 2003, Maclean et al 2000, Marklund et al 2010, Wottrich et al 2004). Maclean et al (2000) and Marklund et al (2010) found that goal setting and establishing a goal orientated work ethic were important factors believed to increase patient motivation. Furthermore, MacLean et al (2000) identified that patients were more likely to achieve goals when they understood the therapeutic reasoning behind their goals. This suggests that involving a patient in the goal setting process may enhance their engagement in their rehabilitation. This may be due to their increased understanding of the therapeutic reasoning for their rehabilitation pathway and/or due to identification of patient centred goals individualised to the patient's needs.

## Therapeutic Connection

The therapeutic relationship between patient and therapist has been suggested to possibly influence the process of engagement within stroke rehabilitation. Literature identified three key ways in which the therapist appeared to influence engagement: 1) through their manner; 2) the level of support they provided patients; and 3) their level of involvement as perceived by the patient (Ewan et al 2010, Gillot et al 2003, Maclean et al 2000, Proot et al 2000a, Proot et al 2000b, Reid and Hirji 2004, Wottrich et al 2004).

The therapist's manner towards their patient seemingly affected the strategies they adopted, both positively and negatively. It also appeared to impact on the patient's ability to engage within their rehabilitation. A study by Proot et al (2000) identified that patients believed therapists should portray consistency, attentiveness, respect and a supportive manner; these were considered key characteristics of an effective therapist. These characteristics were required to ensure appropriate support was provided to enhance an individual's self-determination and self-confidence. Proot et al (2000b) observed that a lack of therapist attentiveness could result in unattainable goals being established and unrealistic patient expectations.

The level of therapist support was another factor perceived to influence an individual's perception of their therapist's attitude.

**Table 2: Characteristics of included studies**

| Author               | Aim of Study  | Design   | Method of data collection  | Perspective                                   | Participants   |
|----------------------|---|--|--|---|--|
| Bendz (2003)         | To investigate different understandings of the implications of having a stroke from the perspective of those who have had a stroke and their health care professionals. | Qualitative: Phenomenographic design   | Interviews using open ended questions and transcripts from health care professionals recorded during first year post stroke  | Health professional and patient perception    | Health Professionals (n=not stated) and stroke patient (n=15); aged less than 65. 10 had had a stroke for the first time and 5 had experienced one or more strokes were recruited from a Swedish hospital over a one year period |
| Daniels et al (2002) | To explore and gain an understanding of Occupational therapists experiences of therapy with patients in inpatient stroke rehab  | Qualitative: Explorative design  | Two focus group semi structured interviews using a case sample.<br>Analysis using Kvale's description of meaning interpretation  | Therapist (occupational therapist) perception | Occupational therapists (n=13) recruited from twelve departments of rehabilitation (community and hospital based) in the Netherlands and Belgium. Therapist experience ranged from an average of 8-19 years.                     |
| Ewan et al (2010)    | To explore 8 peoples experiences and responses to taking part in a personalised observation based intervention for stroke rehab   | Qualitative observation based design   | Semi-structured interviews (based on an interview guide)<br>Analysed using the inductive content analysis approach   | Patient perception                            | Stroke patients (n=8); aged 44-70 ranging from 12-102 months post stroke. Recruited from three UK-based stroke support groups and scored higher than 70 on the modified Mini-Mental State Examination.                           |
| Gillot et al (2003)  | To explore and describe perceptions and experiences of 2 stroke survivors who took part in a Constraint Induced Movement Therapy home rehab program                     | Multimethod approach: phenomenological design. In depth case studies were used to investigate qualitative themes and a within-subject design to obtain quantitative information regarding the participants functional performance. | Five meetings (interviews based on interview guide)<br>Minnesota rate of manipulation test (MRMT), Arm motor ability test (AMAT) & COPM<br>Analysis (open coding, axial coding & selective coding) | Patient perception                            | Convenience sample stroke patients (n=2); aged 42-65 identified through community referrals. Time since stroke ranged from 2-9 years   |
| Higgins et al (2005) | To investigate the delivery of an arts based intervention to stroke patients and sought users and professionals views of perceived barriers                             | Qualitative: Exploratory and descriptive design  | Participant observations & In-depth semi-structured interviews (based on an interview topic guide)<br>Analysis using the framework method  | Therapist and Patient perception              | Participants were recruited from the stroke rehabilitation ward of a London teaching hospital.<br>Purposive sample of therapists (n=8)<br>Purposive sample of Stroke patients (n=21); aged 32-87                                 |

|                       |   |  |   |   |  |
|-----------------------|---|--|---|---|--|
| Leach et al (2010)    | To describe current practices in goal setting within a sub acute rehab setting from the perspective of Occupational Therapists, Physiotherapists and Speech and Language Therapists | Qualitative design   | Semi structured email interviews (7 semi structured open ended questions) with incorporation of case studies                    | Therapist (occupational therapist, speech therapists and physiotherapist) | Active participants: Therapists from the Geriatric Assessment and Rehabilitation Unit within a public metropolitan Australian Hospital setting.<br><br>Purposive sampling - Stroke patients in case studies (n=5); aged 49-68            |
| Lewis et al (2011)    | To evaluate the feasibility and users perspectives of a novel Virtual Reality game based rehab intervention for people with stroke  | Mixed methods: Prospective feasibility design              | Fugl-Meyer Assessment, Box & block test<br><br>Post intervention questionnaire<br><br>Semi-structured interview                 | Patient perception  | Stroke patients (n=6); aged 55-75 ranging between 1.4-9.5 years post stroke who had upper limb hemiparesis   |
| Maclean et al (2000)  | To explore the attitudes and beliefs of patients with stroke identified by professionals as having high or low motivation for rehab   | Qualitative design   | Analysed using the content analysis approach<br><br>Semi-structured interviews.<br><br>Analysed using content analysis approach | Patient perception  | Extreme case sampling of stroke patients currently undertaking rehabilitation (n=22) –high motivation (n=14) and low motivation (n=8); on average 6 weeks post stroke. Recruited from the stroke unit of an inner city teaching hospital |
| Marklund et al (2010) | To describe patients with stroke experiences of training with lower extremity CIMT  | Qualitative: Inductive design                              | Interviews (based on interview guide)<br><br>Analysis -content analysis approach  | Patient perception  | Patients with stroke (n=7); aged 35-74 ranging from 3-16 years post stroke. Recruited from a rehabilitation department in Sweden.  |
| Proot et al (2000)    | To determine facilitating and constraining factors regarding patient autonomy at discharge from nursing homes   | Qualitative longitudinal design - Grounded theory approach | Open ended interviews based on interview guide<br><br>Analysis using the constant comparative method                            | Patient perception  | Consecutive patients with a diagnosis of stroke (n=20); aged 50-85<br><br>Recruited from rehabilitation wards of three nursing homes in Limberg, Netherlands.  |
| Proot et al (2000)    | To determine facilitating or constraining factors regarding patient autonomy during rehab in nursing homes  | Qualitative longitudinal design - Grounded theory approach | Open ended interviews based on interview guide<br><br>Analysis using the constant comparative method                            | Patient perception  | Consecutive patients with a diagnosis of stroke (n=17); aged 50-85. Recruited from rehabilitation wards of three nursing homes in Limberg, Netherlands.  |
| Proot et al (2007)    | To explore patients with stroke experiences of health professionals approach toward autonomy in a longitudinal way  | Qualitative longitudinal design - Grounded theory approach | Open ended interviews<br><br>Analysis using the constant comparative method   | Patient perception  | Consecutive patients with a diagnosis of stroke (n=22); aged 50-85<br><br>Recruited from rehabilitation wards of three nursing homes in Limberg, Netherlands.  |



|                          |  |   |  |  |   |
|--------------------------|--|---|--|--|---|
| Reid & Hirji (2003)      | To explore the use of a virtual reality leisure intervention programme in adult stroke survivors   | Mixed method<br>Exploratory cross-sectional design w/ observation | Volitional Questionnaire version 3.0, demographic questionnaire, satisfaction with life scale, mini-mental state exam, the centre for epidemiological studies depression scale and videotaping of sessions | Patient perception   | Patients with stroke (n=16); aged 49-86 and lived independently in the community. Recruited by convenience sampling through stroke organizations, agencies and community centers within the Greater Toronto area. Patients had only one stroke; mean number of years post stroke was 7.38 years   |
| Roding et al (2003)      | To describe and analyses how younger stroke patients experienced the rehab process and to develop a hypothesis of their after stroke life situation  | Qualitative design  | Thematised in-depth interviews (based on interview guide)<br>Analysis using the grounded theory/ constant comparison approach  | Patient perception   | Purposive sample- patients with stroke (n=5); aged 37-54 ranging from 1-1.5 years post stroke. Recruited through a convenience sample from northern Sweden.   |
| Schouten et al (2011)    | To identify group member and staff perceptions of their involvement in a post acute, multidisciplinary stroke rehabilitation programme   | Qualitative: Interpretive descriptive design                      | Semi structured interviews (based on interview guide)<br>Analysis (In depth thematic analysis)   | Therapist (occupational therapist and physiotherapist) & Patient | Recruited through non-probability purposive sampling Staff clinicians (n=3) and stroke patients (n=4); aged 65-85 ranging 18 months-18 years post stroke who were receiving acute care in a hospital setting  |
| Talvitie & Pyoria (2006) | To describe the communication actions (structures, functions and discourses) of physiotherapists and patients in counseling sessions.  | Qualitative: Discourse analysis design                            | Videotaped measurement and counseling sessions<br>Discourse analysis conducted on transcriptions of these sessions   | Therapist and patient perception                                 | Physiotherapist (n=15) were recruited from a hospital, rehabilitation center, and three health centers in the district of East Savo, Finland., patients with stroke (n=7 female); aged 68-87 were recruited from an experimental group participating in an ongoing controlled study of stroke therapy and were in differing stages of stroke rehabilitation, Caregiver (=3) |
| Wottrich et al (2004)    | To explore, describe and compare the characteristics of physiotherapy sessions with stroke patients from two different perspectives (patient and physiotherapist) in relation to observed behavior | Qualitative- Descriptive and comparative design                   | Observations and semi-structured interviews  | Therapist (physiotherapist) and Patient perception               | Physiotherapists (n= 10) with on average 4 years of professional experience (2.5 specifically working in stroke rehab) and stroke patients (n=9); aged 45-88 ranging from 6-48 months post stroke. Participants were recruited from differing rehabilitation units within the Stockholm area.   |

A number of papers acknowledged the importance of therapist support in the patient maintaining a positive mood state and achieving a high degree of volition within their rehabilitation (Bendz 2003, Ewan et al 2010, Proot et al 2000b, Reid and Hirji 2004, Wottrich et al 2004). With encouragement, attention and support, patients were observed to become more receptive to both mentally and physically engaging tasks (Ewan et al 2010). In addition, Proot et al (2000b) found that positive verbal encouragement helped patients become more actively involved in their rehabilitation and deal with their disabilities in a more positive light.

The final component is the patients' perception of therapist involvement and preparation within their rehabilitation, the time constraints within each session and the multidisciplinary team (MDT) input. Time constraints were seen as a perceived barrier, influencing the way the therapist deliberated with others and delivered the therapy. Gillot et al 2003, Proot et al (2000b) and Proot et al (2007) observed time constraints within rehabilitation caused a drop in the patient's perceived effectiveness of therapy and reduced patient autonomy. Furthermore, the lack of a multidisciplinary approach was observed to cause confusion and reduce an individual's ability to 'attend' their rehabilitation, possibly influencing engagement (Proot et al 2000b). In MacLean et al (2000) one patient stated that receiving contradicting advice from health professionals regarding their rehabilitation decreased their motivation to complete their exercises and actively participate.

### Personalised Rehabilitation

Rehabilitation individualised to the needs and requirements of the patient has been seen as a key factor that may influence patient engagement in rehabilitation. Reid and Hirji (2003) looked at a virtual reality intervention and the factors influencing

patient motivation within the stroke population. The study observed enhanced levels of self-motivation when patients were placed in a rehabilitation environment where they were able to express their creativity and personal identity. In addition, the competitive component of the virtual reality intervention resulted in engagement being sustained throughout the therapy session.

There is evidence to suggest that the familiarity and perceived importance of tasks is an integral component of engagement. Several studies found that patients were less motivated to actively participate in their rehabilitation when given tasks that were unfamiliar and not meaningful to them (Ewan et al 2010, Proot et al 2000a, Proot et al 2007, Rödning et al 2003, Wottrich et al 2004). Proot et al (2007) concluded that rehabilitation needs to be personalised to the individual to whom it is being delivered, helping the patient regain a 'sense of self' and possibly enhancing their level of engagement. In another study, Ewan et al (2010) carried out an observation based intervention involving DVDs that were based on activities that the patients had valued pre-stroke. After taking part in this intervention a participant described how their motivation to take a more active role in their therapy had increased when the therapist based their rehabilitation around activities on his DVD. If individuals believed their rehabilitation was not meaningful, functional or personalised to their needs they may become disengaged from their rehabilitation (Ewan et al 2010, Proot et al 2000a).

### Paternalism versus Independence

The patient's degree of autonomy during their rehabilitation has been seen in present studies to possibly influence patient engagement (Maclean et al 2000, Proot et al 2000a, Proot et al 2000b, Proot et al 2007). Proot et al (2000a) indicated that as patient autonomy increases, patients often take on a more

**Table 3: Critique of current literature – Qualitative design**

| Author/ Date         | Clear Aims | Was qualitative methodology appropriate? | Research design appropriate to address aims? | Recruitment strategy appropriate to the aims? | Appropriate Data collection | Relationship between researcher and participants has been adequately considered? | Ethical issues considered? | Data Analysis | Clear statement of findings? | How valuable is the research? |
|----------------------|------------|--|--|---|-----------------------------|--|----------------------------|---------------|------------------------------|-------------------------------|
| Bendz 2003           | ✓          | ✓  | ✓  | ✓   | ✓                           | ✓  | ✓                          | ✗             | ✓                            | ✗                             |
| Daniels et al 2002   | ✓          | ✓  | ✓  | ✗   | ✓                           | ✓  | ✗                          | ✓             | ✓                            | ✓                             |
| Ewan et al 2010      | ✓          | ✓  | ✗  | ✓   | ✓                           | ✓  | ✓                          | ✓             | ✓                            | ✓                             |
| Higgins et al 2005   | ✓          | ✓  | ✗  | ✓   | ✗                           | ✗  | ✓                          | ✗             | ✓                            | ✗                             |
| Leach et al 2010     | ✓          | ✓  | ✗  | ✗   | ✓                           | ✗  | ✓                          | ✓             | ✓                            | ✗                             |
| MacLean et al 2000   | ✓          | ✓  | ✗  | ✓   | ✓                           | ✓  | ✗                          | ✗             | ✓                            | ✓                             |
| Marklund et al 2010  | ✓          | ✓  | ✗  | ✗   | ✓                           | ✓  | ✓                          | ✓             | ✓                            | ✗                             |
| Proot et al 2000a    | ✓          | ✓  | ✓  | ✗   | ✓                           | ✗  | ✓                          | ✓             | ✓                            | ✓                             |
| Proot et a. 2000b    | ✓          | ✓  | ✓  | ✓   | ✓                           | ✗  | ✓                          | ✓             | ✓                            | ✓                             |
| Proot et a. 2007     | ✓          | ✓  | ✓  | ✓   | ✓                           | ✗  | ✓                          | ✗             | ✓                            | ✓                             |
| Rödning et al 2003   | ✓          | ✓  | ✗  | ✗   | ✓                           | ✗  | ✗                          | ✓             | ✓                            | ✗                             |
| Schoulten et al 2011 | ✓          | ✓  | ✓  | ✓   | ✓                           | ✓  | ✓                          | ✓             | ✓                            | ✓                             |
| Talvitie et al 2006  | ✓          | ✓  | ✓  | ✓   | ✓                           | ✓  | ✓                          | ✓             | ✓                            | ✓                             |
| Wottrich et al 2004  | ✓          | ✓  | ✗  | ✓   | ✓                           | ✗  | ✓                          | ✓             | ✗                            | ✓                             |

**Table 4: Critique of current literature – Mixed method design**

| Author/Date       | Qualitative                                   |  |  |  | Quantitative                                   |                                     |                          | Mixed Method                                  |   |
|-------------------|---|--|--|--|--|-------------------------------------|--------------------------|---|---|
|                   | Sources of data relevant to research question | Analysing process relevant to address the research question? | Appropriate consideration given to how findings relate to the context? | Is appropriate consideration given to how findings relate to researchers influence – through their interactions with participants? | Sampling strategy relevant to address question | Sample representative of population | Measurements appropriate | Research design relevant to address questions | Is the integration of qualitative and quantitative relevant to address the research question? |
| Gillot 2003       | x   | ✓  | x  | x  | ✓  | x                                   | ✓                        | ✓   | x   |
| Lewis et al 2011  | ✓   | ✓  | x  | x  | x  | ✓                                   | x                        | x   | x   |
| Reid & Hirji 2003 | ✓   | ✓  | x  | ✓  | ✓  | x                                   | ✓                        | x   | x   |

active role within their rehabilitation. It was identified that a paternalistic approach portrayed by therapists was valued by individuals when making treatment-based decisions on admission to rehabilitation. Proot et al (2007) highlighted that this approach needed to be followed by provision of information and an opportunity for evaluation and deliberation. However, therapists who displayed a prolonged paternalistic approach were observed to be a constraining factor for patient autonomy, specifically self-determination and independence (Proot et al 2000b). In McLean et al (2000) patients reported feeling stupid and incapable when they were overprotected by their therapists. Motivation levels were seen to be affected by the way the patients were able to link the goal of independence to their progress.

Proot et al (2000a) highlighted the importance of encouraging patient independence. As rehabilitation progressed towards discharge, independent self cares increased and the level of support provided to the patients was adjusted to facilitate their independence. A participant in this study commented on how increased independence enhanced their autonomy:

“At the beginning you only had to say a word. They helped you right away; physically they were there for you, emotionally as well. Now they tend to say: You can do that. I experience that as positive...” (p.280).

Proot et al (2007) concluded that the level of support provided to patients often needed to decrease for their autonomy to increase. Patients felt that increased independence gave them an opportunity to discover their own abilities and take on more responsibility in their rehabilitation. Although not explicitly explored, these findings suggest that enhanced patient autonomy may be a key determining factor for level of patient engagement.

#### *Patient Centred Practice*

Proot et al (2000a, 2000b, 2007) established that patient centred practice within rehabilitation was enhanced through informing patients and giving them an opportunity to deliberate treatment plans and goals. Patient centred practice facilitated patient autonomy and enabled patients to better accept and

deal with their impairments (Proot et al 2000a). In a study by Roding et al (2003), patients felt they were “walking alongside the process” when they were not adequately educated on their stroke or were not actively included in their rehabilitation.

“I was referred to the rehabilitation ward rather quickly after the stroke but I really did not understand what I was meant to do there. Perhaps it was a waste of money, I don’t know. I didn’t believe I needed it.” (Roding et al 2003 p.870)

Daniels et al (2002) noted enhanced motivation levels within the stroke population when patient centred practice was adopted and patient choice respected. Furthermore the physiotherapist population within a study by Wottrich et al (2004) stressed the importance of creating a client centred rehabilitation programme that was structured around the interests, goals and choices of the patient. This was seen to empower and encourage individuals to take a more active role. The patient population indicated that while therapists were often effective in treating specific impairments, they often did not adapt treatment to incorporate the unique characteristics of their patient. A patient reported, “I do not think that my personal qualifications have been taken into account nor has what I knew and did before” (p.1202). Bendz (2003) described patient centred rehabilitation to be based on shared understandings of the patient and therapist thus enabling achievable goals to be established and appropriate treatments provided to patients.

#### *Knowledge is Power*

Educating patients on their stroke and consequent rehabilitation may enable them to become more engaged and contribute more in the decision making process. A lack of information was seen to limit a patient’s independence, autonomy and their level of motivation to take part in rehabilitation (Proot et al 2000a). MacLean et al (2000) looked at the factors that influenced motivation levels within the stroke population. Patients described how they were more motivated to take a more active role in their rehabilitation when they were educated on their stroke and provided with reasoning for rehabilitation choices. A so-called ‘high motivation patient’ stated:



"I'm determined, yes. The physios are very good here, they're very encouraging and they explain things to you. Cos you don't know what the plan is, do you, unless they tell you. So then you know all the pain and everything is worth it" (p.1052).

Patients believed to have low motivation described how a lack of information often resulted in feeling anxious about the future and afraid to take part in their rehabilitation. In Roding et al (2003), patients expressed a lack of information as frustration and the feeling that they were just waiting around with nothing to aim for.

### **Feedback and Achievement**

The provision of feedback is thought to positively influence an individual's motivation to engage within their rehabilitation. In Reid and Hirji (2003) participants partaking in the virtual reality intervention were provided with constant visual feedback by viewing their scores onscreen. Participants felt that this feedback motivated them to achieve their personal best by beating their previous scores. Lewis et al (2011) again looked at a virtual reality intervention and as in Reid and Hirji (2003), found that the constant visual feedback of their score gave them real time feedback of their progress and performance, encouraging them to beat their score. Participants in Ewen et al (2010) reported unconscious movements associated with the visual content in their video playback intervention. Participants found it beneficial to see the task being undertaken to remind them of how they should feel and to gain a better understanding of the movement parameters. These studies have shown that feedback can lead to an increase in patient motivation, possibly enhancing the level that they can engage in their rehabilitation.

When looking at achievement Marklund et al (2010) observed an increase in self-esteem and motivation when patients achieved goals and succeeded in various rehabilitation activities. A patient in Gillot et al (2003) commented, "I've always been competitive, and being competitive, you want to get better... It's not what happens to you, it's how you handle it in your mind" (p. 172). This quote highlights the patient had increasing motivation in response to recognising functional gains. The feedback gathered acted as positive reinforcement.

## **DISCUSSION**

The aim of this review was to gain a more in depth understanding of the barriers and facilitators to engagement in rehabilitation following stroke. Engagement has been identified as an important factor by many clinicians throughout literature in achieving positive treatment outcomes in the rehabilitation of neurological conditions (Lequerica et al 2009, Lequerica and Kortte 2010). Engagement has been linked with improved rates of attendance, adherence, functional improvement and a greater level of function after discharge (Kortte et al 2007, Lequerica and Kortte 2010). Interestingly though, despite there being an increasing interest in engagement in rehabilitation, no papers were identified which explicitly set out to explore engagement in stroke rehabilitation. Rather, the papers included tended to explore experiences of rehabilitation following stroke

and in doing so, offer insight into the barriers and facilitators to engagement. This both has implications for interpretation of findings from this review, as well as highlighting an important weakness in the evidence base.

Seven main themes were identified from included papers. Goal setting was seen to possibly influence the way an individual engages in their rehabilitation and was considered most effective when patients were actively involved in the goal setting process and when goals were based on mutual understanding, negotiation and interaction. The therapist's manner, the level of support they provided and their perceived level of involvement in the rehabilitation process were all factors suggested to influence patient engagement. Patients were observed to be most engaged when both the rehabilitation intervention and environments were personalised to the patient. The level of familiarity and perceived importance of rehabilitation was considered a key component in the level to which an individual involves themselves in their rehabilitation. When patients perceived their rehabilitation to be non-meaningful and non-functional, they appeared more likely to disengage. In addition it was identified that the level of patient autonomy can have a direct effect on the degree that they actively involve themselves, with increased autonomy resulting in enhanced motivation. Patient centred practice was seen to possibly affect patient autonomy, with the importance of shared decision making and respecting patient choice observed within the literature. Rehabilitation structured around the interests, goals and choices of the patient was seen to empower and encourage individuals to take on a more active role in their rehabilitation. It was identified that educating patients about their stroke and reasoning for rehabilitation choices may encourage them to take on a more central role within rehabilitation based decisions. Finally the provision of feedback was seen to possibly affect patient engagement in specific rehabilitation interventions, providing patients with positive reinforcement and enhancing motivation.

The findings of this review should be interpreted with caution given that none of the included studies explicitly set out to explore engagement in rehabilitation. This review does however offer some important insight into perceived barriers and facilitators to engagement in stroke rehabilitation.

## **CONCLUSION**

Although several studies have acknowledged the key role that engagement plays in successful rehabilitation outcomes, (Kortte et al 2007, Lequerica and Kortte 2010) few studies to date have applied a qualitative lens to investigate the key factors that can affect engagement from the patients' perspective. Furthermore there are no studies that have investigated the complexities of patient engagement within the stroke population. Further research is needed to explore this topic in more depth from the perspective of key stakeholders. A deeper understanding of engagement within the stroke population may help to enhance rehabilitation processes and better equip rehabilitation providers with the clinical skills to best facilitate engagement and enhance the effectiveness of rehabilitation interventions.

## KEY POINTS

- Despite engagement being seen to play a key role in achieving positive treatment outcomes in the rehabilitation, no studies were identified which explicitly seek to explore engagement in stroke rehabilitation
- Evidence exploring experience of stroke rehabilitation offers some insight into factors that may serve to help or hinder engagement such as the importance of the therapeutic connection between patient and provider and a tailored, patient centred approach to rehabilitation
- Further research is required to further develop the understanding of the key factors that affect an individual's engagement specifically within the stroke population

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