Considering Client and Caregiver Experience after Stroke: A Systematic Review of Qualitative Studies to Enhance Quantitative Research

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Abstract

Objective: The purpose of this study was to examine the literature on the process of recovery through the perspective of both clients who have experienced stroke and their informal caregivers, in order to discover to what extent the findings of qualitative research enrich those of the quantitative type as to rehabilitation effectiveness.

Method: A systematic review of the salient qualitative research within EBSCOHOST, MEDLINE, AJOT, BJOT, and CJOT resulted in 50 articles identified. Of the articles initially identified, 41 met the inclusion criteria for further examination and critical appraisal. Themes that emerged from this review were compared with the results of a similar review performed by Peoples, Stanick, and Steultjens (2011).

Results: The overarching theme revealed was *expectation versus reality*, with six subthemes also evident: need for meaningful goal-setting, need for long-term support, need for improved education, need for more comprehensive support, need for more family/informal caretaker involvement, and a desire for a sense of control. Overlap between themes discovered here and in Peoples et al. (2011) included the need for improved information-sharing and the need for a long-term view of recovery. Final themes surrounding perspectives on the recovery process were considered in comparison to the quantitative findings of Ma and Trombly (2002) and Trombly and Ma (2002). The articles and this review agree that meaningful, realistic, client-centered goal-setting creates the best opportunity for not only improved function, but also for an improved sense of self.

Conclusion: Including qualitative literature in evidence-based practice can lead to an enriched understanding of the experience of stroke, leading to improved decision-making regarding the direction of therapeutic intervention.

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Stroke remains a leading cause of death in the United States, taking nearly 140,000 lives each year. The mortality rate associated with stroke, however, between 1995 and 2005 decreased by 30%, while the total number of deaths attributable to stroke decreased by 14% ("Stroke Statistics," 2012). Ever-improving modalities of acute care for stroke and stroke-related episodes have resulted in greater survival rates for those with strokes (Dmyterko, 2010). Put another way, an increasing number of people who experience stroke are surviving, a fact which, when viewed through the prism of the United States' predominantly insurance-based health care delivery system, presents both challenge and opportunity for the field of occupational therapy (OT). In the face of the abbreviated recovery times that third party payers will reimburse, now more than ever, the field of OT needs to ask itself if care delivery for this population is being given in the most appropriate, effective, client-centered manner possible.

Occupational therapists work intimately with clients who have experienced a stroke at every step of the recovery process not only to help those with stroke regain independent living skills, but also to teach safe and effective caregiving skills. That OT is fundamentally client-centered is axiomatic; yet, in an effort to become a more evidence-based field, the vast majority of cited research regarding the efficacy of various treatment methodologies is decidedly quantitative in nature (Tomlin & Borgetto, 2011). This emphasis on the quantification of treatment in occupational therapy disregards the patient experience of such. This practice can cause the field not only to lose sight of the individual, but also of the client-centeredness of the field itself. In keeping with a more medical-type model, qualitative research is not included in the American Occupational Therapy Association's (AOTA) hierarchy of evidence; leading one to conclude there is a relative discounting of research related to the qualitative experience of occupational therapists and their clients in practice. While experimental research is fundamental to the advancement of the profession's understanding of the field, a convincing argument can be made that experiential data collection leads to an enriched understanding of the illness experience, therefore improving overall treatment decision-making and effectiveness. Research of this kind generally, and in relation to treatment of clients who have experienced a stroke in particular, can ultimately make a meaningful contribution to the effectiveness of practice.

The general arguments against qualitative research speak to a lack of rigor, the commonly small sample sizes used, and the many different ways in which a situation can be perceived; purportedly, such small samples and the wide varieties of perspective give rise to a lack of generalizability (Mays & Pope, 1995). It has been proposed by some that rather than dismissing qualitative literature, new research should be focused on synthesizing its findings, perhaps leading to bigger, more generalizable themes that can be potentially useful in therapy (Sandelowski, Docherty, & Emden, 1996). As clients who have experienced a stroke constitute a large portion of the population served by occupational therapists (Yamkovenko, 2010), it follows that such a meta-synthesis of qualitative literature surrounding the stroke survivor's experience should be explored.

Background

Occupational therapy services and stroke. One of the primary principles of OT practice is based upon the belief that to best serve an individual one must remain client-centered. Therapy begins with evaluation, including an interview and occupational profile to better understand the needs of the client, and what is of most importance to him/her. Treatment is tailored to the client, and consists of working to improve or regain independence and participation in the areas of everyday living that are important to the client (AOTA, 2008).

In terms of how occupational therapists work with clients who have experienced a stroke, the same principles apply; and overall, such interventions can lead to an increase in quality of living. Through the use of client interviews following a stay in inpatient rehabilitation, Unsworth and Cunningham (2002) found that over half of the clients with stroke attributed their improvements directly to the work done with occupational therapists. As the ability to perform everyday occupations is cited as the most frequently lost function following stroke (Steultjens et al., 2003), it is common for clients who have experienced a stroke to work with occupational therapists (Yamkovenko, 2010). After stroke, an individual can experience an array of changes in his/her body and mind that have the potential to impact function: from physical dysfunction (such as muscle weakness, spacticity, or paralysis), to cognitive deficits (including issues with memory, sequencing, or problem-solving), to psychosocial implications (individuals can have feelings of loss or grief, or experience depression after stroke) (Gillen, 2011).

Clients who have experienced a stroke may see occupational therapists across the continuum of care; from the intensive care unit and acute care settings, to inpatient rehabilitation, through outpatient or home health care services. Occupational therapists, viewing the client in a holistic manner, assess how the new limitations impede functioning on several different levels. Common treatments center on the regaining or improvement of activities of daily living (ADL) and instrumental activities of daily living (IADL) functioning, as well as working with the family of the survivor to educate on reintegration into home, work, and community environments, (Gillen, 2011). Occupational therapists are particularly adept at using therapeutic use of self to inform and adapt their interactions with a client, addressing not only the physical needs, but also emotional needs (Taylor, 2008).

Evidence-based practice and the qualitative research conundrum. With the Eleanor Clarke Slagle lecture of 2000, a call to evidence-based practice (EBP) was instigated (Holm, 2000). EBP is defined as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett et al., 1996). As Holm (2000) put it, occupational therapists need to "justify *why* we do *what* we do in addition to *how* we do it" (p. 576). Although the EBP movement was born in the field of medicine, the field of occupational therapy also feels the drive for EBP by a healthcare reimbursement system that requires functional outcomes and justification for services, (Holm, 2000). In this effort to be evidence-based, the AOTA uses a hierarchy of levels of evidence model to inform practice. At the top of the hierarchy, Level I evidence includes meta-analyses, systematic reviews, and randomized controlled trials; at the bottom of the hierarchy at level V, case reports and literature reviews are found. While some contend that qualitative research in occupational therapy is generally accepted (Sheer, Arbesman, & Lieberman, 2008), it remains that qualitative research on whole is not included at parity in the current evidence hierarchy.

Quantitative research on the other hand, (namely, randomized controlled trials), has been considered the gold standard of research evidence. A randomized controlled trial is considered to have a higher degree of internal validity; such that with varying degrees of confidence, one can conclude that a particular treatment probably caused a particular result. Where quantitative research falls short is in including the personal perspective of treatment. In quantitative research, it is the researcher who determines treatment and the measures of its success. Some (Christiansen & Lou, 2001, Hammell, 2004, Tickle-Degnen & Bedell, 2003) have argued that this type of research, when not included with other types of data (such as varying types of qualitative research, e.g., interview) can have a tendency to demonstrate a hypocritical stance: the profession deems itself client-centered, but then places its highest value and importance on research that lacks insight from its clients.

Other dilemmas arise when discussing the current hierarchy system as a whole. The relegation of qualitative research to the bottom of the evidence hierarchy denotes a discounting of the findings such studies can provide. Yet, if OT is to be evidence-based, shouldn't all current research that has the potential to help make a better, more informed decision on service implementation be taken into account? Tickle-Degnen and Bedell (2003) argued that the current hierarchy may not be wrong under certain circumstances, yet in others, it should be considered erroneous not to take into consideration all relevant, available research.

Highlighting this point is the two-part review of quantitative data of Trombly and Ma (2002) and Ma and Trombly (2002). The researchers found evidence not only for the efficacy of OT working with clients who have experienced a stroke to improve participation and activity after stroke, but also for the use of client-identified goal-setting and occupation in treatment intervention. Decidedly lacking from the two-part review of evidence supporting the use of OT after stroke (Ma & Trombly, 2002; Trombly & Ma, 2002) was any inclusion of qualitative data. The only research articles allowed into the review were randomized control trials, non-randomized control trials, and single-subject designs. Therefore, while the information was valuable (in that it supported the use of OT with this population), it ultimately lacked the insight of the client perspective. While the studies investigated for the review demonstrated some amount of quantifiable improvement, it cannot be known for sure what the client service experience was. Was it appropriate given the client's goals and circumstances? Were the services delivered in an optimal manner? This point is further emphasized by Sabari (1998). Sabari specifically questioned whether clients who have experienced a stroke currently receive the right care at the right time. Knowing what constitutes effective and appropriate intervention is important when considering the short amount of rehabilitation time allowed by third party payers. It follows that therapists can be better equipped to tackle these considerations when they take into account client perceptions of effectiveness (Sabari, 1998).

The Occupational Therapy Practice Framework (OTPF), revised in 2008 (AOTA, 2008), illustrates the current scope of OT practice in the U.S., and highlights the different domains that influence a client's occupational performance. The context and environment of the client are noted as underlying the entire OT process of evaluation, intervention, and assessment of outcomes. According to the OTPF (AOTA, 2008, p. 614), "The client's internal context…affects service delivery by influencing personal beliefs, perceptions, and expectations. The cultural context, which exists outside of the person but is internalized by the person, also sets expectations, beliefs, and customs that can affect how and when services may be delivered." As context can be a difficult and complex phenomenon to measure, creating an operational definition for quantitative studies can be complicated (though not totally unattainable, as is seen with quality of life questionnaires or caregiver burden scales). It follows that a large portion of the practice framework may be potentially overlooked in current research reviews. Qualitative research excels at capturing the first person experience (including the internal context that exists within the person), thus substantially helping to tie in the contextual portion of the OTPF. Yet context is not the only relevant factor in understanding and improving service delivery. As opposed to its qualitative counterpart, quantitative research is most valued for its ability to measure outcomes, often focusing more on the person-aspect of treatment rather than the environment or context. Thus, for EBP to be most effective, all types of research, including qualitative and quantitative, should be utilized in conjunction with one another. This argument for triangulation, or mixed methodology, in healthcare research speaks to its potential to present a richer, more whole picture of both the client and the illness experience (Al-Busaidi, 2008; Lingard, Albert, & Levinson, 2008; Risjord, Dunbar, & Moloney, 2002).

The qualitative meta-synthesis. The general reason for the continued relegation of qualitative research remains the idea that it lacks generalizability due to its small samples and the notion that there is immense potential for differing experiences and perspectives (Mays & Pope, 1995). However when certain techniques are employed such as member-checking, triangulation, and peer-checking, the amount of rigor (or trustworthiness) rises (Krefting, 1991). Furthermore, transferability in qualitative research (similar to external validity in quantitative research) can be established by providing dense descriptions of the population under investigation (Thomas & Magilvy, 2011).

In an effort to find a solution to the current hierarchy limitations, Tomlin and Borgetto (2011) argued for an entirely different approach to evaluating evidence. According to the researchers, all major types of research, experimental, outcome, descriptive, and qualitative, should have a place in evidence-based practice. Three types of research are organized to create a pyramid (symbolizing the notion that each type should be regarded as of equal importance compared to the others), with descriptive research supporting the pyramid as its base. Within each type of research (each side of the pyramid and the base), there remains a hierarchy of less rigor to more rigor, and, in general, potentially less internal validity to more internal validity. At the top of the qualitative side of the pyramid sits the qualitative meta-synthesis. Similar to the quantitative meta-analysis, the qualitative version attempts to cull through the relevant research in order to discover the bigger themes surrounding care-delivery which practitioners could use to better-inform the clinical reasoning and decision-making processes. Tomlin and Borgetto are not alone in their reasoning for the inclusion of qualitative research; others have argued for the need of qualitative meta-synthesis in order to better understand the *total* picture of healthcare service-delivery (McKevitt, Redfern, Mold, & Wolfe, 2004, Sandelowski et al., 1997, Sheer et al., 2008).

In terms of how this relates to clients who have experienced a stroke, Salter et al. (2008) suggested from their qualitative meta-synthesis findings that stroke represents a "sudden, overwhelming and fundamental change for the survivor" (p. 601), and that themes surrounding loss, uncertainty, and social isolation are common. This knowledge has the potential to be paired with quantitative research in order to improve and better-inform treatment and intervention planning. Salter et al. (2008) also wrote of the need for additional qualitative meta-syntheses in order to continue to improve the understanding of the stroke process and how it relates to this population of clients. It is suggested from their research that rehabilitation professionals should work to be more aware of the patient's goals and perspectives. By focusing care on what is relevant to the individual, Salter et al. (2008) proposed that a more meaningful recovery can take place. The findings of McKevitt et al. (2004) further bolstered the need for more collaboration among service providers, researchers, and clients within the realm of stroke care. Their systematic review of qualitative research found that often the client and/or caregiver perspective were not taken into account by the service provider, definitions of recovery were divergent, and the timing of information and service delivery was not always ideal. A systematic review of qualitative research surrounding the client experience of rehabilitation performed by Peoples, Stanick, and Steultjens (2011) discovered that there is significant internal struggle felt within the person experiencing stroke surrounding notions of power versus empowerment, i.e. the right to make decisions versus the right *not* to make decision.

As stroke remains a leading cause of disability ("Stroke Statistics," 2012) and a large portion of the population served by OT (Yamkovenko, 2010), it is imperative that the profession continues to seek *all* relevant knowledge with the potential to improve client care and outcomes. How else will practitioners know that the interventions chosen fit well with the needs and desires of the client? If the profession is to remain client-centered, more qualitative meta-syntheses will be required.

To that end, and in keeping with the spirit of the research pyramid proposed by Tomlin and Borgetto (2011), the purpose of this study was to examine the literature on the experience of recovery through the perspective of clients who have experienced stroke and their informal caregiver, in order to discover to what extent the finding of qualitative research enrich those of the quantitative variety as to rehabilitation effectiveness. The ultimate goal is to obtain a more robust understanding of the client experience, so that the decision-making process of the OT practitioner may be enhanced.

Method

Research Design

The research method employed was a systematic review of the salient qualitative research. Utilizing a systematic review, (as opposed to a review with less rigor) ensured that the process could be replicated. How articles were chosen, reviewed, and analyzed followed the system of Sandelowski et el. (1996), such that the researcher attempted to decipher the universal meaning behind the use of various language in reviewed articles (i.e., be an "expert translator"), set inclusion criteria that were purposefully broad so that valid research was not erroneously excluded, and explain article exclusion by the lack of appropriate reasons to include them. In order to assist in the interpretation of universal themes from the articles, content analysis also roughly followed a summative approach, as laid out by Hsieh and Shannon (2005), where the researcher sought to identify and quantify word and content usage.

Inclusion Criteria

The process of researching and reviewing relevant literature began via an exhaustive search through online databases MEDLINE and EBSCOHOST, and through online searches of specific journals, namely, the *American Journal of Occupational Therapy (AJOT),* the *British Journal of Occupational Therapy(BJOT),* and the *Canadian Journal of Occupational Therapy (CJOT).* Articles needed to be specifically qualitative in method, addressing perspectives on therapy services through the eyes of clients who had experienced a stroke. The search focused on studies published between January 1992 and March 2013, providing about a twenty year span.

Another key criterion for inclusion in the search for literature was that the articles were in English. There was no exclusion of international journal articles, (in fact, it was explicitly noted how many relevant articles came from outside the U.S.). Key search terms used include *occupational therapy, stroke, qualitative research, patient perspective, care-delivery, and rehabilitation experience after stroke.* It was the researcher's hope that the number of articles eventually reviewed and found important for the project would total around 35. That was a number that seemed realistic for one researcher to systematically review, and was also a number from which overarching themes should have been able to be extracted.

Methodological quality of the included articles was important in order to ensure that the broader themes being extracted were sound and included as much transferability (comparable to external validity for qualitative research) as possible. Therefore, in order for an article to be selected for inclusion, it needed to have demonstrated attempts at increasing the overall trustworthiness of the research (through such tactics as member-checking, peer-checking, triangulation, reflective journaling).

Content Analysis: Coding and Theme Extraction

Throughout the search process and into the coding and theme-extraction process, it was of the utmost importance that an auditable, documented trail be made in order to keep the greatest degree of transparency possible. This was executed via researcher journaling and peer-checking with committee members; helping to ensure that future researchers could replicate the search and content analysis process, and that the trustworthiness (comparable to internal validity) of this systematic review is sound.

There was one researcher for both the review and the coding process, with the addition of one research committee member performing a code-recode of a data sample in order to help establish the replicability of data analysis. Several passes were made through the articles identified. The initial pass gathered publication information, including year, country of journal, from whose perspective the article was written (person with stroke, family, caregiver, etc), what type of (and how many) measures of trustworthiness were employed, author-identified themes, and what therapy implications were considered to be. This gave the researcher enough information to begin creating categories (and possibly subcategories) that aided in extracting possible themes across the articles.

Once the basic characterizations and categorizations of each paper were assigned, themes were sought. The process by which themes emerged roughly followed a summative approach (Hsieh & Shannon, 2005), where the aim of the analysis was to explore and quantify the frequency with which particular words were used or content was explained, in an attempt to decipher universal meanings. Concentrated effort was placed at extrapolating greater meanings from each article's discussion and therapy-implication section (a condensed version of which is included in Appendix), and commonalities were sought. Using information drawn from these sections allowed for integration of the author's conclusions along with larger meta-themes as they revealed themselves to the researcher. When at points similar wording was used to describe a perspective, phenomenon, or issue, it was noted and received a code color. Each commonality that emerged to the researcher was color-coded to assist with organization. Some articles received numerous codes, as they seemed to address several issues, while other articles received only one code, as only one theme appeared to the researcher. This coding process was deemed satisfied when it was felt that the most pressing implications from each paper had been addressed and assigned one or more codes, and the wording selected to describe each code best fit with its universal meaning, as determined by the researcher.

A general framework of themes previously identified by Peoples et al. (2011) served as a point of comparability and contrastability for the researcher, as the authors of that study sought to review a similar topic (the client experience of rehabilitation), and interpretations were made through an OT lens. However, as the Peoples et al. (2011) study was intentionally restricted to the rehabilitation experience only, it was expected that additional themes not identified for their purposes would be found.

There were two occasions that the researcher decided that additional passes through the literature would be beneficial in order to strengthen the emerging themes. This was due to the desire to reinforce the researcher's emerging themes. This decision to continue searching for articles was discussed with the research chair, and the conclusion was made that additional literature would add to the findings.

The final results of the content analysis process were three tables and one appendix. The first table displays relevant descriptive characteristics of the included articles. The second table displays the researcher's overarching themes and theme subcategories along with the studies from which each theme and subcategory originated. The third table displays the themes of Peoples et al. (2011) side by side with the themes revealed by this review. The appendix displays the characteristics of the articles reviewed (year, country, etc.), themes of each article, and therapy implications. Charting the content analysis helped with the theme extraction process, as having only the most important information together highlighted key points. The use of tables was also helpful from an organizational standpoint, by keeping the categories already documented readily visible.

Results

Article Search

An initial search of EBSCOHOST, MEDLINE, AJOT, BJOT, and CJOT resulted in 50 articles identified. Of the articles initially identified, 41 met the inclusion criteria for further examination and critical appraisal.

Article characteristics. Of the 41 identified articles, the majority were the result of research performed outside the U.S. (35 of 41 articles); with Scandinavian countries the most strongly represented (see Table 1). The journal *Disability & Rehabilitation* produced almost half of the articles included in this review. While the researcher allowed a twenty-year span from which to search for articles, the majority of articles found were published between the years 2007-2013. Though the researcher left the article search open to various perspectives (the person with stroke, the family member, or the therapist), the majority of articles found were written about the perspective of the person with stroke (33 articles). Thirteen articles included the perspective of a family member, and three included the perspective of a healthcare provider. Ten articles included various combinations of more than one perspective, either the person with stroke and the spouse, or the person with stroke and the healthcare provider. The most common methods used to insure rigor in the articles found were peer-checking (27 articles) and journaling (15 articles). Of note, it was discovered during the article retrieval process that many articles used varying language to describe the methods of trustworthiness that were applied. Therefore, the researcher documented when a study mentioned terms such as "group discussion" or "consensus coding" and it was decided with the research committee that as long as the rigor process was discussed and documented for the study, it would be allowed inclusion into this review. Finally, five of the articles included in this review were also examined in Peoples et al. (2011).

Themes

From the 41 articles in the review, seven themes emerged (see Table 2). The overarching theme can be distilled to the idea of *expectation versus reality*, which was evident in each of six subthemes: need for meaningful goal-setting, need for long-term support, need for improved education, need for more comprehensive support, need for more family/informal caretaker involvement, and a desire for control over the recovery process. Each of these subthemes can be thought of as solution-based; where problems or issues identified by the client, caregiver, or healthcare professional could potentially be rectified if the following appropriate measures were taken.

Meaningful goal-setting. Twenty-six articles were identified that spoke on some level to the need for increased or improved goals for rehabilitation, eight of which specifically noted that not only should the client's past roles, habits, and routines be taken into account, but the client's expectations should also be balanced with the realities of his/her diagnosis (see Table 2). One important aspect of meaningful goal-setting includes the client's self-concept. A client's acceptance of his/her new identity, personal beliefs developed about abilities, even unfavorable comparisons made between other people with stroke or perceived negative feedback can all make a difference in how goals for recovery are formulated and met or potentially not met (Gillot, Holder-Wallis, Kurtz, & Varley, 2002;

Maclean, Pound, Wolfe, & Rudd, 2000). As a participant from a study by Gustafsson and Bootle (2012) described the frustration of her new condition:

> Just actually being able to stand there and actually do [the dishes], until they're done. I just can't, can't do that. I struggle in the shower with wash[ing] my hair and stuff, but the nurses were doing that at the hospital.

Failure to achieve goals due to a client's high, unrealistic expectation can lead to disappointment, a decreased sense of self-worth, isolation, or occupational deprivation (Mangset, Dahl, Forde, & Wyller, 2008; Patomella, Johannsson, & Tham, 2009; Wottrich, Astrom, & Lofgren, 2012). Ten articles (see Table 2) noted that a lack of meaningful, collaborative goal-setting was perceived between the client and his/her healthcare professional. Bendz (2003) found that much divergence was present in the way healthcare professionals and clients regarded recovery goals and treatment expectations. Patients had non-specific goals for recovery and were influenced by fatigue, fear, and loss of control; versus their healthcare professionals, who were focused on simply reducing dysfunction and training the individual. Therapists in these studies did not appear to take into account the varying emotions clients were experiencing after their strokes, and how these could impact goal-setting (Bendz, 2003).

Additionally, a lack of collaboration between the client and the healthcare professional appears to exacerbate unrealistic goals and unmet needs of the client (Bendz, 2003; Graven, Sansonetti, Moloczij, Cadihac, & Joubert, 2013; Kubina, Dubouloz, Davis, Kessler, & Egan, 2013; Lewinter & Mikkelsen, 1995; Wottrich et al., 2012). This lack of collaboration is demonstrated through poor communication and a lack of discussion. Wottrich, Stenstrom, Engardt, Tham, and von Koch (2004) found that often the healthcare professional and the client too easily slide into expert-subordinate roles during the rehabilitation process. This role relationship can lead to poor collaboration in goal-setting and an overall plethora of unmet needs.

Need for long-term support. Fifteen articles made some reference to the need for long-term support for the person with stroke, the caregiver, or both. These articles implied that taking a long-term perspective towards recovery, and trying to change the thought process about recovery (to acknowledging that it's an ongoing process) can improve not only therapy outcomes (because goals are more realistic), but also the client's self-perceptions in the recovery progress. Olofsson, Andersson, and Carlberg (2005) found that the transition between inpatient rehabilitation and discharging to home for clients can result in new insights into one's abilities (or lack thereof); and can thus result in changes in goals or in their perspective about recovery.

Each of the 15 articles identified for this theme found that persons with stroke (along with caregivers or healthcare providers) felt that there is not enough support for the person with stroke and his/her caregiver after returning home. Five of these articles further noted that it would be beneficial for healthcare providers to check-in after discharging clients, (see Table 2). As one caregiver from a study by Lawrence and Kinn (2013) explained, "There doesn't appear to be a lot of help, there's a bit of initial consultant, 'Right, what's caused this?' 'Oh, very unusual' and they did a few tests…and they discharged her after a week," (p. 592).

Wottrich et. al. (2004) found that both the healthcare provider and the person with stroke feel frustrated about the lack of time for rehabilitation services. Four of these articles (see Table 2) identified community support groups as a viable way to provide the support clients need; healthcare providers should become better aware of such resources in the community and/or create support groups within the rehabilitation center.

Need for better education. Ten articles addressed the need for improved education for the person with stroke and his/her informal caretakers. Seven studies (see Table 2) made mention of the fact that those with stroke and often their informal caretaker were overly cautious once returning home, fearful of potentially causing another stroke, or further hurting themselves. "I bring a friend who usually comes along as a precaution, for you can collapse at any time," (Bendz, 2003, p. 219). At times, a therapist's words of advice or caution were taken literally, and so caused the person or caretaker to avoid an activity altogether. Furthermore, these articles found that many people with stroke who left rehabilitation were still very unsure of their abilities. Proper communication between the healthcare provider and the person with stroke was identified by five of these articles (see Table 2) as an important factor in the recovery process. Lack of communication among healthcare providers was also noted as a potential barrier to recovery for the person with stroke. One study noted that healthcare providers needed to communicate with each other more on the types and extent of education provided so that services and communication could be more consistent across the recovery process.

Need for comprehensive support. Ten articles identified the need for more comprehensive rehabilitation services for both people with stroke and their informal caregivers. For nine of these articles (see Table 2), comprehensive support often translated into including more emotional and social support than is traditionally provided during inpatient rehabilitation. Jongbloed (1994) concluded that social circumstances surrounding the person with stroke (upon returning home) can often more profoundly influence recovery than the (perhaps somewhat arbitrary) ability to perform a particular task independently. It was further concluded that the person with stroke should be considered within his/her context in order to improve recovery outcomes. One strategy used to establish greater support was through the use of stroke-specific support groups, both in the community and during the inpatient rehabilitation process. Participation in a stroke-specific group led to a greater sense of self-awareness, self-confidence, self-efficacy, and potentially greater adaptation that could enable further participation. One participant from a study by Carlsson, Moller, and Blomstrand (2008) noted:

> You could speak about everything, and no one found you stupid. Everyone had the same experiences. When I say the same things at home, well, they kind of listen, but I feel like they don't understand what I'm talking about, (p. 779).

A participant in Wood, Connelly, and Maly (2009) spoke of how social situations have changed since experiencing stroke:

> I used to be social and I'm not so much anymore because we don't have the same interests anymore because you know, you have friends at work, they stay at work, you have friends at bowling, they stay at bowling, they just stay in their own groups. I don't go bowling anymore and I don't go to work so I've got nothing to talk about…You run out of things to talk about unless you're out there mingling. I don't have anything to say anymore, nothing, (p.1052).

Increased family involvement. Eleven articles identified increased family involvement in the rehabilitation process as vital to improving long-term recovery outcomes. As Buley, Shiels, Wilkie, and Salisbury (2010) noted, informal caregivers are not given enough attention during the rehabilitation process. The articles identifying the need for increased family involvement noted that the family/informal caregiver's role in the rehabilitation process is not currently well defined; with four articles noting that family-centered intervention should become more incorporated into therapy (see Table 2). Without more involvement from family members, Kerr and Smith (2001) concluded, services will be inadequate, poorly tailored, and inappropriate. The timing of this involvement is also important. As Cameron, Naglie, Silver, and Gignac (2013) found, caregiver needs are highest during the initial transition to home. As one participant in Cameron et al. (2013) stated:

> They cast us adrift, you're into the community and you're on your own. I would have- you know how they have- when you're a new mother and you get home, you have the hospital calling to check in on you and to see how you're doing and that type of stuff. I would have loved something like that, (p. 320).

It was concluded by Cameron et al. (2013) that caregiver information and support provision needs change across the care continuum, and healthcare professionals need to react to those changing needs accordingly in order to provide the most appropriate care.

Increasing sense of control. Eight articles in this review found that having a sense of control over the recovery process improved the client's outlook surrounding rehabilitation and increased perceptions of overall improvement after stroke; six specifically mentioned the importance of self-efficacy during recovery (see Table 2). Olofsson, Andersson, and Carlberg (2005) concluded that being in an inpatient situation can lead to a sense of passivity for the client, while going home is seen as taking control of their situation. This is supported by Wottrich et al. (2004), who, as previously noted, found that therapists and patients often too easily slide into expert/subordinate roles during rehabilitation. Olofsson et al. (2005) further concluded that often this sense of taking control is not utilized enough during the inpatient rehabilitation process. This sense of control, over a person with stroke's body, living situation, ability to make decisions, or overall recovery process may influence further improvements in function (Jones, Mandy, & Partridge, 2007).

Discussion

Theme Comparison (Peoples et al., 2011, vs. current study)

The themes that emerged from this review are somewhat in contrast to the themes discussed in Peoples et al. (2011) review (see Table 3). Although expected (as their study sought to review articles surrounding the experience of rehabilitation only), it is nonetheless interesting to note as there were five overlapping articles reviewed. Peoples et al. (2011) identified an overarching theme of *power and empowerment* along with the following subcategories: coping with a new situation, information needs, physical and non-physical needs, being personally valued and treated with respect, collaboration with healthcare professionals, and assuming responsibility and seizing control.

The themes found here centered more on perceived needs, or where support was lacking during recovery. These differences may be due to the scope of articles included for review. Peoples et al. (2011) focused on articles that sought to understand the experience of rehabilitation. As such, their themes tended to center more on internal processes, like coping skills, having a sense of control, and how he/she preferred to be treated. At the point of inpatient rehabilitation, it is very likely that a person recovering from stroke is only beginning to grapple with understanding his/her new condition.

Conversely, this review was kept purposely broad. A portion of the articles reviewed dealt with the experiences of people with stroke and their caregivers once they had returned home. This is perhaps in large part why the overarching theme discovered was *expectation versus reality*. During inpatient rehabilitation, it is nearly impossible to truly understand the scope of the changes caused by a sudden, traumatic event like stroke. Inpatient rehabilitation is spent attempting to come to terms with the new situation. The reality of such a situation can only be understood upon discharge from rehabilitation services. Only then might it be possible for the recovering person, and his/her caretaker, to realize the many changes that have occurred. It is once this recognition has happened that someone is able to reflect back on what he/she wishes had been discussed more, practices more, etc. And so with inclusion of perspectives related to recovery once returning to home, clients and their caregivers began to open up more about external processes like rehabilitation-related problems (such as timing, amount, and type of education and support provided). Knowing that this may be a common way in which a client processes a traumatic event such as stroke can potentially help with treatment planning: both goal-setting and priority treatment allocation.

Despite the difference in theme discovery between the current research and Peoples et al. (2011), similarities abounded; most prominent of which were the need for improved information-sharing and the need to take a long-term approach to recovery from stroke.

Need for improved information-sharing. Peoples et al. (2011) concluded that rehabilitation participants expressed a need for sufficient, individual information. This gathering of information was viewed as a way to self-direct and gain control over their own recovery. Appropriate knowledge of the causes of stroke, evaluation and treatment planning, and decisions about discharge helped the participants to understand rehabilitation goals and recognize when progress was being made. A lack of information, consequently, was seen as preventing the participant from taking an active role in rehabilitation.

The articles reviewed also often touched on themes surrounding the need for improved information-sharing, which is in agreement with the Peoples et al. (2011) subtheme regarding collaboration between healthcare professionals and people with stroke. Several articles made mention that poor information-sharing resulted in people with stroke (and sometimes their informal caregivers) being unsure of how to proceed once returning home. Some people with stroke were overly cautious, others were unsure of what they were able to do, or why they were cautioned not to do particular activities. Barnsley, McCluskey, and Middleton (2012) discussed the idea of healthcare professional as gatekeepers. Namely, healthcare professionals needed to be more aware of the consequences of the recommendations made to their clients. Families can become anxious about safety based on what therapists say, and perceived rules set by therapists are often taken literally. On the other side of this situation, of course, is not providing enough information for the client or family member. This too, can lead to anxiety, or a sense of not being in control of recovery. Without appropriate, individualized, timely information-sharing, clients are more apt to be left with unanswered questions, and may falter once discharged home.

As Roding, Lindstrom, Malm, and Ohman (2003) concluded, clients need the right information at the right time in order for rehabilitation to be appropriate and successful in the long run. Cameron et al. (2013) utilized a relatively new framework, Timing it Right

(TIR), to help understand the informational needs of informal caregivers and develop specialized educational and supportive programs based on its findings. The TIR framework consists of five phases that correspond to perceived caregiver support needs. Information needs were reportedly lowest during the diagnosis and stabilization phases of recovery and highest during the preparation and implementation phases, (Cameron et al., 2013, p. 318). Furthermore, the type of information needed changed over time. Cameron et al. (2013) found their participants felt that during the diagnosis phase, information should remain focused on treatment of the acute event; during transition to home however, information needed to be related for such topics as providing care, navigation of the healthcare system, and long-term goals. Cameron et al. (2013) concluded that at certain points during the recovery process, it may be more beneficial if the informal caretaker were more of the focus of treatment sessions.

One way discovered during this review to improve information-sharing is through the utilization of stroke support groups, both in inpatient rehabilitation and in the community, for both the person with stroke and the informal caregiver. Peer support was found to provide an opportunity to share emotions, information, and gain an improved sense of identity after stroke. Cameron et al. (2013) noted that caregivers sought the support of other caregivers, especially when at a point where the loved one with stroke was returning home. It was felt that a caregiving peer could provide practical information on how to reintegrate back into the community. Taking the client's social circumstances into consideration during the recovery process is also important. Robinson et al. (2009) concluded that social and psychological factors should be regarded as just as important as a physical disability when seeking a holistic recovery.

Recovery as a long-term process. The use of a community support group may also assist in solving the need for long-term support for recovery. Several of the studies found that a large portion of participants (both people with stroke and informal caretakers) felt unprepared to go home after rehabilitation. It was only upon returning home that reality set in and participants realized what activities they could no longer perform. This topic was not within the scope of the Peoples et al. (2011) review. However, it is possible to relate the concept of power and empowerment to having a sense of control over his/her own future, knowledge of a realistic recovery process, and possible resources in the community to help continue what was started during rehabilitation.

It was repeatedly concluded by authors in this review that a long-term outlook on recovery would benefit the person with stroke and his/her informal caretaker. It could be argued that this relates back to the need for improved information-sharing. Despite a handful of weeks (perhaps fewer) in an inpatient rehabilitation setting, participants often still felt unprepared to go home; or put another way, they simply didn't know what they didn't know. Expectations for recovery were high, hope swelled; the prospect of going home was itself motivating while the person was in rehabilitation. However, upon returning home, the realities of a new body, and potentially a new life, set in. This would be a prime time to engage a client in realistic, meaningful goal-setting. Again, it is important for rehabilitation professionals to strike the right chord between hope/expectation and reality, and understand that the majority of people with stroke (and their family members) will have little ability to realize the extent to which their lives have changed.

Implications for Occupational Therapy

In terms of occupational therapy effectiveness with people with stroke, Ma and Trombly (2002) and Trombly and Ma (2002) concluded from their reviews of quantitative studies that occupational therapy can effectively improve participation and activity after stroke, and help remediate physical and cognitive impairment. In particular, the use of occupation in a familiar context was found to successfully improve abilities, as was using a task-specific approach. Meaningful goals and client-chosen activities appeared to improve participation, as did providing a thorough home program upon discharge.

The overarching theme discovered during this review was that of *expectation versus reality*. Balancing the client and informal caretaker's hopes and high expectations for recovery with a measured dose of reality (which considers the person's new limitations) can result in more meaningful, appropriate goal-setting. However, in order to establish meaningful goals, there needs to be improvement in information-sharing and comprehensive, long-term support. Therefore, this review not only supports the conclusions of Ma and Trombly (2002) and Trombly and Ma's (2002) that meaningful, client-centered treatment can produce effective results, it also enhances them. Furthermore, this review supports the use of a comprehensive, detailed, meaningful home program, such that an appropriate home program could potentially help the person with stroke and his/her caretaker to continue the recovery process upon returning home. Ma and Trombly (2002) and Trombly and Ma (2002) stressed in their results the use of familiar context and familiar objects during treatment; the results of this review enhance those findings by expanding that goals and intervention need to be meaningful, balance expectation with reality of the diagnosis, and have a stronger emphasis on long-term success/recovery.

Limitations

This study was limited by the amount of time available to work on its creation. If there had been more time to sit with the project, it may have been possible to delve more deeply into each study's themes and the commonalities between them. The lack of time also affected the amount of code-recodes that were able to be accomplished. There was only one code-recode completed regarding the therapy implications section of the Appendix. An additional code-recode during theme extraction would have benefited the final project, allowing for greater strength of the study's trustworthiness.

Suggestions for Further Research

No one type of research is capable of offering all of the necessary information required to make informed decisions regarding a person's care. As such, further research is needed to strengthen and expand upon the idea that inclusion of all types of research, including quantitative and qualitative, is important in order to ensure that the rehabilitation community remains fully informed regarding effective, meaningful healthcare provision. Specifically, mixed methodology would ensure that the client perspective is not lost when considering treatment effectiveness. Additionally, current research still tends to lean heavily towards examining the inpatient portions of the stroke recovery process. As a result, more research is needed to examine the effectiveness of outpatient rehabilitation services and home health services. This would be especially important because the articles repeatedly stated that there is not enough comprehensive support after discharging from inpatient rehabilitation.

Conclusion

This literature review attempted to discover to what extent the qualitative research on the client perspective on the rehabilitation process enhanced the quantitative findings of treatment effectiveness after stroke. The conclusions of Peoples et al. (2011) were used to compare and contrast qualitative analysis results. Final themes surrounding perspectives on the rehabilitation/recovery process were considered in comparison to the quantitative findings of Ma and Trombly (2002) and Trombly and Ma (2002). Conclusions of both those articles and this review were similar: meaningful, realistic, client-centered goal-setting creates the best opportunity not only for improved function, but also for improved sense of self. This review also enriched the findings of Ma and Trombly (2002) and Trombly and Ma (2002) by demonstrating ways in which goals can become more meaningful (through balancing hope and expectation with the reality of the new situation), and ways in which appropriate support can be provided throughout the recovery continuum. Improvements in information-sharing, along with comprehensive, long-term support for both the person with stroke and their informal caretaker, could potentially lead to improved participation and enhanced quality of life for both parties throughout the recovery process.

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Note: asterisk indicates article was included within the systematic qualitative review

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	Appendix								
#	**Title**	**Author**	**Year**	**Country**	**Perspective**	**Measure Trust-worthiness**	**Author's themes**	**Journal**	**Implications for therapy**
1	Upper limb recovery after stroke: The stroke survivors' perspective	Barker & Brauer	2005	Australia	Person w/ stroke & their spouse	Re-reading transcripts, field notes, member-checking, peer review	Continued hope, hanging in there, keep moving forward, drawing on support. No time limit on recovery, benefit of support groups, therapy must match goals.	Disability & Rehab	Service would benefit from a self-management and self-improvement approach that would help prepare and guide persons with stroke through all of the psychological, social, physical, & educational demands for recovery; benefits of stroke support groups need to be explored & formally incorporated into stroke recovery services; upper limb should be as involved in recovery as lower limb;
2	Acceptance and Meanings of Wheelchair Use in Senior Stroke Survivors	Barker, Reid, Cott	2004	U.S.	Person w/ stroke	Journaling, member-checking, check-in w/ participant to make sure interpretation correct	Reluctant, internal, or grateful acceptance, understanding of prestrike lifestyle	AJOT	Self-concept, attitudes, values attributed to mobility and independence contribute to acceptance of w/c; most people felt they were same person as before w/c use; w/c acceptance also increased if it was perceived to decrease caregiver burden
3	What people are saying about traveling outdoors after their stroke: a qualitative study	Barnsley, McCluskey, & Middleton	2012	Australia	Person w/ stroke	Peer-checking	Factors that influence travel: emotional disposition, having meaningful destinations, expectations of recovery, sphere of influence	Australian JOT	Health professionals as gatekeepers- professionals need to be aware of consequences of recommendations made to clients-families can become anxious about safety & set limits/monitor stroke survivor; perceived rules set by

									therapists often taken very literally; activity level prior to stroke is linked with activity level after stroke-benefits of knowing that information can inform therapy; level of knowledge therapists have about return to driving unclear & not the same across the board.
4	Art after stroke: the qualitative experience of community dwelling stroke survivors in a group art programme	Beesley, White, Alston, Sweetapple, Pollack	2011	Australia	Person w/ stroke	Consensus coding, group discussion	Experience of stroke, benefit of art, benefit for self, benefit of group experience	Disability & Rehab	Enjoyment gained from social interaction & exploration of a new activity; personal & rehabilitative benefits experienced from attending an art group included increased self-confidence, self-awareness, social interaction, improved self-efficacy; improved speech & cognition; participants preferred to attend stroke-specific groups compared w/ community-based services-gap in knowledge-important for service provision-increased need for group-based stroke services
5	The first year of rehabilitation after stroke: from two perspectives	Bendz	2003	Sweden	Person w/ stroke, their healthcare professional	reflexivity	A stroke hits people without any warning; people who have had a stroke lose their normal functions, physical training as the means to recovery	Scand Journal of Caring Science	Importance of documentation for other HCP's-whomever writes the most notes (usually the physician) will tend to give the most shape to the rehab process; rehab should be viewed as a process, based on a shared understanding between the patient and HCP; much divergence found

									between HCP and patients regarding goals and treatment expectations- patients had non-specific goals of returning to prior life (normal); patients engaged in tasks asked of them but were part of the goal-creation process; not enough education about causes of stroke- lots of fear of having another stroke; not enough interaction between HCP and stroke survivor on collaborating toward realistic, structured, meaningful goals, not enough discussion about how goals would be met.
6	Dysarthria following stroke: the patient's perspective on management and rehabilitation	Brady, Clark, Dickson, Paton, & Barbour	2011	UK	Person w/ stroke	Constant comparison, collaborative review, coding framework	Maximizing communication, rehabilitation, preparatory activities, speech production, communication facilitation	Clinical rehab	A striking amount of non-observable processes go on when a patient w/ dysarthria is speaking; therapists should not just take observable language alone when considering the abilities of the patient; formal speech therapy is often viewed as stigmatizing & embarrassing, & often not challenging enough; speech practice is more meaningful when practiced during meaningful/relevant activities
7	Carer experiences of life after stroke: a qualitative analysis	Buley, Shiels, Wilkie, Salisbury	2010	UK	Spouse of person w/ stroke	Participant verification of interview summaries, peer-checking	Lives turned upside-down, increased workload/caregiving, reduced participation, altered	Disability & Rehab	Importance of caregivers not only for stroke survivor, but also for healthcare system- without informal caregivers, there would be a much greater load on the system; need for practical & emotional support

							expectations of life. Need for more information & help to understand & care for spouse.		at various stages of stroke recovery, more information needed; empowerment needed by healthcare providers; process of changing expectations can be difficult.
8	Stroke family caregivers' support needs change across the care continuum: a qualitative study using the timing it right framework	Cameron, Naglie, Silver, & Gignac	2013	Canada	Family of person w/ stroke & healthcare professional	Multiple researchers, peer-debriefing,	Types and intensity of support given, who provides support and method of providing support, primary focus of care	Disability & Rehab	Caregivers needs for support changes across the stroke survivors recovery process; caregivers and HCP often have very similar perspectives on caregiver needs for support-needs are highest when preparing for transition home; caregivers need for more hands-on practice as well as feedback on their abilities to perform care-giving task; HCP & caregiver disagreement on who should be focus of treatment-HCP belief that patient should always be center of treatment while caregiver would like more focus at certain points; change in stroke care delivery to 7 days per week would benefit caregiver & give more time for HCP to provide all info needed; need for additional improvements to service delivery in the community-participants were interested in receiving info by phone, mail, or internet.
9	"Managing an everyday life of uncertainty"	Carlsson, Moller, Blomstrand	2008	Sweden	Person w/ stroke	Peer-checking, observation	Health promotion, self-reliance, emotions,	Disability & rehab	Variety and complexity of situations participants needed to cope with; a need for long-

							personality traits, values, goals, view of life/future		term perspective concerning rehabilitation & counseling after stroke, even for mild stroke; purposeful leisure activities as important to coping- coping process filled with both positive and negative emotions throughout;
10	Stroke survivors perceptions of a leisure-based virtual reality program	Farrow & Reid	2004	Canada	Person w/ stroke	Constant comparison, peer-review, member-checking	Decrease in leisure participation, VR as opportunity for participation, VR as a form of therapy, older adults as comfortable with this technology	Technology & Disability	Leisure activities often overlooked by healthcare professionals; meaningful leisure goals should be addressed in therapy;
11	User perceptions of gaming interventions for improving upper extremity motor function in persons with chronic stroke	Finley & Combs	2013	US	Person w/ stroke	Field notes, collaboration, member checking	Musical encouragement, focus and attention, motivation provided by performance feedback	Physiotherapy Theory and Practice	Music selection and screen appearance are very important to users; extrinsic feedback & knowledge of results is pivotal should be incorporated into gaming experience; lack of motivation can be barrier to exercise- gaming can improve motivation
12	Spouses of first-ever stroke patients: their view of the future during the first phase after stroke	Forsberg-Warleby, Moller, Blomstrand	2002	Sweden	Spouse of person w/ stroke	None noted. Transcription & statistical analysis.	Severity of impairment impacting outlook, individual perception of disease, spouses coping capacity	Clinical Rehab	Spouses cognitive image of what life after stroke would look like varied and depended upon their perception of the disease, its impact on future health, perception of change in daily life; perceptions of one's own coping capacities;
13	Becoming connected: the lived experience	Garrett, Immink, & Hillier	2011	Australia	Person w/ stroke	Field notes, journaling, peer-	Greater sensation, feeling calmer, becoming	Disability & Rehab	Yoga led to an increased sense of body awareness through the process of visualization;

	of yoga participation after stroke					checking	connected. Perceived physical improvements, acceptance of a different body		yoga perceived to improve strength, range of motion, walking ability; increased sense of calmness; improved mood; acceptance of new body
14	Positive Consequences of surviving a stroke	Gillen	2005	U.S.	Person w/ stroke	None noted. Interview, analytic software	5 positive outcomes: increased social relationships, increased health awareness, change in religious life, personal growth, altruism	AJOT	Ability to identify positive consequences after stroke is an underestimated adaptation to adverse events; further research should see if this ability can be learned or if it is innate, could lead to improved quality of life for stroke survivors
15	Perceptions and experiences of two survivors of stroke who participated in constraint-induced movement therapy home programs	Gillot, Holder-Wallis, Kurtz, Varley	2002	U.S.	Person w/ stroke	Field notes, member-checking,	Rehab should continue as long functional deficits exist; perceived changes in function as representation of perceived changes in efficiency, effectiveness, satisfaction; personal desire to increase function & environmental demand create press for participation in CIMT.	AJOT	Patients should be given the option of consultative OT after termination of formal rehabilitation with the goal of refining functional performance; therapists need to explore patient's occupations and provide them with home programs that are valued to client; patient dissatisfaction at perception of negative feedback from healthcare providers regarding prognosis
16	Stroke survivor and carer perspectives of the concept of recovery: a	Graven, Sansonetti, Moloczij, Cadihac, & Joubert	2013	Autralia	Person w/ stroke & informal carer	Open coding, grouped sub-themes, consensus	Individual recovery expectations, essential elements of recovery, returning home,	Disability & Rehab	Post-stroke management should integrate a process of identifying barriers to recovery- ongoing education about what to expect after

	qualitative study					meetings	the environment of rehabilitation		discharge & strategies to best support & facilitate long-term recovery; unmet expectations of carer –informal respite options rarely as available as imagined; community-based therapy perceived as facilitating adaptation to change & enhanced generation of realistic & client-centered goal setting
17	Loss of autonomy, control, and independence when caring; A qualitative study of informal carers of stroke survivors in the first three months after discharge	Greenwood, Mackenzie, Cloud, & Wilson	2010	UK	Informal carer of stroke survivor	Constant comparison, discussion, member-checking	Reduced control & unpredictability, choice, helplessness, planning ahead, increasing survivor autonomy & reducing carer autonomy, unrelenting dependency on the carer, benefits of reliance	Disability & rehab	Carer's autonomy could be increased if they were given more choices and control over the support provided; differences between carers of first-time stroke survivors vs. recurrent stroke survivors- recurrent carers need less assistance; families are generally more than willing to take on caregiver role, none spoke of resentment;
18	Client and carer experience of transition home from inpatient stroke rehabilitation	Gustafsson & Bootle	2012	Australia	Person w/ stroke & carer	Coded interviews, independent & collaborative analysis, member checking	Client: rehab was okay, it's a struggle, suppots & assistance. Carer: purpose of rehab, life is different now, & looking to the future.	Disability & rehab	Differences in how clients and carers experienced the time at home- need for enhanced family-centered preparation and support for transition; need for more opportunities for client and carer to practice meaningful activities prior to transiton home; need for more support after discharge & assistance w/ life changes
19	"You needed to rehab…families as well": family	Howe, Davidson, Worrall,	2012	Australia	Family members of person	Peer-review, field notes, journaling,	Family member goals: to be given support, info, to	International Journal of Language &	Clinician s sometimes overly cautious w/ privacy concerns for patient- need for increased

	members' own goals for aphasia rehabilitation	Hersh, Ferguson, Sherratt, & Gilbert			w/ aphasia		be able to communicate w/ person, to be included in rehab, provded w/ hope, coping, look after their own well-being	Communication Disorders	supportive/informative/sensitive knowledge from therapist; family members have their own goals for rehab; need for improved communication; increase family involvement in rehab process;
20	Adaptation to a stroke: the experience of one couple	Jongbloed	1994	Canada	person w/ stroke & their spouse	Peer-checking, field notes	Stroke cannot be viewed as individual phenomenon, change in spousal roles, altered roles of stroke survivor, increased dependence, attitudes influenced by society	AJOT	Restructuring life after a stroke is an ongoing process; social circumstances surrounding a person at home after stroke can likely influence in more profound ways than the ability to perform a task independently; contextual issues need to be given more importance in rehab than they are currently;
21	"Reasons for recovery after stroke: A perspective based on personal experience"	Jones, Mandy, Partridge	2007	UK	Person w/ stroke	Field notes, peer-checking, personal reflection	Internal Factors: Personal control over progress, optimism & fears of dependency. External factors: influence of therapeutic interactions, success w/ specified marker of independence	Disability & Rehab	Influence of positive self-appraisals highly beneficial in supporting recovery-sense of self-efficacy; personal beliefs one develops about their ability to improve is vital w/in first few weeks of recovery-influences further improvement at home after rehab. Need sense of control
22	Experiences of adult stroke survivors and their parent carers: a qualitative study	Jones & Morris	2012	UK	Person w/ stroke & parental carer	independent audit (member checking)	Emotional turmoil, significance of parents, negotiating independence vs. dependence,	Clinical Rehab	Policy and guidelines for the long-term support of stroke survivors and their carers should consider factors associated w/ survivor-carer relationships, such as age,

							changed relationship		there is a need for approaches tailored for young stroke survivors, need for theoretical & evidence-base for family-centered intervention
23	Stroke: an exploration of the experience of informal caregiving	Kerr & Smith	2001	UK	Informal carer of person w/ stroke	Constant comparison, author discussion, thematic analysis	Physical preparation, emotional support, supply of information & advice, provision of appropriate services	Clinical Rehab	Carers find the provision of support by a specialized 'stroke sister' beneficial; major shortcomings of stroke services a perceived by both person w/ stroke & their informal caregiver; carers should be more involved in the development of services-w/out their help services will continue to be inadequate, poorly tailored, inappropriate
24	The process of re-engagement in personally valued activities during the two years following stroke	Kubina, Dubouloz, Davis, Kessler & Egan	2013	Canada	Person w/ stroke	Audit trail of chronological notes, 3 coding phases, triangulation	Social connection & being in charge	Disability & Rehab	Being able to engage in valued activities critical aspect of maintaining hope for recovery & promotes engagement; lack of success during experimentation with valued activities can lead to lowering expectations & activity adaptation & engagement in same activities in altered manner; medical personnel could help with activity selection by listening to patients; social support important for resumption of participation
25	Needs, priorities, and desired rehabilitation outcomes of	Lawrence & Kinn	2013	UK	Family members of person w/ stroke	Discussion of themes w/ colleagues, unstructured interviews;	Disruption of temporal being; uncertainty, disrupted/altered relationships,	Disability & Rehab	Need for understanding the experience of stroke from perspective of family members; rehab professionals need to address fears of

	family members of young adults who have had a stroke: findings from a phenomenological study					use of quotes	situatedness.		second stroke; failure to achieve goals source of disappointment & reinforced awareness of difference in young adult-essential for healthcare professionals work together to create/achieve feasible goals.
26	Patient's experience of rehabilitation after stroke	Lewinter & Mikkelsen	1995	Denmark	Person w/ stroke	Transcription vs. interview tape analysis, interview compared w/ medical charts & other interviews	Positive effects of stroke survivor support, need for more rehabilitation, non-physical problems did not receive enough attention, positive effects of rehab (helping them to organize life after rehab)	Disability & Rehab	Rehabilitation unit viewed as small self-help community, benefits from being with others in similar situation, though also possibly considered isolating; family's role in rehab process needs more defining; big differences lie between expectations of staff & the patient-patient wishes to go back to normal while staff have experience in knowing that is very difficult
27	The experience of stroke for men in retirement transition	Lobeck, Thompson, & Shankland	2005	UK	Person w/ stroke	Journaling, member-checking	Ambivalence about retirement, impact of stroke, healing and adjustment	Qualitative Health Research	Stroke and retirement should not be viewed separately, they are similar in that fear of lost identity is similar between retirement and stroke; retirement felt as a complex, mixed experience; acceptance of new identity as difficult but necessary; positive impact on marital status-several participants noted feeling closer to wives, and relationship felt more valued after stroke.
28	Qualitative analysis of stroke patients'	Maclean, Pound, Wolfe, &	2000	UK	Person w/ stroke	Constant comparison; coded	Patients can have high or low motivation during	British Medical Journal	Overprotection from family members & healthcare professionals, lack of

	motivation for rehabilitation	Rudd				transcription process;	rehab- this can affect recovery process; high motivation patients view rehab as more important than low motivation patients;		information, mixed messages from healthcare professionals, & unfavorable comparisons to other patients can have a negative impact on motivation;
29	“We’re just sick people, nothing else”: factors contributing to elderly stroke patients’ satisfaction with rehabilitation	Mangset, Dahl, Forde, & Wyller	2008	Norway	Person w/ stroke	Independent analysis & collaborative discussion;	Being treated w/ humanity; being acknowledged as individuals, having autonomy respected; having confidence & trust in professionals; dialogue & exchange of information	Clinical rehab	The patient’s need to be treated with dignity and respect can be strongly related to a stroke patients feelings of vulnerability and dependence; satisfaction with training depended on a balance between expectations, delivery of care, and results of training; being treated with dignity & respect can be more closely associated with positive feelings about rehab vs. involvement in treatment decisions;
30	Participants’ Perspectives on the feasibility of a novel, task-specific intervention for individuals with chronic stroke: a qualitative analysis	Merlo, Goodman, McClenaghan, & Fritz	2011	US	Person w/ stroke	Audit trail (journal); peer review, member checking;	A manageable amount of fatigue; difficult/doable level of intensity; disappointment in duration of therapy; enjoyment of therapy; muscle soreness	Physical therapy journal	Therapists may be too cautious/hesitant to implement an intensive program; 7/8 patients tolerated & enjoyed the therapy program even though difficult; patients were surprised at their own abilities to complete program
31	Striving for control in eating situations after	Medin, Larson, von Arbin,	2010	Sweden	Person w/ stroke	Observation, peer-checking	Striving for control, eating safely & properly,	Scandinavian Journal of Caring	Complexity of eating issues after stroke; participant description of being

	stroke	Wredling, Tham					need for help from others.	Sciences	scrutinized while eating or judged when eating difficulties occurred; shame when food was spilled; desire for control over eating
32	Elderly persons' experience and management of eating situations 6 months after stroke	Medin, Larson, von Arbin, Wredling, Tham	2010	Sweden	Person w/ stroke	Member-checking, journaling	Desire to master eating related to values & past experiences; difficulties as disgusting & uncomfortable; need for help embarrassing. Healthcare worker needs awareness of individual's values & previous habits.	Disability & Rehab	Dialogue is needed with the stroke survivor experiencing eating difficulties, old values and habits were the basis of mastering new eating situations;
33	"If only I manage to get home I'll get better"; Interviews with stroke patients after emergency stay in hospital on their experiences and needs	Olofsson, Andersson & Carlberg	2005	Sweden	Person w/ stroke & close family member	Separate analysis & collaborative discussion	Responsible & implicated; depersonalized object for caring measures; the striving for repersonalization and autonomy	Clinical rehab	Patients can have a lot of anxiety over leaving the hospital; going home can result in new insights about a patient's state & can be an important part of the recovery process; being a patient seen as being passive vs. homecoming seen as taking back control; healthcare system should develop strategies to make use of the power of coming home;
34	"Lived experience of driving ability following stroke"	Patomella, Johansson, Tham	2009	Sweden	Person w/ stroke	Field notes	The meaning of driving remained throughout life; being advised to not to drive as untenable; being	Disability & Rehab	Advice not to drive seen as violation of self-determination; testing viewed as insulting; disruption in ability to participate in activities & inability to adapt

							out of control and violated by the driving eval; driving safely during on-road test; perceiving consequences in everyday life.		could lead to occupational deprivation; emotional support needs to be provided
35	Meeting stroke survivors' perceived needs: a qualitative study of a community-based exercise and education scheme	Reed, Harrington, Duggan, & Wood	2010	UK	Person w/ stroke	Journaling, member-checking;	Creating a social self; provision of responsive services in the community; informal support network;	Clinical Rehab	Stroke survivors wish to continue to work towards reconstructing lives post-stroke; stroke survivors respond to their condition in active/creative ways; community stroke group provides physical activity, goal-setting, knowledge acquisition through social stroke-specific group; importance of peer support; most valued elements of group where participant had greatest control & active participation;
36	"Resuming previously valued activities post-stroke: who or what helps?"	Robison, Wiles, Ellis-Hill, McPherson, Hyndman, Ashburn	2009	UK/New Zealand	Person w/ stroke & informal caregivers	Audit trail, peer-checking, field notes,	A long-term role for rehabilitation; ID'ing important activities, access to support for symptoms, social network	Disability & Rehab	Social & psychological factors are just as important as physical disability when considering holistic recovery; addressing behavioral/emotional factors could lead to developing adaptive strategies to enable participation; rehab professionals should work with wider support networks to reduce isolation; still need to strive toward a right balance between letting people maintain hope & support

									adjusting to current level of function.
37	Frustrated and invisible: younger stroke patients' experiences of the rehabilitation process	Roding, Lindstrom, Malm, & Ohman	2003	Sweden	Person w/ stroke	Member-checking, triangulation of researchers	Frustration, outside & invisible. Rehab settings not acknowledging the different needs of younger stroke patients compared w/ older stroke patients.	Disability & Rehab	Rehabilitation as not age-adapted; needs of young stroke patients are not being met; lack of information left many participants with questions unanswered-need for right information at the right time based on where the client is in the rehabilitation process; greater need for patient groups with this population of stroke survivors.
38	Reflections upon rehabilitation by members of a community based stroke club	Sabari, Meisler, & Silver	2000	US	Person w/ stroke	Member-checking, group discussion	Concerns that individualized needs were not addressed during rehab process; services were insufficient to ease the transition to community living	Disability & Rehab	Stroke rehabilitation needs to be an ongoing partnership among stroke survivors, family members, and rehabilitation professionals; adherence to diagnosis-based healthcare services limits amount of allowable rehabilitation services; follow-up services are insufficient to meet people's needs in adjusting to community living.
39	Getting back to real living: a qualitative study of the process of community reintegration after stroke	Wood, Connelly, & Maly	2010	Canada	Person w/ stroke	Peer-checking, research team discussion throughout process.	Balance between expectation & physical capacity, establishing independence, ongoing change in goals. Need for realistic goal setting	Clinical Rehab	Healthcare professionals need to address the importance of creating balance between capacity and personal expectations for their clients; meaningful roles helped to resolve changes in self-perception after stroke; community reintegration improved by identifying the ongoing changes in goals over the first year post stroke;

									needs of stroke survivor changes over first year; stroke survivors need to reevaluate & reset expectation to a level congruent w/ new reality; healthcare professional key in facilitating realistic goals
40	Characteristics of physiotherapy sessions from the patient's and therapists perspective	Wottrich, Stenstrom, Engardt, Tham, & von Koch	2004	Sweden	Person w/ stroke & their physical therapist	Collaboration during analysis, member checking	Setting & attaining goals, focusing on motor activity, finding optimal training strategy, facilitating active patient involvement, making use of enviro factors, adjusting to structural reorganization of the rehab services	Disability & Rehab	Therapists and patients often easily slide into expert/subordinate roles- this does not lend itself to collaborative goal setting; PT's felt they had worked hard to tailor therapy for the individual- though this feeling was not shared w/ the patient or via observations; both PT and patient felt that therapy was too short, both expressed dissatisfaction & frustration at the organization.
41	On parallel tracks: newly home from hospital-people with stroke describe their expectations	Wottrich, Astrom, & Lofgren	2012	Sweden	Person w/ stroke	Discussion, open coding	Safety of ward vs. the unknown of home; high expectations for improvement; waiting for improvement; adjusting to home	Disability & Rehab	Importance of being able to practice all kinds of everyday home situations in order to increase comfort & increasing feeling of control with going home after rehab; well-prepared discharge should focus on the expectations and needs of the patient, and should balance expectations & physical capacity; umet expectations about recovery can lead to patients postponing activities; confidence can be high initially high but can wane as time passes and less improvement

									is seen.

Table 1

Article Distribution by Country, Year, Perspective (N=41)

Country:	Scandinavia: 12 (29%)
	UK: 11 (27%)
	Australia/New Zealand: 7 (17%)
	United States: 6 (15%)
	Canada: 5 (12%)
Journal:	Disability & Rehabilitation: 20 (48%)
	Clinical Rehabilitation: 8 (20%)
	American Journal of Occupational Therapy: 4 (10%)
	Scandinavian Journal of Caring Sciences: 2 (5%)
	Australian Journal of Occupational Therapy: 1 (2%)
	Qualitative Health Research: 1 (2%)
	International Journal of Language & Communication Disorders: 1 (2%)
	Physical Therapy Journal: 1 (2%)
	British Medical Journal: 1 (2%)
	Physiotherapy Theory & Practice: 1 (2%)
	Technology & Disability: 1 (2%)
Year Published:	Before 1995: 1 (2%)
	1995-1999: 1 (2%)
	2000-2004: 10 (24%)
	2005-2009: 9 (22%)
	2010-2013: 20 (49%)
Point of View:	Person with stroke: 34 (83%)
	Caregiver/Family member: 13 (32%)
	Healthcare provider: 3 (7%)

Table 2

*Summary of themes and study origination (N=41)**

Theme	Subtheme & Study of Origin	Subcategory & Study of Origin
Expectation versus reality	Importance of goal setting: 2, 3, 5, 6, 7, 10, 11, 13, 14, 15, 16, 18, 21, 22, 24, 25, 26, 27, 28, 29, 32, 33, 26, 29, 41	Meaningful goals: 5, 6, 10, 15, 16, 18, 19, 24, 25, 39 Balance hope & expectation: 7, 16, 24, 25, 26, 29, 36, 39
	Long-term support: 5, 7, 8, 9, 15, 16, 18, 20, 22, 33, 35, 38	Community support: 4, 8, 16, 35 HCP check-in: 7, 15, 22, 39, 40
	Improved education: 3, 5, 15, 19, 24, 25, 28, 30, 37, 40	Overly cautious: 3, 5, 19, 25, 28, 30, 37 Communication needs: 3, 5, 8, 19, 37
	Comprehensive support: 1, 4, 7, 20, 24, 34, 35, 36, 37, 38	Social & emotional: 1, 4, 7, 20, 24, 34, 35, 36
	Family involvement: 7, 8, 12, 17, 18, 19, 22, 23, 25, 26, 38	Family-centered care: 18, 22, 23, 25
	Sense of control: 4, 17, 21, 31, 33, 34, 35, 41	Self-efficacy: 21, 31, 33, 34, 35, 41

Table 3

Summary of Theme Comparison

Author:	Peoples, Stanick, and Steultjens, 2011	Ryan, 2013
Theme:	Power and empowerment	Expectation versus reality
Subthemes:	Coping with a new situation	Goal-setting
	Informational needs	Long-term support
	Physical and non-physical needs	Improved education
	Being personally valued and treated with respect	Comprehensive support
	Collaboration with health professionals	Increased family involvement
	Assuming responsibility and seizing control	Increased sense of control

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I would like to thank my research chair, Dr. George Tomlin, for leading me through this research journey with enthusiasm and wisdom, helping me to tackle a project that at times felt insurmountable. I would like to also thank my committee's reader, Dr. Tatiana Kaminsky, for the suggestions and questions she raised throughout this process, which challenged me and ultimately led to an improved final product. Without this committee, I would have been lost in the "research forest" for the foreseeable future. Instead, I now say with confidence that I have found my way out, and carry with me a passion for research and exploration that will serve me well throughout my future career.

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