

International Encyclopedia of Rehabilitation

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Adjustment

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Introduction

A fundamental goal of rehabilitation is to facilitate recovery and promote individuals' adjustment to their impairments, activity limitations and role changes (Wilson and Gracey 2009). Adjustment can be understood as the process of making sense of, coming to terms with and adapting to changes in functioning (typically loss of function) following the onset of an injury or illness. The process of adjustment is likely to differ considerably between adults and children with an acquired disorder. A disorder with childhood onset typically disrupts skills that are *developing* or those *yet to be developed*, while a disorder during adulthood leads to a *loss of function* that may be progressive or non-progressive in nature (Kolb and Whishaw 2003). Due to the broad scope of health conditions to which an individual may adjust, this article focuses on neurological disorders that occur during adulthood with particular emphasis on brain injury. Adjustment in this context typically relates to impaired function, activity restrictions and altered lifestyle circumstances including socioeconomic changes. The stressors faced are often chronic in nature as individuals consistently attempt to cope with and adjust to the effects and implications of their condition.

The Adjustment Process

Awareness of illness and loss of function

The adjustment process typically commences when individuals recognise a change in their physical, cognitive and/or behavioural functioning. This may arise from neurological conditions that have a sudden onset, such as a traumatic brain injury or stroke, or a more gradual onset (e.g., brain tumour or dementia), as well as conditions with more intermittent or episodic symptomatology (e.g., multiple sclerosis). Due to the very nature of these disorders, in terms of the damage to particular neural systems and/or their insidious onset, individuals may not initially recognise changes to self (Ownsworth et al. 2006). Although lack of awareness may initially protect individuals from emotional distress, it can often complicate the adjustment process as the initiation of appropriate medical investigations, assessment and treatment may be delayed (Salander et al. 1999).

Lack of awareness of impairment can have a neurological aetiology (i.e., brain damage compromises self-reflective capacity), a psychological basis (i.e., motivated denial and defensive coping), or reflect both factors in combination (Ownsworth et al. 2006, Fotopoulou 2008). Impaired awareness also exists in a social context, whereby persons with brain injury who are viewed as having poor self-awareness may contest their primary caregivers' account

of problems in order to preserve their sense of continuity of identity (Yeates et al. 2007). Although accurate awareness of the effects of a disorder is not a *prerequisite* for successful adjustment, there may be negative implications of poor self-awareness for rehabilitation. In particular, individuals may have unrealistic expectations of the future and be reluctant to participate in rehabilitation and, consequently, make fewer functional gains. Further, the views and concerns of family members and health professionals may influence the focus of rehabilitation to a greater extent than the individual's own goals (Ownsworth and Clare 2006). As discussed later, clinicians often use various approaches to facilitate awareness in effort to maximise individuals' participation in rehabilitation and ongoing adjustment to their injury.

Appraisal: Sense making

When individuals begin to recognise changes to self they are likely to undergo various cognitive appraisal processes in order to make sense of what is happening and determine what these changes mean for them (Strang and Strang 2001). The Transactional Model of Stress and Coping (Lazarus and Folkman 1984) has been broadly applied to explain adjustment to illness and injury, including traumatic brain injury, multiple sclerosis and Alzheimer's disease (e.g., Godfrey et al. 1996). In this model, the primary appraisal involves evaluating the personal significance of the stressor (e.g., changes in function or an illness prognosis) and the degree of threat or challenge it poses. In the secondary appraisal, individuals evaluate the adequacy of their own coping resources to manage the demands or challenges faced. Higher levels of emotional distress are proposed to occur when individuals perceive greater threat, compromised ability to cope and inadequate support (Godfrey et al. 1996).

Conversely, it has been well demonstrated that individuals can experience positive psychological changes even in the most severe and aversive circumstances surrounding illness (Folkman 1997). Thus, traditional models of coping and adjustment have been modified to account for positive psychological changes, including post-traumatic growth. From this perspective, appraisal processes may relate to increased sense of challenge, greater personal strength, enhanced appreciation of life and improved relationships with others (Linley and Joseph 2004). Importantly, these appraisals occur even in the context of severe cognitive impairment. In the brain injury literature, posttraumatic growth is found to increase over time, generally years (Powell et al. 2007), and be inversely associated with depression and anxiety (Hawley and Joseph 2008). However, in one long-term brain injury study it was found that increased anxiety was associated with greater post-traumatic growth, suggesting that some heightening of emotion may be important and possibly serves as a catalyst for individuals to experience a positive change in their outlook (Collicutt McGrath and Linley, 2006). Nochi's (2000) qualitative studies of post TBI adjustment highlighted narrative themes among those who felt they had adjusted well post-injury. Among these themes included positive reappraisal of the meaning of the injury, such that individuals saw themselves as in some ways better (e.g. through surviving such an ordeal, being prompted by the injury to make better life decisions such as giving up drugs or alcohol, or becoming involved in representing or supporting others affected by injury). Overall, research investigating posttraumatic growth is a relatively new field and further investigations are needed to understand the potential influence of self-awareness, emotional well-being, functional level and social roles changes on individuals' capacity to derive meaning from their injury.

Coping and adaptation

The appraisal process is closely related to coping responses, which refer to the thoughts and behaviours an individual employs to manage the impact of the stressor (Glanz et al. 2002). Emotion-focused coping refers to strategies used to regulate distress and includes the generally more adaptive approaches of trying to understand one's feelings and emotional expression, as well as less adaptive approaches such as denial and emotional avoidance (Stanton et al. 1994). Problem-focused or action-orientated coping relates to efforts to manage the problem and include seeking support, planning, and developing strategies to cope with the stressor (Carver et al. 1989). As an example, assistive technology may be employed to manage the effects of physical, communication and cognitive impairments (Cunningham et al. 2009). Meaning-based coping involves efforts to maintain positive well-being through positive reappraisal and searching for positive aspects of a situation (i.e., benefit finding) (Glanz et al. 2002). The use of particular coping strategies is likely to vary according to premorbid coping behaviour, the nature of the stressor and stage of adjustment in the context of neurological disorder. The ability to flexibly apply a range of strategies as needed in different situations is generally viewed as more adaptive rather than rigidly adhering to a particular coping approach (Carver et al. 1989).

It is well recognized that the onset of a neurological disorder is an extremely stressful event and its consequences expose an individual and his/her family to an array of additional stressors (Godfrey et al. 1996). In the more acute medical phase, stressors may include the experience of unusual and even life threatening symptoms, emergency procedures to save the person's life (e.g., in a road trauma accident), lack of answers regarding the cause of symptoms despite extensive medical investigations, diagnosis of a serious neurological condition and invasive or prolonged treatments. The majority of individuals face uncertainty regarding the future in terms of their survival, treatment outcome, loss of function and potential changes over time (i.e., rate and degree of recovery and/or decline). Ongoing stressors are typically experienced beyond the acute medical phase, as individuals leave the hospital or treatment setting and attempt to return to or maintain pre-morbid activities and roles. During this transition phase individuals may be faced with changes in their daily routine, increased dependency on others, loss of productivity and vocation, relationship strain or breakdown, financial difficulties and difficulty accessing support (Karlovits and McColl, 1999). Such stressors are typically chronic in nature as individuals constantly attempt to manage and adjust to the effects and implications of their condition. Despite experiencing similar disorders and functional limitations, it is apparent that individuals vary considerably in their process of adjustment and sense of well-being.

Modelling the adjustment process

In an integrated review of the literature on awareness, adjustment and coping, Gracey, Evans and Malley (in press) introduced the 'Y' shaped model which suggests that post-injury adjustment can, for some, lead to increased social and personal discrepancies. Social discrepancies relate to reduced or altered social contacts, quality of close relationships and family functioning, as well as actual or perceived social stigma. Personal discrepancies are experienced when individuals make unfavourable comparisons between their pre- and post-injury functioning, for example, attending to losses and negative changes or 'wishful thinking'. The model predicts that these discrepancies pose a "threat to self" and place individuals at heightened risk of emotional distress.

The model builds on Goldstein's (1959) notion of the 'catastrophic reaction' following brain injury, which is described by Ben-Yishay (2000) as representing major threat to the person's very existence. Goldstein proposed that problems following brain injury can relate to the direct consequences of the injury, 'catastrophic reactions' and 'loss of abilities' due to attempts to avoid the catastrophic reaction. Such attempts may include conscious or non-conscious suppression of thoughts relating to one's post-injury impairments, or efforts to avoid or withdraw from activities that expose these difficulties. Although such coping efforts may initially protect individuals from the reality of their post-injury circumstances, in the long-term, they may lose skills, miss opportunities to develop awareness, and fail to 'update' their identity to incorporate post-injury reality. Accordingly, avoidant coping and denial have been found to be associated with poorer emotional outcomes post injury (e.g. Anson and Ponsford 2006a, Ownsworth 2005). Recent studies have also highlighted that ratings of increased self-discrepancy or discontinuity of self are correlated with distress (both anxiety and depression) post TBI (Cantor et al. 2005) and stroke (Secrest and Zeller 2006, Ellis-Hill and Horn 2000). Further, perceived disruption to important personal relationships has been found to impact on social identity and well-being (e.g. Haslam et al. 2008). Therefore, the adjustment process following brain injury could be seen to entail individuals' appraisals of 'threat to self' or identity, and their coping responses aimed at preventing discrepancies in self from arising (e.g., through denial or avoidance), or seeking to modify and manage these threat appraisals (e.g., through active coping or benefit finding) in order to maintain positive emotional well-being.

Self and other adjustment

The individuals' process of adjustment is closely intertwined with that of their family support system. Following the onset of the injury or illness, interactions and relationship dynamics within the family (significant others) often drastically change as particular members assume a caregiver role. These circumstances can include a child becoming a caregiver for a parent, a wife or husband caring for their spouse, and parents caring for an adult child who had previously left home and established independence. Thus, significant role adjustments are often made and family members and/or significant others commonly experience caregiver strain (Marsh et al. 2002). Empirical research indicates that the role strain associated with the consequences of brain injury is a consistent predictor of caregiver emotional distress; however, appraisal and coping characteristics (i.e., preparedness, mastery), may moderate the impact of strain on caregiver well-being (Sherwood et al. 2007). Further, the individual's own emotional and behavioural function appears to be related to the caregiver's mental health, suggesting that there are reciprocal effects between self and other adjustment (Ownsworth et al. in press). Such research highlights that rehabilitation approaches incorporating support for both individuals and their family caregivers are potentially most effective.

Factors Influencing the Adjustment Process

As highlighted by the International Classification of Functioning, Disability and Health (ICF, World Health Organisation 2001), individuals' adjustment to changes in their functioning and lifestyle is influenced by a range of personal and environmental factors. Accordingly, biopsychosocial frameworks have been applied to explain the adjustment process for many neurological disorders (see Gracey et al. in press, Ownsworth et al. 2009). The biological component relates to the underlying nature of the neuropathology (i.e., type, severity, location, extent and course) and its direct impact on body functions and structures. Psychological factors involve internal characteristics, including the individual's personality, coping resources, motivation, and self-concept. The social and environmental component

includes a range of contextual factors such as access to information, family adjustment, social support and social group membership, rehabilitation services, financial support, policy and legislation and the healthcare context. The interactive influence of these components on adjustment can be illustrated by brief characterizations of three different neurological conditions, which were chosen due to their common occurrence at different stages of adulthood (e.g., younger adults with traumatic brain injury and older adults with Alzheimer's disease). Brain tumor was selected due to its common occurrence in middle adulthood, and the unique challenges posed by a condition with the combined effects of cancer and brain injury.

Traumatic brain injury

Individuals with traumatic brain injury are often young, typically male, and at the start of their independent and working lifestyles. The damage to the brain may be diffuse or more localised, but commonly affects the frontal and temporal regions of the brain, which regulate cognition, behaviour and emotion (Wilson et al. 2009). After a severe injury, the period of hospitalisation is typically lengthy and involves intensive rehabilitation. Upon discharge, individuals leave the structured environment and routine of the hospital and are faced with the reality of their post-injury circumstances, such as an inability to return to work and drive (Turner et al. 2008). Many individuals initially have poor self-awareness of their complex cognitive, behavioural impairments, set unrealistic goals and feel frustrated by their lack of progress, and the restrictions imposed. During the first few months and years post-discharge individuals typically undergo a process of testing their abilities (usually with feedback from others), recognising changes to self, and experiencing heightened emotional distress. A major shift occurs when individuals learn to manage an "uncertain self" and develop a sense of personal autonomy (Connelley 2003). Various social and environmental factors are found to impact this process, including family support and cohesiveness, public and societal reactions, access to funding, and the continuity of rehabilitation and support (Turner et al. 2008).

Brain tumour

A malignant brain tumour combines the serious effects of brain injury and cancer and is usually a progressive condition associated with functional decline rather than recovery. Those with a benign tumour also face considerable uncertainty regarding their prognosis and risk of recurrence. The mechanisms of brain damage include gradual displacement, compression or infiltration of surrounding brain tissue. Functional outcomes are in part influenced by the grade, size, spread and location of the tumour; however, neurological factors are unable to adequately account for differences in subjective well-being (Ownsworth et al. 2009). Research suggests that many individuals strive to make sense of their situation by seeking detailed information about their illness, and draw on internal resources to manage stressors and existential issues. Those with strong family support and those who are able to redefine their roles and values in life have been found to derive greater meaning from their illness (Strang and Strang, 2001). Social and environmental factors found to promote enhanced adjustment included access to information, effective communication with professionals, support/advocacy to navigate the medical system and membership of support groups (Ownsworth et al. 2009).

Alzheimer's disease

Alzheimer's disease is the most common form of dementia, which is characterised by progressive neuropathology, most marked in the frontoparietal and temporal brain regions, and associated decline in cognitive, behavioural and physical status (Kolb and Whishaw

2003). Many individuals appear unaware of the onset and progression of the disease; an observation that typically contributes to opinions formed regarding the likely existence of the condition (Clare 2003). Intriguingly, self-awareness of impairments can increase over time despite deterioration of cognitive functions, suggesting that neurocognitive factors alone cannot account for the presence and degree of awareness (Ownsworth et al. 2006). Psychosocial perspectives instead conceptualise the onset of Alzheimer's disease as a "threat to self" which impacts on sense of personal autonomy and social interaction and roles. Accordingly, the individual decides how to adaptively manage the threat to self and minimise negative social reactions. Self-presentation styles may vary from efforts to hide impairments to fully disclosing the effects. Consistent with this perspective, Clare (2003) found that individuals' response to their memory difficulties ranged on a continuum from "self-maintaining" (efforts to normalise, minimise or explain away problems in order to preserve continuity with prior sense of self) to "self-adjusting" (efforts to acknowledge problems, express concerns and adapt sense of self). Social and environmental factors that may shape the process of becoming aware and adjusting to the disease include the degree of supportive interactions with family, friends and professionals, societal attitudes and cultural representations of dementia (Ownsworth et al. 2006).

Implications for Rehabilitation

Emotional or psychological adjustment following the onset of neurological disorder is a key issue for management and rehabilitation. Interventions to facilitate adjustment to brain injury vary in focus and intensity. The holistic or milieu-oriented approach to neuropsychological rehabilitation was devised specifically to address the combined challenges of cognitive impairments, awareness problems and emotional adjustment in an integrated programme. Building on the ideas of Kurt Goldstein (1959), the holistic approach aims to provide a safe therapeutic milieu, which minimises challenges by being structured and supportive, and a context for individuals to give and receive feedback to one another about strengths and weaknesses. Although holistic approaches may differ according to specific models and their application to the adjustment process (e.g., the relative emphasis placed on psychodynamic or cognitive-behavioural frameworks) these programmes are fundamentally characterized by the integration of intervention across social, emotional, cognitive and functional domains. They are delivered with a strong emphasis on intensity of interventions, group work and the therapeutic milieu (for review, see Trexler, 2000).

The holistic rehabilitation approach based upon the 'Y-shaped model' (Wilson et al. 2009, Gracey et al. in press) starts with the idea, as set out previously, that following injury some individuals can experience an increased sense of personal and social discrepancy (i.e., the top of the Y), which ultimately leads to poor psychosocial outcomes. The holistic idea is to create a safe therapeutic milieu within which change and self-reflection can be supported to reduce these discrepancies, with the person then better able to resume a trajectory of meaningful lifespan development and psychological growth (i.e., the bottom of the Y). In this context, people with brain injury work together with the clinical team, develop skills and strategies in groups and individual sessions, and explore and practice these skills through activities within the rehabilitation setting and in real life situations. Such approaches seek to address clients' awareness, adjustment, practical and social issues in an integrated way. Behavioural experiments are used to scaffold the clients' learning experience, providing activity or social contexts within which they are supported to find out about themselves, their strengths and weakness and potential strategies. Specific behavioural experiments can involve testing performance predictions of a client with poor awareness of deficits in a task against the therapist's predictions, genuinely exploring the relative efficacy of different strategies for

achieving a task, or consolidating new but tentative positive or adaptive assumptions (see Gracey et al. 2009, McGrath and King 2004).

The evidence regarding the efficacy of holistic approaches in controlled trials is mounting. For example, relative to a 'standard' multidisciplinary rehabilitation program, outcomes at 6-months post-rehabilitation were superior for those who had completed a holistic program (see Cicerone et al. 2008). Due to the comprehensive nature and the time and resource intensity of holistic programs, however, they may not be feasible in various rehabilitation settings. Clinicians may also want to target a particular aspect of adjustment for one or more individuals, and thus seek to determine the impact of a more tailored intervention. The rationale for and evaluation of individual or "standalone" psychological interventions for enhancing adjustment have been described extensively in the brain injury literature (e.g., Fleming and Ownsworth 2006). The PsycBITETM database was specifically developed to report and evaluate individual psychological therapy interventions for a range of neurological disorders (see Tate et al. 2004). In general, such interventions prioritise an aspect of adjustment as the intervention target (e.g., self-awareness), although the broader impact on adjustment is typically also measured (e.g., emotional status). Examples of effective standalone interventions in the literature include group or individual therapy formats for awareness deficits (McGrath and King 2004, Ownsworth et al. 2008, Ownsworth et al. 2000), cognitive-behavioural therapy for emotional disorders such as depression (e.g. Khan-Bourne and Brown 2003) or posttraumatic stress disorder (e.g. Williams, Evans and Wilson, 2003), and group-based coping skills training (Anson and Ponsford 2006b). Metaphoric identity mapping (see Ylvisaker et al. 2008) focuses on identity reconstruction and goal setting and appears to more generally provide a useful framework for enhancing engagement and addressing a range of adjustment issues throughout rehabilitation.

Although there are numerous benefits of focused interventions, including their feasibility and typically reduced costs, particular approaches may be limited in their broader or more long-term impact on adjustment and community functioning (e.g., return to work). Rehabilitation professionals in most settings have large and complex caseloads and are often faced with the ultimate dilemma of how to maximise individuals' functional gains and adjustment in a timely and cost-effective manner. Various contextual factors influence the type of rehabilitation provided, including the therapists' skills and training, and the scope, intensity, and resources of the treatment context (Ownsworth and Clare 2006). It is important to note that although these issues are typically considered relevant in the Western tradition of healthcare, the issues impacting access to, and the nature of rehabilitation in other cultural traditions of healthcare, and in developing countries are likely to be quite different (World Health Organisation 2004). Overall, it is critical that evidence from ongoing empirical evaluation of rehabilitation in different cultural settings translates into clinical practice guidelines for the management of neurological disorders.

Conclusion

Individuals' adjustment to neurological disorder involves an ongoing process of becoming aware of, making sense of, and coping with loss of functioning. The ways in which individuals appraise the meaning of their illness or injury (e.g., as a threat to self or as an opportunity for growth) is likely to influence the coping strategies employed and their emotional well-being. Individuals' adjustment is likely to reflect a complex interplay between the neuropathology of the disorder, their psychological characteristics and social and environmental factors. In general, rehabilitation approaches for supporting adjustment to brain injury include more targeted and brief interventions as well as more comprehensive

holistic or milieu-orientated approaches. The approach adopted may vary according to the individual client and the socio-cultural context within which they are receiving support.

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