Participation After Stroke: Do We Understand All the Components and Relationships As Categorised in the ICF?

Melanie Hoyle, Louise Gustafsson, Pamela Meredith and Tamara Ownsworth

Brain Impairment / Volume 13 / Special Issue 01 / July 2012, pp 4 - 15
DOI: 10.1017/BrImp.2012.9, Published online: 14 June 2012

Link to this article: http://journals.cambridge.org/abstract_S1443964612000095

How to cite this article:
Melanie Hoyle, Louise Gustafsson, Pamela Meredith and Tamara Ownsworth (2012). Participation After Stroke: Do We Understand All the Components and Relationships As Categorised in the ICF?. Brain Impairment, 13, pp 4-15 doi:10.1017/BrImp.2012.9

Request Permissions : Click here
Participation After Stroke: Do We Understand All the Components and Relationships As Categorised in the ICF?

Melanie Hoyle,1 Louise Gustafsson,1 Pamela Meredith,1 and Tamara Ownsworth2

1 The University of Queensland, Australia
2 School of Psychology and Griffith Institute for Health, Griffith University, Australia

Although advances in stroke care have been shown to improve functional outcomes and survival, evidence suggests that stroke survivors continue to report restricted participation and dissatisfaction with life after returning home. There remains a need to identify ways to improve participation after stroke, considering the person within their context. The International Classification of Functioning, Disability and Health (ICF) provides a valuable framework that can be useful for categorising key components associated with participation. The two parts of the ICF — (a) Functioning and Disability and (b) Contextual Factors — encourage consideration of the functions/body structures, activity and participation, and personal and environmental factors, respectively. Previous research has identified links between body functions, structures and activity, with increasing attention being given to the ways in which these link with participation. Although some of the components influencing participation poststroke are well defined, there is a need to further develop our understanding of how personal and environmental factors may affect participation. In this article, stroke literature is categorised using the ICF and a range of personal and environmental factors are investigated as potential contributors to levels of participation poststroke. This article concludes that research investigating contextual factors and their interactions with participation is warranted.

Keywords: stroke, participation, ICF, identity, self-concept, environment

During their transition to community living, people who have experienced a stroke face many challenges including ongoing difficulties with participation. The International Classification of Functioning, Health and Disability (ICF) defines participation as ‘involvement in a life situation’ (World Health Organization [WHO], 2001, p. 10). While a range of components have been linked to poststroke participation, these have been drawn largely from the functioning and disability part (i.e., body functions, body structures, activity) of the ICF. In contrast, the impact of contextual (personal and environmental) factors on participation is not well understood or documented. The ICF can be effectively used to categorise key concepts that are associated with participation (Rimmer, 2006). Therefore, this review aims to identify from the literature how contextual factors influence participation after stroke and to identify gaps in the literature using the ICF as a framework.

This review initially provides an overview of the long-term impact of stroke, with a focus on participation. A broad literature review is then presented that links body functions, structures and activity to participation after stroke. The existing literature regarding environmental and
personal factors and their influence on participation is also reviewed. The gaps evident in existing literature regarding contextual factors and participation after stroke are highlighted, along with recommendations for future research.

**Stroke As a Chronic Condition**

Review of the literature reveals that there have been many developments in stroke management (Aziz et al., 2008). Advances in stroke-specific care have resulted in improved functional outcomes and survival poststroke (Indredavik, Bakke, Slordahl, Rokseth, & Haheim, 1999). Furthermore, quality inpatient stroke care is associated with an increased likelihood of regaining independence and returning home poststroke (Stroke Unit Trialists’ Collaboration, 2007). Even with this progress, stroke remains the leading cause of complex disability in adults, with evidence of greater disability impact and a greater range of associated disabilities than any other chronic condition (Adamson, Beswick, & Ebrahim, 2004). Despite the significant functional impairments associated with stroke, the majority of people (70–85%) return home to participate in their lives (Mayo, Nadeau, Daskalopoulou, & Cote, 2007; Reutter-Bernays & Rentsch, 1993) and readjust to life in the community (Brock et al., 2009). As a result, the long-term effects of stroke extend beyond the individuals to their families and the broader society (Mayo, Wood-Dauphinee, Cote, Durcan, & Carlton, 2002).

The process of recovery from stroke has been described as consisting of several stages (Brock et al., 2009), with the rehabilitation stage occurring immediately prior to the return to community living. Rehabilitation after stroke, conventionally received in a hospital setting (Early Supported Discharge Trialists, 2005), aims to assist clients to achieve a level of functioning that is necessary to ensure a safe and successful discharge home (Cott, Wiles, & Devitt, 2007). As a result, inpatient rehabilitation characteristically focuses on impairments that are impacting on a person’s ability to achieve independence in basic activities of daily living (Brock et al., 2009). Many studies have demonstrated that inpatient rehabilitation after stroke is effective in improving functional outcomes (Indredavik et al., 1991, 1999; Leonard, Miller, Griffiths, McClatchie, & Wherry, 1998; Teasell, Foley, Bhogal, & Speechley, 2011). For example, Leonard et al. (1998) documented that functional levels, as calculated by the Functional Independence Measure, increased significantly from rehabilitation admission to discharge and from discharge to 1 year after discharge. This study also reported nonsignificant gains in function between 1 to 3 years after discharge, however noted significant declines in function from 3 years postdischarge. Further to this study, Indredavik and colleagues (1999) noted that people who received their rehabilitation in a combined acute and rehabilitation stroke unit were more likely to be independent or partly independent in activities of daily living after 10 years, as measured by the Barthel Index, when compared to people treated in general wards.

However, functional outcome as measured by the Functional Independence Measure (Deutsch, Braun, & Granger, 1997) and Barthel Index (Mahoney & Barthel, 1965) is only one component of recovery. Stroke survivors believe recovery is represented by the ability to return to their life as it was before the stroke, including resumption of activities that matter to them and provide a sense of control and identity (Doolittle, 1992; Tyson & Turner, 2000). This was confirmed by Eriksson and Tham (2010), who identified that participants in their study were eager for rehabilitation to address regaining occupations that were closely linked to their personal identity. People experienced pleasure when resuming desired occupations and a sense of relief when they had returned to their former routines. Despite this, longitudinal studies have found that stroke survivors experience reduced social roles (Rochette, Desrosiers, Bravo, St-Cyr/Tribble, & Bourget, 2007), activity limitations, participation restrictions and associated longstanding dissatisfaction with life (Hartman-Maeir, Soroker, Ring, Avi, & Katz, 2007). Therefore, while inpatient stroke rehabilitation presently improves survival and elements of function, there is a need to expand the focus of rehabilitation beyond acute stroke management to identify ways to improve participation both immediately after stroke and over the longer term (Wolf, Baum, & Connor, 2009). Using the ICF’s comprehensive conceptual framework, key components and domains that are associated with participation will now be discussed.

**International Classification of Functioning, Disability and Health (ICF)**

The ICF has been advocated as a framework to structure rehabilitation (Tempest & McIntyre, 2006) as it aims to provide a way to understand health, health-related states, determinants and outcomes, while also establishing a common language between different health professions (WHO, 2001). This framework considers the complex interactions that occur between the person with the health condition and the context of that person (Bornman, 2004). The ICF includes two parts: (a)
Functioning and Disability and (b) Contextual Factors. Functioning and Disability considers body functions and structures, activity and participation. Contextual factors include factors relevant to both the person and the environment that may either facilitate or inhibit functioning. Disability is not seen as a feature of the individual but instead is a result of interaction between the health condition, personal factors related to the individual and his or her environment (Bornman, 2004; WHO, 2001). Therefore, restrictions to participation are influenced by functional impairments and activity limitations experienced, as well as the interactive influence of factors related to the individual and the environment.

The ICF has been suggested as a valuable framework for illustrating the impacts of stroke (Goljar et al., 2010), with comprehensive and brief ICF core sets developed for this population (Geyh et al., 2004). As previously noted, the ICF provides a framework for understanding the influence of key components on participation poststroke, the current knowledge base for which will now be considered.

Functioning and Disability – Activity and Participation

The impacts of stroke have traditionally been reviewed and evaluated based on outcomes of functional recovery and independence that focus on activity and task completion. Desrosiers and colleagues (2006) emphasised participation as a concept worthy of attention and, accordingly, there has been a shift in the desired outcomes of rehabilitation to optimising participation (Viscogliosi, Desrosiers, et al., 2011). The ICF defines participation as ‘involvement in a life situation’ and activity as ‘the execution of a task or action by an individual’ (WHO, 2001, p. 10). Participation is an important component for consideration as it reaches beyond disability, acknowledging daily activities and social roles and provides a more comprehensive understanding of overall functioning and quality of life poststroke (Cardol, De Jong, & Ward, 2002; Desrosiers, Noreau, & Rochette, 2004; Desrosiers et al., 2006). Furthermore, participation has been found to be a significant predictor of life satisfaction 1-year poststroke (Hartman-Maeir et al., 2007).

This emphasis has given rise to research examining how participation is both impacted by, and influences, the person and the environment. Reduced participation after stroke may arise from a combination of personal and environmental factors that impede people’s ability to complete activities or roles (Fougeyrollas et al., 1998). A study by Robinson and colleagues (2009) found that the ability to resume valued activities was influenced by aspects of physical or cognitive disability arising from the stroke, environmental factors and personal factors. This study also highlighted that, in turn, participation in valued activities impacted on the person’s sense of self and subsequent quality of life (Robinson et al., 2009). Such findings are consistent with the interactions described in the ICF model which identify that an individual’s functioning in a particular domain is a result of a complex two-way relationship between the health condition and contextual factors (environmental and personal) (WHO, 2001). These interactions are not always predictable but are described as being dynamic, specific, bidirectional relationships that exist between the ICF components (WHO, 2001). Therefore, to understand participation after stroke using the ICF, it is important to understand the other relevant components, including body functions/structures and personal/environmental contextual factors, as they relate to stroke.

Functioning and Disability – Body Functions and Body Structures

Body functions and structures are identified in the ICF respectively as the physiological functions of body systems (e.g., consciousness functions, orientation functions, muscle power functions, mental functions of language, attention functions and memory functions) and the anatomical parts of the body (e.g., structure of the brain and structure of the upper limb) (Geyh et al., 2004; WHO, 2001). While these domains are classified in two different sections they are often considered in parallel (WHO, 2001). It is known that stroke can result in a wide range of difficulties (Mayo et al., 1999; Tatemichi et al., 1994) across these domains. Neurological deficits related to stroke affect motor function, cognition, language (Carod-Artal, Gonzalez-Gutierrez, Herrero, Horan, & De Seijas, 2002), mood, perception (Mayo et al., 1999) and sensation (Carey, 1995). These difficulties and their subsequent influences on activities and participation after stroke have been examined widely in stroke research and literature. Each of these will be broadly discussed below.

Neuromusculoskeletal and movement-related functions and sensory functions. Difficulties with motor function are the most common of all the impairments caused by stroke (Langhorne, Coupar, & Pollack, 2009) and are typically localised to one side
of the body, impacting on body structures including the face, the upper limb and the lower limb (Warlow, van Gijn, Dennis, Wardlaw, & Bamford, 2008). The ability to perform skilled motor movements, however, is closely linked with the ability to perceive and discriminate a variety of sensations (Carey, 1995). Motor difficulties impact approximately 80% of people who have experienced a stroke (Langhorne et al., 2009), while sensory deficits have also been reported to be present in up to 80% (Doyle, Bennett, Fasoli, & McKenna, 2010). Movement and sensation are both associated with the ability to participate in daily occupations (Doyle et al., 2010). Desrosiers and colleagues (2006) identified better lower extremity coordination as a predictor of higher levels of participation in short-term daily activities and social roles. In addition, better lower extremity coordination and upper extremity ability, including aspects of sensation, were also predictive of better long-term participation in daily activities and social roles (Desrosiers et al., 2006).

Mental functions.

Emotional functions. Emotional functions, according to the ICF, are ‘specific mental functions related to the feeling and affective components of the processes of the mind’ (WHO, 2001, p. 55). This category of functions includes emotional states associated with psychiatric conditions including anxiety, lability of emotion and flattening of affect (WHO, 2001). Psychiatric conditions, including depressive and anxiety disorders, are common poststroke and have the potential to interfere with outcomes and recovery (Astrom, 1996; Dafer, Rao, Shareef, & Sharma, 2008).

Psychological and emotional implications for recovery and participation poststroke have received increasing acknowledgment in research literature. Research completed within this field has largely focused on depression, rather than other common psychiatric disorders such as anxiety (Astrom, 1996). Nevertheless, considerable overlap exists between the symptoms of anxiety and depression and these conditions are both found to impact on daily functioning and quality of life poststroke (Astrom, 1996; Pohjasvaara, Vataja, Leppavuori, Kaste & Erkinjuntti, 2001; Sturm et al., 2004)

As the most commonly documented psychiatric condition, depression has been identified as a major factor that contributes to reduced participation (White, MacKenzie, Magin, & Pollack, 2008). Using a qualitative analysis, White and colleagues (2008) demonstrated the negative impact of depression on participation and occupational engagement after stroke. These authors concluded that the promotion of participation, support and education regarding mood are necessary poststroke (White et al., 2008). While this research demonstrates the influence of depression on participation, recent empirical findings suggest that this is not a unidirectional relationship. A study completed by Landreville and colleagues (2009) highlighted that restrictions to participation in daily activities and social roles were associated with poststroke depression following discharge from hospital. This research demonstrated that, with the exception of interpersonal relationships, restriction in all subdomains of daily activities and social roles, as defined by the Assessment of Life Habits, was correlated with more depressive symptoms (Landreville et al., 2009). Due to the prevalence of depression and its apparent bidirectional relationship with participation it is suggested that this increasing acknowledgment of emotional functions poststroke is warranted.

Cognitive and perceptual functions. Cognitive difficulties occur frequently poststroke and have significant functional impacts that are independent of the physical consequences of stroke (Tatemichi et al., 1994). Specifically, cognitive impairments have been noted to result in restricted participation in daily activities, social and educational activities, leisure activities and social roles (Spitzer, Tse, Baum, & Carey, 2011; Viscogliosi, Desrosiers, et al., 2011). Executive function, a domain of functional cognition, is defined as ‘…the group of cognitive processes responsible for guiding, directing, and managing cognitive, emotional, and behavioral functions, during novel tasks such as organizing thoughts and activities, prioritizing tasks, managing time efficiently, and decision making’ (Donovan et al., 2008, p. 132). Executive functions support meaningful interpersonal relationships and assist individuals to remain productive members of the community by facilitating performance in activities of daily living (Katz & Hartman-Maier, 2005). Therefore, executive dysfunction has the potential to constrain an individual’s ability to fully participate in society (Baum, Foster, & Wolf, 2009).

Difficulties with memory and visual perception have also been linked to problems with five domains of participation from the Assessment of Life Habits, namely: communication, leisure, nutrition, community life and responsibilities (Viscogliosi, Desrosiers, et al., 2011). Unilateral spatial neglect (USN) has been identified as a disabling feature poststroke (Teasell, Salter
et al., 2011). Teasell, Salter and colleagues’ (2011) evidence-based review revealed that USN has a negative influence on functional recovery, length of rehabilitation stay and need for assistance post-discharge. However, other researchers found that USN did not significantly restrict participation after stroke (Viscogliosi, Desrosiers et al., 2011). These mixed findings suggest that further research investigating the impact of USN on participation is warranted.

Despite indications that difficulties with cognition and perception can impact on participation after stroke, Viscogliosi, Belleville and colleagues (2011) have demonstrated that positive changes in participation can occur when returning to the community, even in the presence of cognitive deficits. More generally, the conditions that promote greater participation in the context of cognitive and perceptual impairments are important to identify.

**Mental functions (of language) and voice and speech functions.** People with aphasia experience a reduction in their ability to negotiate life’s social actions and interactions (Shadden & Agan, 2004). Difficulties with language have been found to influence participation in communication and social roles including social responsibilities, community life and leisure (Viscogliosi, Desrosiers, et al., 2011). The relationship between language, communication and social participation identified in this study supports that of previous studies examining the impacts of aphasia and dysarthria. Cruice, Worrall, Hickson, and Murison (2003) identified that communication was strongly linked to social health-related quality of life for people with aphasia. This study highlighted that individuals with better functional communication ability had fewer social functioning limitations (Cruice et al., 2003). The impact of speech-related disorders, such as dysarthria, has been highlighted more recently. Dickson, Barbour, Brady, Clark and Paton (2008) identified links between communication difficulties resulting from dysarthria following stroke and changes in relationships and social and emotional disruptions. These findings all suggest that communication difficulties have significant implications for participation in social situations poststroke.

**Contextual Factors**

In addition to the influences of the body functions and structures on participation, it has been highlighted by Bornman (2004) that, when using the ICF, it is important to move beyond the individual and body level. The ICF suggests that personal factors related to the individual and the environmental factors associated with their current circumstances also influence participation (Jette, Keysor, Coster, Ni, & Haley, 2005). While the aforementioned traditional components, including body functions, body structures, activity and participation, are clearly defined, the environmental and personal factors continue to require further exploration by the research community.

Presently, the ICF describes environmental factors as ‘the physical, social and attitudinal environments in which the people live and conduct their lives’ (WHO, 2001, p. 10). Personal factors include characteristics of the individual not related to their health condition or state, as well as age, gender, race, lifestyle, coping styles, past and current experience, overall pattern of behaviour and character style, individual psychological assets and other attributes (WHO, 2001). Environmental and personal contextual factors represent the background of an individual’s life (WHO, 2001) and the setting in which he or she functions. As noted earlier, these factors have been identified as elements that can influence participation (Fleming, Kuipers, Foster, Smith, & Doig, 2009; Rimmer, 2006) and should be addressed in order to meet the long-term needs of people who have experienced a stroke (Sumathipala, Radcliffe, Sadler, Wolfe, & McKeivitt, 2011). These factors will each be discussed in turn.

**Environmental factors.** The ICF outlines a model of disability in which the environment interacts with the impairment to either facilitate or inhibit a person’s function, activities and participation (Fleming et al., 2009). The application of the environmental factors component of the ICF to particular disabilities has been increasingly explored in research and clinical practice (Fleming et al., 2009). Despite this, Viscogliosi, Desrosiers and colleagues (2011) have noted that people’s participation in roles and activities within their natural environment has not been examined in depth in the stroke literature. They emphasised the influence of the environment on participation, noting that the ability to complete a task in one environment does not provide assurance that the individual will be able to complete the same task within other environments. Understanding the environment, its facilitating and inhibiting features and the way in which it influences participation for people with disabilities still requires further investigation (Hammel, Jones, Gossett, & Morgan, 2006).

Environmental interventions after stroke have previously focused on architectural barriers within the home (Rochette, Desrosiers, & Noreau, 2001). However, aspects of both the physical and social
environments are important determinants in how individuals complete their daily activities (Rochette et al., 2001). Social and physical environments may present barriers to participation for people returning to community living after stroke (Ekstam, Uppgard, von Koch, & Tham, 2007). Such barriers include difficulties with access across many domains, including physical, cognitive, communication, transportation, information and public interactions (Hammel et al., 2006). Further, social issues, including interactions with the general public (Hammel et al., 2006) and limited social networks have also been documented (Ekstam et al., 2007). Robinson et al. (2009) highlighted the influence of the environment on the resumption of activities within the community. Specifically, participants in their study acknowledged concerns about access outside the home and felt less able to control their bodies in environments that were unfamiliar (Robinson et al., 2009). Management strategies adopted by participants in this study included avoidance, environmental change and additional social support (Robinson et al., 2009).

In addition to barriers, potential facilitating influences of the environment have been identified. Previous literature has reported that social support is associated with improved functional outcomes (Bhogal, Teasell, Foley, & Speechley, 2003; Glass, Matchar, Belyea, & Feussner, 1993) and participation opportunities poststroke (Hammel et al., 2006). In a systematic review, Bhogal and colleagues (2003) determined that there was moderate evidence that social support improves outcomes. Most notably, emotional support was consistently associated with better functional outcomes. This review also concluded that families influenced the rehabilitation outcomes and community integration of people who experienced a stroke. Specifically, family attitudes were found to be positively associated with activities of daily living (ADL) scores and well-functioning families improved rehabilitation outcomes.

The social environment has also been found to facilitate positive changes in participation after discharge home, despite the presence of cognitive deficits (Viscogliosi, Belleville, et al., 2011). In particular, caregiver support was concluded to improve participation (Viscogliosi, Belleville et al., 2011). Further, social support from family and friends was documented as a key facilitator of better functioning in long-term stroke survivors (Sumathipala et al., 2011). Erikson, Park and Tham (2010) reaffirmed the importance of the social environment in their study, which showed that a sense of belonging was integral to participation.

While the aforementioned studies have begun to demonstrate the influence of the environment on participation, further research is required. In particular, environmental factors as defined by the ICF and their influence on health and wellbeing should be considered in the context of individual personal factors (Fleming et al., 2009).

**Personal factors.** The ICF defines personal factors as features of the individual that are not part of the health state or condition. Although personal factors are, by definition, outside the health state or condition, they may still be related to or impact on it (Huber, Sillick, & Skarakis-Doyle, 2010). In particular, Huber et al. (2010) identified that individual characteristics, including a person’s unique background, will subsequently influence how the person experiences disability. Despite the significance of personal factors for understanding the adjustment of people with disabilities, this component represents the least discussed aspect of the ICF ( Threats, 2007) and has been largely neglected in research and literature (Badley, 2008). Contrary to Becker (2009) suggested that this failure to recognise the impact of personal factors is one aspect that limits the ICF in its current form.

Further to these deficiencies, it has been noted that while personal factors are important determinants of functioning and disability, the current version of the ICF does not contain a classification of personal factors that is consistent with that included for other domains (Geyh et al., 2011). In a systematic review and content analysis of 79 articles, Geyh et al. (2011) sought to provide an overview of personal factors as currently presented in scientific literature. This study identified that, while personal factors: (a) are relevant across a range of settings, (b) impact on functioning and disability outcomes and (c) may influence understanding of functioning, disability and health, there is a need for further standardisation of this component of the ICF (Geyh et al., 2011). Difficulties in consistent application were highlighted by the inclusion of a number of examples of personal factors that are not specifically named in the current version of the ICF (e.g., changes in self-view, identity, personality, self-concept, self-esteem, self-efficacy etc.). The World Health Organization (2001) has suggested that development of the personal factors component is a possible future direction for the ICF. Therefore, developing a further understanding of potential personal factors relevant for stroke and their interactions with other components of the ICF would be valuable.

**Personal factors and participation.** While consideration of all possible personal factors is outside the scope of this article, factors such as
identity, self-concept and changes in self-view were noted as examples of personal factors not included in ICF definition (Geyh et al., 2011). These important aspects of adjustment have long been highlighted within the stroke literature identifying that survivors often experience changes in their self-image, self-concept and role capabilities (Cott et al., 2007; Glass & Maddox, 1992) and a negative sense of self (Ellis-Hill & Horn, 2000). Research suggests that changes to the physical self (Vanhook, 2009) and the individual’s ability to participate in meaningful life roles, previously valued activities and relationships (Clarke & Black, 2005; Ellis-Hill & Horn, 2000; Rittman et al., 2004) can affect identity and self-concept post-stroke. Consistent with the relationships between participation and personal factors illustrated in the ICF, this research provides support for the influence of participation on personal factors; however, specific mechanisms of this relationship remain unclear. Furthermore, the inverse relationship remains largely unexplored, such that the influence of a person’s identity and self-concept on their ability, or willingness, to participate in the community is not clearly understood. A review of the research in the area of stroke and brain injury more broadly has revealed a range of constructs and theories, drawn from psychological literature, which may further understand the potential bidirectional relationship between these personal factors and participation. A number of these, including biographical disruption, self-discrepancy theory and threat appraisal will now be discussed further.

The construct of biographical disruption has been used to illustrate how the experience of a stroke interrupts the trajectory people had anticipated for their lives, causing a disconnection between the past and the future (Bury, 1982; Pound, Gompertz, & Ebrahim, 1998; Robinson et al., 2009). Biographical disruption poses a threat to personal habits, activities, roles, relationships, way of life and sense of self (Robinson et al., 2009). Changing how a person lives their life, their perceived trajectory or their ability to participate in valued activities, can impact on their identity and continuity of self. Robinson and colleagues (2009) confirmed the importance of activities to people’s identity and indicated that poststroke people may require support to adapt to a changed way of life and to adjust to a change in identity.

Theories on the development of self-concept and identity are also relevant to understanding personal adjustment to stroke. These theories include self-discrepancy theory (Higgins, 1987), personal construct psychology (Kelly, 1955) and social identity theory (Turner, 1982). Unlike biographical disruption, these theories have received less attention in stroke. However, there is preliminary research regarding the application of these theories to understanding adjustment of people with stroke and other forms of brain injury.

Cantor and colleagues (2005) applied self-discrepancy theory to understand the role of self-comparison processes in affective disorders after traumatic brain injury (TBI). Self-discrepancy theory, originally proposed by Higgins (1987), suggests that emotional states are related to the level of similarity or difference between the ‘actual self’, ‘ideal self’, and ‘ought self’. Self-discrepancies occur when the assessment of a person’s actual self (who they perceive themselves to be) is in contrast to a person’s ideal self (who they ideally would like to be), or a person’s ought self (who they feel they ought to be) (Waters, Keefe, & Strauman, 2004). Cantor and colleagues (2005) highlighted that people who have experienced a TBI live with two images of themselves: who they were before the injury (pre-injury self — actual self), and who they are now (postinjury self — actual self). They hypothesised that a discrepancy between these two selves may be similar to discrepancies between actual and ideal or ought selves, leading to emotional difficulties that would prevent people creating a satisfying life after sustaining a TBI (Cantor et al., 2005). This study demonstrated that discrepancies between pre-injury and postinjury selves were associated with emotional difficulties. Self-discrepancy theory provides a model for understanding the development of identity post-disability, which may be useful in conceptualising affective distress after injury (Cantor et al., 2005). Other researchers have similarly found that discrepancy between pre-injury selves and postinjury selves is a key issue influencing psychological adjustment after brain injury (Gracey et al., 2008). While self-discrepancy theory has not been presented in detail within the stroke literature, discrepancy between poststroke self and prestroke self has been examined by Ellis-Hill and Horn (2000). This study identified that people portrayed themselves in more negative terms poststroke, highlighting that they saw themselves as less interested, capable, independent, in control, satisfied and active (Ellis-Hill & Horn, 2000). Ellis-Hill and Horn (2000) concluded that people’s self-concept changed after stroke, with many seeing their future as more restricted due to their expectations of life with a stroke-related disability.

A final construct for consideration, emerging from cognitive appraisal theory, is that of appraisal (Lazarus & Folkman, 1984). Appraisal is the process of classifying a situation with respect to its significance for wellbeing (Lazarus & Folkman,
Appraisal incorporates both the subjective meaning assigned to a potentially threatening situation (primary appraisal) and an evaluation of what can be done to manage the situation (secondary appraisal) (Lazarus & Folkman, 1984). Stress appraisal includes the appraisal of threat that is concerned with harms or losses that are anticipated but have not yet occurred (Lazarus & Folkman, 1984).

Threat appraisal was first described by Goldstein (1939, 1952) who recognised that anxiety was related to avoidance of activities after brain injury (Riley, Brennan, & Powell, 2004). According to Goldstein (1952), anxiety is triggered when an individual experiences difficulty completing tasks that were completed easily prior to the injury. Goldstein (1952) suggested that this anxiety was elicited by the threat that the task failure posed to the individual’s self-concept. In order to protect this self-concept and avoid the anxiety posed by the threat, individuals were thought to avoid situations that may end in failure and therefore restrict participation in activities. This theory was more recently investigated in TBI literature by Riley et al. (2004), who found that task failure may lead to avoidance of tasks. In addition, this study reported that while threat appraisals and avoidance were associated with task performance, other situations including social circumstances and situations where personal safety may be at risk, may also bring about threat appraisals and avoidance (Riley et al., 2004).

Little is known about appraisals poststroke and how these may be related to long-term outcomes such as participation (Rochette, Bravo, Desrosiers, St-Cyr/Tribble, & Bourget, 2007). One exception is a study by Rochette et al. (2007) investigating adaptation processes, participation and depression after stroke, which demonstrated that appraisal changes over time. This study also found that changes occur in primary appraisal rather than secondary appraisal for people who have experienced stroke and that perception of threat tends to decrease in the first 6 months poststroke (Rochette et al., 2007). Furthermore, participation levels were higher at 6 months poststroke when associated with greater initial perceived threat and challenge (Rochette et al., 2007). The authors of this study proposed that appraisal of a situation could be influenced by time, information, education and support. That is, as an individual knows more about stroke and understands what to expect, the greater the reduction in the perceived threat. This research indicates that while threat appraisal can restrict participation, appraisals can be modified over time through suitable interventions, resulting in increasing participation in the longer term. To this end, a better understanding of threat appraisal and its influence poststroke would be beneficial.

Based on this preliminary review of the psychological literature it is apparent that a bidirectional relationship may exist between personal factors and participation poststroke. Specifically, the application of biographical disruption and self-discrepancy theory in both stroke and brain-injury research has suggested that there are potential mechanisms by which participation influences personal factors. Furthermore, research incorporating threat appraisal has demonstrated how this construct, as it relates to personal factors, may restrict participation. It is proposed that the literature supports the development of research investigating how the constructs of biographical disruption, self-discrepancy theory and threat appraisal may influence the relationship between participation and personal factors poststroke.

Understanding the interplay of contextual factors and participation. As previously noted, the ICF provides a framework for examining the complex multidimensional nature of the interaction that occurs between the individual who has experienced a stroke and the context of that person. Stroke research to date has emphasised the influence of body functions and structures on activities and participation. However, the application of the ICF as a framework for examining the interrelationships among these components and specifically, the ways in which these may be influenced by contextual factors has not been explored in detail (Badley, 2008). Furthermore, the interplay between personal factors, environmental factors and participation is not clearly understood (Jette et al., 2005) or documented in the stroke literature. The present body of stroke literature demonstrates the influence of the physical and social environment on participation; however, there is scope for research that more widely investigates the complex influences of environment on participation. In addition, while research has indicated that participation impacts on personal factors after stroke, the mechanisms by which this occurs are unclear and there is limited literature that explores the inverse relationship of how personal factors may impact on participation. While limited, the available literature suggests that personal and environmental factors may demonstrate a relationship with participation poststroke; nevertheless, these factors do not exist in isolation and little research has investigated the interplay that occurs between these components. These are areas that require further investigation in the future.
Conclusion

Stroke is a chronic condition that has the potential to restrict people’s participation in their everyday lives (Mayo et al., 2002). Participation during transition to community living is influenced by many components as defined by the ICF and research has clearly demonstrated that deficits in body functions and structures can impact participation post-stroke. Currently, the influences of environmental and personal factors for participation are not strongly represented within the stroke literature. While studies have examined the influence of some personal and environmental factors on participation post-stroke, additional research is warranted to strengthen the understanding of these complex interrelationships. Establishing an understanding of these factors and relevant relationships may assist in facilitating therapeutic approaches that are suited to personal factors and that meet environmental needs to maximise participation in the community for people who have experienced a stroke.

References


