Limb Amputation

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Abstract: Limb amputation is both a life-saving procedure and a life-changing event. The aims of rehabilitation following amputation are to restore acceptable levels of functioning that allow individuals to achieve their goals, to facilitate personal health, and to improve participation in society and quality of life either with or without a prosthesis. Individual responses to limb loss are varied and complex; some individuals experience functional, psychological and social dysfunction, many others adjust and function well. This chapter highlights critical psychological and social issues in amputation, summarizes current knowledge in these domains, and provides a brief overview of psychological interventions designed to address these issues.

Keywords: Adjustment; Amputation; Limb; Pain; Participation; Psychology; Rehabilitation

Introduction:

The multiple pathways that may lead to limb amputation include disease (e.g. diabetes, peripheral vascular disease, malignant tumors), traumatic injury (e.g. motor vehicle and industrial accidents) and congenital causes. In many cases limb amputation is both a life-saving procedure and a life-changing event. Individual responses to limb loss are varied and complex, and are influenced by a range of personal, clinical, social, physical and environmental factors. No single professional group can address all of the multifaceted care needs that patients and their families present; comprehensive, effective, patient-centered rehabilitation after amputation requires an interdisciplinary team approach in partnership with the patient. Psychologists play vital roles in assessment of cognitive and psychological functioning, formulation of the patient's presenting difficulties, and in the design and delivery of interventions to optimize mental health and adjustment outcomes. However, the totality of the rehabilitation experience and the entire rehabilitation team can impact on the patient's psychological and social wellbeing. Working within the limits of their professional competencies, team members, including the patient and their family, share responsibility for attending to psychosocial health across the continuum of care (Wegener, Hofkamp, & Ehde, 2008). This chapter highlights critical psychological and social issues in amputation, summarizes current knowledge in these domains, and provides a brief overview of psychological interventions designed to address these issues.

Epidemiology of amputation

Incidence and Prevalence of Amputation

The global incidence of amputation is unknown; available data evidence considerable variation both between and within countries (Ephraim, Dillingham, Sector, Pezzin, & MacKenzie, 2003; Renzi, Unwin, Jubelirer, & Haag, 2006; Unwin, 2000). Using a standard protocol for data collection, the Global Lower Extremity Amputation Study Group (Unwin, 2000) assessed the incidence of lower limb amputation in ten different locations worldwide and reported marked differences among test sites in their annual rates of lower limb amputation. Comparison of all-cause amputation rates during the 1995-1997 period, revealed lowest age-adjusted rates of first major lower limb amputation in Madrid, Spain (0.5 per 100,000 women, 2.8 per 100,000 men) while highest rates were reported in the Navajo region of the United States (22.4 per 100,000 women, 43.9 per 100,000 men). In the United States it is estimated that one out of every 190 persons has lost a limb; the number of persons living with amputation in the U.S. is projected to increase over two-fold to 3.6 million by the year 2050 if current trends continue (Ziegler-Graham, MacKenzie, Ephraim, Travison, & Brookmeyer, 2008). Internationally, men are more likely than women to undergo amputation and there is an age-related increase in lower limb amputation secondary to dysvascular disease (Ephraim et al., 2003; Heikkinen, Saarinen, Suominen, Virkkunen, & Salenius, 2007).

Cause and Level of Amputation

Amputation may involve a single limb (unilateral), both the upper or lower limbs (bilateral), or a combination of upper and lower limb amputations (multiple amputations). Amputation may be performed at various anatomical levels. Lower limb amputation may involve removal of one or more toes, part of the foot, ankle disarticulation (disarticulation is the amputation of a body part through a joint), transtibial (below the knee) amputation, knee disarticulation, transfemoral (above the knee) amputation, hip disarticulation and hemipelvectomy (removal of half of the pelvis). Upper limb amputation may involve the removal of one or more fingers, wrist disarticulation, below elbow amputation, elbow disarticulation, above elbow amputation, shoulder disarticulation and forequarter amputation (amputation of the arm, clavicle and scapula).

In high income countries, dysvascularity is the foremost cause of amputation; as a corollary the majority of amputations involve the lower limbs (Ziegler-Graham, MacKenzie, Ephraim, Travison, & Brookmeyer, 2008). The typical dysvascular patient with an amputation is older than 60 years of age and commonly experiences comorbidities; postoperative morbidity and mortality rates are high (Dillingham & Pezzin, 2008; Dillingham, Pezzin, & Shore, 2005; Ploeg, Lardenoye, Vrancken Peeters, & Breslau, 2005; Schofield et al., 2006). Amongst individuals with dysvascular amputations, higher amputation levels are generally indicative of more advanced disease stage. Furthermore, older age is associated with higher levels of amputation reflecting the progression of vascular disease with advancing age. The risk of losing the contralateral limb following unilateral amputation ranges from 15-20% in the first two years after the initial procedure, and rises to 40% by four years post-amputation (Cutson & Bongiorni, 1996); patients with amputation secondary to diabetes have elevated morbidity (Schofield et al., 2006). The patient's overall health status complicates the challenge of amputation rehabilitation. Traumatic amputation (associated with mechanical, chemical, thermal and/or electrical injuries), is more common amongst working-age adults who are otherwise in good health. Trauma is the most common cause of acquired upper limb amputation (National Amputee Statistical Database, 2009) and the most common cause of all-level amputations in non-industrialized countries (Ephraim et al., 2003). Amputation as a result of military conflict or civilian violence continues to constitute a serious public health problem in some regions (Burger, Marincek, & Jaeger, 2004; Fergason, Keeling, & Bluman, 2010; Williams, Rajput-Ray, Lassalle, Crombie, & Lacoux, in press). It is clear that the circumstances surrounding disease-related amputation differ substantially from those surrounding traumatic amputation whether military or civilian (Dougherty, 2001). Nonetheless, much of the literature is based on mixed samples i.e. including individuals with disease-related and traumatic amputations; with notable exceptions, relatively little research has addressed outcomes of amputation related to trauma as a specific focus (Desmond, 2007; Desmond & MacLachlan, 2004; Desmond & MacLachlan, 2006b; Dillingham, Pezzin, & MacKenzie, 1998; Dougherty, 2003; Pezzin, Dillingham, & MacKenzie, 2000).

Physical Adjustment to Amputation

The primary goals of rehabilitation following amputation are to restore acceptable levels of functioning that allow individuals to achieve their goals, to facilitate personal health, and to improve participation in society and quality of life (van Velzen et al., 2006) either with or without a prosthesis. Individuals with amputations have a complex range of rehabilitation needs and are faced with multiple and evolving physical, psychological and social threats and challenges including impairments in physical functioning, pain, prosthesis use, alterations in body image and self-concept, changes in close personal relationships, employment status or occupation, and disruptions to valued activities and lifestyle (Desmond & Gallagher, 2008; Desmond & MacLachlan, 2006b; Horgan & MacLachlan, 2004; Rybarczyk, Edwards, & Behel, 2004). Comprehensive rehabilitation requires an interdisciplinary team approach in collaboration with partnership with the patient and their family.

The medical and physical consequences of amputation serve as the centerpiece in acute care and are commonly at the forefront of prosthetic rehabilitation. Prosthetic prescription aims to compensate for functional and/or cosmetic losses where possible (van Velzen et al., 2006). Prostheses may be considered “intimate extensions of the body” (Biddiss & Chau, 2007a, pp. 236) and consequently prosthesis users often have a wide range of personal requirements, expectations and priorities which pose challenges for prosthetic prescription, fabrication and delivery and are influential across the continuum of care (Biddiss & Chau, 2007a; Smit & Plettenburg, 2010). Attrition in the use of prescribed prostheses is high, particularly amongst individuals with upper limb amputations, and there is substantial variability in the extent of prosthesis usage (Biddiss & Chau, 2007b). (Note: the amputation literature lacks standardized comprehensive definitions of *successful prosthetic fit* or *use*; such definition is rendered difficult because of differences in expectations and priorities expressed by patients and clinicians, and because outcomes of importance differ from person to person (Bhangu, Devlin, & Pauley, 2009; Schaffalitzky, Gallagher, MacLachlan, & Ryall, 2010; Schaffalitzky et al., 2009). Reasons for non-referral for prosthetic fitting, unsuccessful prosthetic restoration and prosthesis abandonment include mortality, comorbidities, cognitive deficits, residual limb condition and length, pain, delayed prosthetic fitting, limited device functionality, patient preference, patient dissatisfaction and pre-amputation ambulatory status (lower limb amputation) (e.g. Biddiss & Chau, 2007a; Biddiss & Chau, 2008; O’Neill, 2008). Individuals who are not candidates for prosthetic use or who do not use their prostheses may require alternative assistive devices (e.g. wheelchairs) and such assistive technologies may in themselves require significant self image and lifestyle adaptations (MacLachlan & Gallagher, 2004).

The main phases of prosthetic rehabilitation are: pre-prosthetic management; postoperative care; prosthetic training; and long-term follow-up care (including community reintegration and vocational rehabilitation) (Esquenazi, 2004). During prosthetic training, the patient must learn how to don and doff the prosthesis appropriately and must practice the skills necessary to perform activities of daily living in different environmental conditions. Basic training serves as a foundation for more complex skills which are learned with progressively less physical support and supervision over the course of rehabilitation. The complex behavioural tasks inherent in prosthetic rehabilitation require both an adequate level of physical fitness and the cognitive capacity to learn new skills and adapt them to different situations and environments. Persons with cognitive deficits may struggle to retain this new information or to initiate new behaviours necessary for optimal rehabilitation (Larner, Van Ross, & Hale, 2003; O'Neill, Moran, & Gillespie, 2010; O’Neill, 2008). Cognitive screening may be beneficial in identifying impairments and potential barriers to new learning, in informing planning and setting of rehabilitation goals and, when appropriate, identifying compensatory strategies to assist in achieving rehabilitation goals (O'Neill et al., 2010;

O'Neill & Evans, 2009; O’Neill, 2008). For example, cognitive rehabilitation techniques and compensatory strategies, such as errorless learning and vanishing cues techniques, may be of benefit in the amputation rehabilitation process for those with cognitive impairments.

Pain secondary to limb amputation is a very common occurrence and may be manifest at multiple anatomical sites (Desmond & MacLachlan, 2006a; Desmond & MacLachlan, 2010; Ehde & Wegener, 2008). The spectrum of potential pain problems experienced after amputation includes phantom limb pain (painful sensation perceived in the amputated body part), residual limb/stump pain (pain emanating from the residual or remaining portion of the limb/stump) and pain in regions beyond the amputated limb which may be associated with comorbidities, increased forces on the intact limb, alterations in the biomechanics of movement associated with prosthesis use and secondary musculoskeletal pathologies (Gailey, Allen, Castles, Kucharik, & Roeder, 2008). Chronic back pain is a significant problem amongst individuals with lower limb amputations in particular; prevalence estimates are approximately double those documented in the general population (Ehde et al., 2000; Ehde et al., 2001; Ehde & Wegener, 2008; Hagberg & Brånemark, 2001). Although estimates vary considerably (see Borsje, Bosmans, Van der Schans, Geertzen, & Dijkstra, 2004, for details), both phantom and residual limb pain appear to be common and persistent in the long term (at least intermittently) for a substantial number of persons with limb loss (lower limb amputation: PLP prevalence ~ 60-80%; RLP prevalence ~ 60-70%; upper limb amputation: PLP prevalence ~ 40-83%; RLP prevalence ~10-50%) (Desmond &

MacLachlan, 2010; Dijkstra, Geertzen, Stewart, & van der Schans, 2002; Dudkiewicz, Gabrielov, Seiv-Ner, Zelig, & Heim, 2004; Ehde et al., 2000; Ephraim, Wegener, MacKenzie, Dillingham, & Pezzin, 2005). Amongst individuals with amputations, pain has been associated with a variety of negative outcomes such as poor adjustment, affective distress, decrements in quality of life, interference with prosthesis use, and activity and participation restriction (Desmond, Gallagher, Henderson-Slater, & Chatfield, 2008; van der Schans, Geertzen, Schoppen, & Dijkstra, 2002; Whyte & Carroll, 2004; Williamson & Schulz, 1995). Appropriate pain management is critical to ameliorate the potentially profound impact of pain on the individual. In keeping with other persistent pain conditions, the interplay of physiological and psychological factors (e.g. pain-coping responses and pain-related cognitions) is central to pain experience post-amputation. Thus, multidisciplinary pain management, integrating physical, psychological and social factors has greatest potential to achieve optimal outcomes. For a review of the management of pain after limb loss refer to Ehde and Wegener (2008).

Psychological and Social Adjustment to Amputation

Amputation is a distressing experience that is likely to pose considerable challenges in terms of psychological and social adjustment. Not only does this procedure incur permanent physical loss, it may also lead to restrictions in many other important life domains. Limb amputation can lead to significant psychological and social dysfunction among some individuals, while many others adjust and function well (Desmond & MacLachlan, 2006a; Pezzin et al., 2000). Models delineating important factors in such variation (e.g. Livneh, 2001; Taylor, 1983) describe a complex interplay between *risk* *factors*, including disease/disability parameters, functional limitation and psychosocial stressors, and *resistance factors or psychosocial assets* including stress processing factors, intrapersonal factors, and social-ecological factors such as social support and family environment (Desmond & Gallagher, 2008). According to Livneh and Antonak (1997), adaptation is a dynamic and evolving process through which the individual strives to approach an optimal state of congruence with their environment. Adjustment is the final phase in an evolving process of adaptation distinguished by: (1) maintaining psychosocial equilibrium; (2) achieving a state of reintegration; (3) positively engaging in the pursuit of life goals; (4) evidencing positive self-esteem, self-concept and self-regard; and (5) experiencing positive attitudes towards oneself, others and one's disability. The multidimensional nature of psychosocial adjustment (Antonak & Livneh, 1995; Livneh & Antonak, 1997) has stimulated investigation of a range of outcomes resulting in a snapshot of particular indicators of adjustment, typically at one time-point. Negative impacts of amputation (e.g. depression, anxiety) have formed the central focus of most of the research (absence of psychological disorder is interpreted as an indicator of favorable adjustment) (Desmond & Gallagher, 2008). Despite this emphasis, there is little consensus regarding the prevalence of clinically significant psychological dysfunction following limb amputation, either in the short or longer terms (Desmond & MacLachlan, 2006a) and understanding of the processes through which favorable outcomes emerge is limited (Murray, 2010).

Affective Distress

Depressive symptomatology is the most commonly documented mood disturbance following amputation, estimates suggest that between 13% and 32% of individuals with limb amputations might experience significant depressive symptoms at any one time (Atherton & Robertson, 2006; Cavanagh, Shin, Karamouz, & Rauch, 2006; Desmond & MacLachlan, 2006a; Phelps, Williams, Raichle, Turner, & Ehde, 2008; Rybarczyk et al., 1992). Disparities in such estimates are attributable to methodological differences in assessment of depression and heterogeneity in study samples in terms of demographic and amputation-related factors such as age, amputation etiology, pre-existing psychological morbidity, and time since amputation (Cavanagh et al., 2006; Desmond & MacLachlan, 2004; Horgan & MacLachlan, 2004; Singh et al., 2009). Converging evidence suggests that the initial two years following amputation may be a period of elevated risk (see Horgan & MacLachlan, 2004, for review), however, this does not preclude the possibility of depression much later on. The presence of depressive symptomatology has been linked with a wide variety of negative outcomes such as increased pain intensity, activity restriction, anxiety, public self-consciousness, vulnerability, body image anxiety, and reduced quality of life (Asano, Rushton, Miller, & Deathe, 2008; Atherton & Robertson, 2006; Behel, Rybarczyk, Elliott, Nicholas, & Nyenhuis, 2002; Donovan-Hall, Yardley, & Watts, 2002; Ephraim et al., 2005; Hanley et al., 2004; Jensen et al., 2002; Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995; Williamson, Schulz, Bridges, & Behan, 1994).

Increased anxiety is common in the early postoperative period and amongst inpatients. However, similar findings also emerge in other patient groups and are considered an '*appropriate*' response in light of potentially life threatening surgery or injury and prolonged hospitalization (e.g. Kennedy & Rogers, 2000). Anxiety does not appear to persist in the long term following limb amputation (Horgan & MacLachlan, 2004). Potential for post-traumatic stress disorder (PTSD) following limb amputation is widely recognised yet poorly researched, even amongst those with traumatic limb loss (Desmond & MacLachlan, 2004; Wegener et al., 2008). Available estimates suggest that between 15% and 26% of people with limb loss might experience PTSD (Desmond & MacLachlan, 2006a; Fukunishi, Sasaki, Chishima, Anze, & Saijo, 1996; Phelps et al., 2008). The relationship between PTSD and cause of amputation is unclear; two recent studies have examined PTSD symptoms in samples with mixed amputation etiologies. Cavanagh et al. (2006) interviewed 26 rehabilitation patients, an average of 6 weeks after amputation surgery, and found that only one of 23 patients with non-traumatic amputations in the sample met the criteria for PTSD (the patient had previously experienced combat-related PTSD), whereas two of the three persons with traumatic amputations in this sample met the criteria for PTSD, the third demonstrated elevated scores just under the threshold for diagnosis. Phelps and colleagues (2008) failed to observe a significant relationship between amputation etiology and PTSD symptomatology in their sample (n=83), two thirds of whom had lost their limb due to illness.

Body Image Disturbance

The image of one's body is a critical element of the individual's formulation of the 'sense of self' (Klapheke, Marcell, Taliaferro, & Creamer, 2000). Experiences of one's own body are the basis for all other life experiences (Novotny, 1991) hence the disruption of body image engendered by amputation can have significant and long-lasting impact on the individuals' sense of identity and agency (MacLachlan, 2004) as well as on personal relationships and interactions with others (Desmond & MacLachlan, 2002; Rybarczyk et al., 1995). Gallagher, Horgan, Franchignoni et al. (2007) propose that limb loss necessitates adjustment to changed images of the body: from the "complete" or familiar body before the limb loss, to the traumatized body, the healing body, and the extended body (i.e., a body supplemented with prosthetic devices and/or mobility aids). Rybarczyk and Behel (2008) note that for some the transformative impact of amputation on body image and self concept is tolerated with minimal distress while for others it results in long-lasting negative self-appraisals. Anxiety may be experienced over the changes in one's body image that occur as a result of limb loss. In an evaluation of a counselling service for persons with amputations, Price and Fisher (2002) noted that 31% of clients sampled raised the issue of body image in their counselling sessions. Body-image anxiety following amputation is associated with depression, anxiety, reduced quality of life, lower self-esteem, greater public self-consciousness, and poorer psychosocial adjustment to amputation and participation in physical activity (Atherton & Robertson, 2006; Breakey, 1997; Coffey, Gallagher, Horgan, Desmond, & MacLachlan, 2009; Donovan-Hall et al., 2002; Murray & Fox, 2002; Rybarczyk et al., 1995).

Pereira, Kour, Leow et al. (1996) argue that in some circumstances, prostheses can act to substantially 'repair' compromised body image, in addition to restoring relatively normal appearance and form, and improving physical capabilities. Examination of the role of prostheses in mediating body image distress by Fisher and Hanspal (1998) revealed an association between moderate satisfaction with one’s prosthesis and low levels of body image disruption. Similarly, Murray and Fox (2002) reported an association between higher levels of prosthesis satisfaction and lower levels of body image disturbance. Findings from a qualitative study by Gallagher and MacLachlan (2001) suggest that prosthesis appearance is an integral component in establishing positive self-image. In their focus group discussions, concerns regarding public appearance and desires to appear *normal* emerged as dominant themes and many participants indicated that taking delivery of their prostheses was an important element in restoring normality to their lives.

Social Impact

The social impact of amputation can be substantial. Recovery and rehabilitation encompasses reintegration into the family, community, and for some the work place, and may require negotiation of evolving roles, relationships and identities. Major lower limb amputation which significantly compromises mobility can necessitate significant adaptations to the patient’s home or transition into residential care. Changes and restrictions in participation are commonly reported after limb amputation and may be related to personal (e.g. functional abilities, balance confidence, social discomfort, public self-consciousness, emotional impact of amputation, changes in goals and priorities) and/or external constraints (e.g. lack of accessibility, climate, transportation issues) (Couture, Caron, & Desrosiers, 2010; Donovan-Hall et al., 2002; Gallagher, Donovan, Doyle, & Desmond, 2011; Hamill, Carson, & Dorahy, 2010; Miller, Deathe, Speechley, & Koval, 2001; Rybarczyk et al., 1995; Sjödahl, Gard, & Jarnlo, 2004). Limb amputation also impacts on sexual functioning, relationships and satisfaction (Geertzen, Van Es, & Dijkstra, 2009; Ide, 2004). Despite the importance of sexual expression in contributing to quality of life, research on sexuality amongst individuals with amputations is very limited. A recent review of sexuality and amputation identified just 11 published studies addressing issues of sex and sexuality over the past 60 years (Geertzen et al., 2009). For individuals of working age, return to work and issues of employment are pertinent and changes in occupation and alterations in work practices and patterns may be required (Burger & Marincek, 2007; Schoppen et al., 2001; van der Sluis, Hartman, Schoppen, & Dijkstra, 2009).

Positive Psychological and Social Consequences of Amputation

The majority of research on adjustment to amputation has tended to focus on negative outcomes and to interpret the absence of psychological disorder as an indicator of favorable adjustment (Desmond & Gallagher, 2008). This unidimensional conceptualization of adjustment is by no means unique to the study of persons with amputation and can be observed across the literature on adaptation to chronic illness and disability (Bishop, 2005). However, the emerging emphasis on resilience and adaptive psychological processes evident in the general psychological literature has lead to growing consideration of positive indicators of adjustment in the amputation field. A number of qualitative studies have detailed positive adjustment and growth amongst individuals who have experienced the loss of a limb (Couture, Desrosiers, & Caron, in press; Gallagher & MacLachlan, 2000b; Oaksford, Frude, & Cuddihy, 2005; Saradjian, Thompson, & Datta, 2007). For example, men with upper limb amputations reported having gained a high sense of self-worth from their success in overcoming the functional and psychosocial challenges posed by limb loss and being able to fulfill personally meaningful activities and roles (Saradjian et al., 2007). Oaksford and colleagues (2005) noted that ten out of the twelve people with lower limb amputations interviewed for their study reported they had experienced psychological growth as a result of their limb loss. Benefits included gaining a new appreciation of what it is like to live with a disability, being more inclined to help others, having greater patience, and having more appreciation of one's own resilience as well as of the kindness of others.

A small but growing body of quantitative research also addresses positive psychosocial adjustment to amputation (e.g. Oaksford et al., 2005; Phelps et al., 2008; Unwin, Kacperek, & Clarke, 2009). For example, Dunn (1996) examined the salutary effects of finding positive meaning in the experience of amputation among 138 members of a golfing association for persons with amputation. More than three quarters of participants reported that something positive had happened since their limb loss. Of these, 60% found benefits such as becoming more outgoing or making positive life changes. Others found positive meaning in their experiences by engaging in downward social comparison or focusing on the positive aspects of their limb loss. Those who were able to see a positive side to their amputation experienced significantly fewer symptoms of depression than those who were unable to find a 'silver lining'. Benefit finding among persons with amputations was also observed in a study by Gallagher and MacLachlan (2000b), 46% of participants reported that something good had happened as a result of their limb loss. The beneficial effects of amputation reported included gaining independence through the use of a prosthetic limb, developing a more positive outlook, leading a better life, viewing the experience as character-building, and experiencing less pain as a result of amputation.

Finding positive meaning in amputation was associated with better self-reported health and physical capability, and greater adjustment to limitations.

Factors Associated with Adjustment to Amputation

Attempts to identify specific factors that may account for the diversity of responses to amputation have stimulated investigation of an array of medical/amputation-related factors (e.g. amputation aetiology, level of amputation), demographic variables (e.g. age) and individual psychological variables (e.g. perceived social support, coping). In general, relationships between medical, amputation-related, and demographic variables and adjustment have been weak or inconsistent; exceptions include post-amputation pain and age at amputation, where greater consistency emerges (Horgan & MacLachlan, 2004; Rybarczyk et al., 2004). A number of studies have linked older age with better adjustment (Behel et al., 2002; Desmond & MacLachlan, 2006b; Dunn, 1996; Phelps et al., 2008; Singh et al., 2009; Williamson et al., 1994). Drawing on life-span theories of development, explanations for such findings centre on proposals that older adults may not react as strongly to amputation as younger individuals, because they view changes in functional abilities and body image resulting from limb loss as undesirable but somewhat expected at their age (Horgan & MacLachlan, 2004). As noted previously, persistent post-amputation pain has been highlighted as a significant risk factor for poor adjustment (Gallagher, Allen, & MacLachlan, 2001; Jensen et al., 2002). In keeping with the wider literature on chronic illness and disability, which repeatedly demonstrates that objective measures of physical impairment tend to be poor predictors of psychological well-being, research has failed to support a significant association between level of amputation and adjustment (e.g. Asano et al., 2008; Behel et al., 2002; Unwin et al., 2009). Rybarczyk and colleagues (1997) argue that degree of impairment is too simplistic to serve as an important predictor of overall adjustment and suggest that while physical impairment may have an impact on one's self-concept and related factors, the restrictions it causes in activities of daily living and other life domains are more likely to play a pivotal role in the adaptation process.

Amongst the psychosocial correlates of adjustment, variables such as hope (Unwin et al., 2009), optimism (Dunn, 1996), perceived control (Dunn, 1996), sense of coherence (Badura-Brzoza, Matysiakiewicz, Piegza, Rycerski, & Hese, 2008), self-esteem (Breakey, 1997; Donovan-Hall et al., 2002), illness perceptions (Callaghan, Condie, & Johnston, 2008), balance confidence (Asano et al., 2008), public self-consciousness (Atherton & Robertson, 2006; Williamson & Schulz, 1995), vulnerability (Behel et al., 2002), and perceived social stigma (Rybarczyk et al., 1995) have been found to be significantly associated with psychosocial adjustment. However, given the small number of studies addressing these domains further research is necessary before substantive conclusions may be reached. Coping (e.g. Desmond, 2007; Desmond & MacLachlan, 2006b) and social support (e.g. Asano et al., 2008; Unwin et al., 2009; Williamson et al., 1994) have received most, albeit still relatively limited, research attention. As limb amputation may be considered a major stressful life event, characterized by evolving and recurrent stressors which pose significant challenges (Desmond & Gallagher, 2008) a number of studies have adopted a stress-coping framework investigating the types of coping strategies employed in adapting to limb loss (e.g. Desmond & MacLachlan, 2006b; Gallagher & MacLachlan, 1999; Livneh, Antonak, & Gerhardt, 1999; Livneh, Antonak, & Gerhardt, 2000; Oaksford et al., 2005). In accordance with the broader literature on coping, the use of problem-focused and approach coping appears to be more adaptive than emotion-oriented and avoidant strategies in adjusting to amputation (Desmond, 2007; Desmond & MacLachlan, 2006b; Livneh et al., 1999). The importance of meaning-making and meaning-based coping strategies has also emerged in a number of qualitative studies (Gallagher & MacLachlan, 2000b; Oaksford et al., 2005; Saradjian et al., 2007). For an extended review of issues relating to coping with limb amputation see Desmond and Gallagher (2008).

The importance of the support provided by family and friends in the post-amputation recovery process has been emphasized by both rehabilitation specialists and patients alike (Furst & Humphrey, 1983; Schoppen et al., 2003). Social support is likely to help people adapt to limb loss in a number of different ways. Firstly, people with good social resources are likely to benefit from the assistance offered by these relationships in attempting to renegotiate their physical and social environments following amputation. Indeed, Williams and colleagues (Williams et al., 2004) noted that individuals with amputations who had higher levels of social support consistently reported more time out of bed, out of the house, and in their communities, as well as greater participation in social, leisure, vocational and other meaningful activities. The presence of high-quality social support after amputation is also likely to enhance psychological well-being by providing the person with the emotional support needed to come to terms with this life-changing experience. Perceived social support has been identified as a significant predictor of both physical and mental health outcomes including depressed affect (Rybarczyk et al., 1995; Williamson et al., 1994), quality of life (Asano et al., 2008; Rybarczyk et al., 1995), and activity restriction (Williamson et al., 1994). Prospective studies indicate that greater perceived social support aids individuals in both physically and psychologically adjusting to their limb loss over time (Bosse et al., 2002; Hanley et al., 2004; Jensen et al., 2002; Unwin et al., 2009; Williams et al., 2004). In a two-year prospective study of patients with traumatic lower limb amputations, Bosse and colleagues (2002) reported that reduced levels of perceived social support were predictive of poorer self-reported health status. Jensen and colleagues (2002) found that perceived social support at one month post-amputation was a significant independent predictor of improvements in pain interference and depression over the following five months. Perceived social support on commencement of rehabilitation has also been found to predict both positive affect and general adjustment to amputation six months later, making a significant independent contribution in the case of general adjustment (Unwin et al., 2009).

Assessment

A variety of psychometric instruments have been developed to assess psychosocial outcomes specifically associated with lower limb amputation. These include the Trinity Amputation and Prosthesis Experience Scales (TAPES; Gallagher, Franchignoni, Giordano, & MacLachlan, 2010; Gallagher & MacLachlan, 2000a; Gallagher & MacLachlan, 2004), the Prosthesis Evaluation Questionnaire (PEQ; Boone & Coleman, 2006; Legro et al., 1998), the Orthotics and Prosthetics User's Survey (OPUS; Heinemann, Bode, & O'Reilly, 2003) and the Questionnaire for Persons with a

Transfemoral Amputation (Q-TFA; Hagberg, Brånemark, & Haag, 2004). Each of these questionnaires assesses a range of psychological, social and physical functioning outcomes. A recent review recommends all of the instruments undergo further testing and use, and suggests that "the TAPES seems especially useful for assessing psychosocial adjustment" (Wolfe et al., 2008; p.84). The TAPES measures psychosocial adjustment, activity restriction and satisfaction with the prosthesis, as well as severity and frequency of stump and phantom limb pain. It has been translated into more than 10 languages and used with both lower and upper limb amputation and across the age range from the elderly to children. The revised TAPES (TAPES-R; Gallagher et al., 2010) incorporated a Rasch analysis across several data sets to further strengthen its psychometric properties. (It is freely available to download: www.tcd.ie/psychoprosthetics).

As noted above, body image is a salient factor in adjustment for some people post-amputation; various scales have also been developed to assess body image in people with amputations specifically. Although numerous self-report scales exist, a recent comparative review (Wolfe et al., 2008) noted that each had been used in just a few studies, and none had a strong psychometric evidence base. The only assessment with multiple reports providing data for validity and reliability is the Amputee Body Image Scale (Breakey, 1997), and this scale has also recently been submitted to a Rasch analysis to provide further evidence of its psychometric properties (Gallagher et al., 2007). A range of more generic measures may be used to assess quality of life, coping styles, cognitive and executive functioning, and affective disorders; these are not specific to people with amputation and are hence beyond the scope of this review. The use of the Hospital Anxiety and Depression Scale is however of note, as it was designed to avoid conflating the physical symptoms of depression that may be a primary feature of physical illness or disability, such as amputation. Psychometric properties of the HADS have also been reported for people with amputations (Desmond & MacLachlan, 2005). The use of the TAPES-R, the ABIS-R and the HADS for people with amputations may provide a reasonably broad assessment of psychosocial, body image and affective functioning. These self-report measures which are relatively quickly and easily administered can be valuable in complementing routine clinical interviews and in monitoring adaptation and the impact of interventions. Additionally, in light of the prevalence of amputation due to peripheral vascular disease, the systemic nature of this condition, and the noted increase in age at amputation, screening for cognitive impairments should be considered as part of routine clinical practice for rehabilitation psychologists (O'Neill & Evans, 2009; O’Neill, 2008). A routine cognitive screen for mild cognitive impairment or vascular dementia might include assessment of orientation, immediate and delayed visual and verbal memory, new learning, attention, executive functions, expressive and receptive language and visuospatial abilities.

Role of the Psychologist in the Interdisciplinary Rehabilitation Team

Wegener et al. (2008) outline four principles guiding psychological care of persons with limb loss which include: 1) recognizing that there are biological, psychological, and social dimensions of medical conditions and that it is necessary to consider all relevant factors when assessing and treating a patient (Engel, 1977); 2) adopting a *patient* *centered care* approach distinguished by empowering patients through increasing self-efficacy and activation; 3) recognizing that many individuals with physical impairments are *resilient* and that mood disturbances or other psychological symptoms are not inevitable; and 4) appreciating that effective assessment and intervention recognizes, capitalizes on and develops the *patient's strengths*. Within this approach patients, who have unique abilities, resources and experiences, are recognised as the *central workers* in the rehabilitation process.

Key areas for psychologists working in interdisciplinary rehabilitation teams with people with limb loss include: providing a psychological perspective within the context of the interdisciplinary team at planning, reviews, family meetings and discharge planning; assessment of psychosocial outcomes, including anxiety, post-traumatic stress symptoms, depression, coping, quality of life, body image and pain; assessment and interpretation of cognitive abilities using appropriately selected screening tools; formulation of the individual's presenting difficulties in the context of a biopsychosocial framework; providing psychological interventions at an individual level to increase coping skills and self-efficacy and to empower the individual to manage their adjustment to limb-loss; facilitating group interventions and peer support using cognitive behavioural and solution-focused approaches with the aim of normalizing the adjustment process, and provision of psycho-education around mood management; evaluation of the interventions; application of clinical research knowledge to enhance understanding of the experience of limb-loss and to increase the evidence-base for effective treatments;

systemic working with individuals and their families to enhance family adjustment and support.

Intervention

Individuals after limb loss may require assistance in managing a number of obstacles in their recovery. We have already noted a range of factors that promote psychosocial adjustment to limb amputation. For some individuals, psychological intervention may be designed to promote successful adaptation and growth. For others, who develop significant depression, anxiety or other maladaptive responses psychologists will need to utilize specific interventions (MacLachlan, 2004). In addition to affective disturbances, intrapersonal issues such as body image adjustment, interpersonal issues such as social stigma, intimacy and sexual functioning previously discussed, the clinician must be mindful of substance use. Rates of pre- and post-morbid substance abuse among people with limb loss have not been systematically investigated; the potential for substance abuse to contribute to the development of chronic conditions and/or to slow the rate of recovery is clear and thus appropriate assessment, and intervention where necessary, is warranted (Wegener et al., 2008).

There are several classes of interventions that may assist persons with limb loss adapt successfully or manage clinical symptoms or syndromes. With rare exceptions, the efficacy of these interventions for persons with limb loss lacks a strong evidence base. Their utilization with this population is based on data in other populations or on clinical judgment rather than rigorous clinical trials; much remains to be researched in the context of amputation rehabilitation. Here we briefly consider a variety of interventions that are utilized in the rehabilitation of persons with limb loss.

Peer interactions and self-management: Peer interactions and support groups, are premised on the idea that through exposure to successful individuals with similar illnesses or injuries, less experienced persons can learn and adopt more effective behaviors and improve social support (Wegener et al., 2008). Support groups can form part of formal rehabilitation programs or may be facilitated via patient advocacy/ consumer organizations. The Peer Visitor Program offered by the Amputee Coalition of America (http://www.amputee-coalition.org), a consumer organisation in the United States, is perhaps the most widely used model in the context of amputation. While peer support is often welcomed by patients, there are limited reports of improved outcomes, and the appropriate timing of visits and specific benefits to amputation patients have yet to be empirically established (Wegener et al., 2008).

Self-management (SM) interventions incorporate the principles of cognitive behavioral theory; key elements include knowledge, self-monitoring, skills acquisition and problem solving (Lorig & Holman, 2003). SM approaches have gained widespread application with chronic conditions in which pain and disability are common (Wegener et al., 2008). Given secondary conditions such as depression and pain that accompany limb amputation, interventions that specifically focus on preventing or reducing these have been developed. One such intervention is the *Promoting Amputee Life Skills* (PALS) self-management course. This intervention consists of eight weekly 90-minute group sessions followed by a booster session two weeks later. The groups are led by trained leaders, one of whom is a person with limb loss. Recently, the first randomized controlled trial investigating the effectiveness of this SM intervention for people with amputations found that the PALS programme improved the outcomes (i.e. less depression, fewer functional limitations and higher self-efficacy) of people with limb amputations beyond benefits that would have been offered by support group participation (Wegener, Mackenzie, Ephraim, Ehde, & Williams, 2009). There is considerable scope for research to adapt the PALS programme and to assess the impact of its implementation in settings other than the United States of America where it was originally developed and trialed. Furthermore, there is scope to explore the delivery of such interventions using new and emerging technologies (Wegener et al., 2008).

Psychotherapy: Psychotherapy can take many forms and utilize a variety of techniques. While data support the beneficial effects of psychotherapy for the typical mental health patient (see Kendall & Chambless, 1998), there are no published controlled trials of psychotherapy specifically focused on persons with limb loss. Most, but not all, of the evidence-based treatments to address psychological difficulties use cognitive-behavioral, behavioral or interpersonal techniques (Chambless, 2005). Data support specific treatment approaches, as well as suggesting that the therapy relationship accounts for much of the treatment outcome (Wampold, 2001). Primary targets of cognitive behavioral therapy (CBT) interventions are affective problems such as depressive symptoms, anxiety, and anger. While there is no specific evidence in persons with limb loss, it is likely that social problems, such as dealing with social stigma and increasing social skills, may also be addressed effectively with CBT (Wegener et al., 2008). Interpersonal psychotherapy (IPT; Klerman, Weissman, Rounsaville, & Chevron, 1984) is appropriate for treatment of acute psychological distress as well as prolonged maintenance of symptoms that are mild to moderate in severity. IPT focuses on relationship issues, but also takes into account the biopsychosocial factors that contribute to the problem. The goal of IPT when working with a person with limb loss would be to assist the individual with identifying and changing unhelpful interpersonal interactions, as well ameliorate depressive symptoms.

Coping Skills and Problem Solving: In general, coping behaviors that are active and goal-oriented are more helpful to the patient (see Desmond & Gallagher, 2008; Elfström, 2007). Interventions focused on building coping skills should include: (1) analysis of the situation and current coping techniques, (2) description of the problem, (3) goal setting, and (4) modification of the coping strategies. These steps can be accomplished though brief, structured interventions with the patient (Heim, 1995). Catastrophizing, a cognitive response to an event that is marked by exaggerated negative expectations and concerns, has been found to predict both self-reported and objective measures of disability in a variety of chronic pain conditions (Sullivan et al., 2001). Amongst individuals with limb loss and phantom limb pain, catastrophizing predicts increased pain interference, depressive symptoms, self-reported disability and psychosocial dysfunction (Hill, 1993; Hill, Niven, & Knussen, 1995; Jensen et al., 2002). CBT interventions for catastrophizing focus on monitoring, challenging, and changing negative thoughts as well as behavioral activation to increase self-efficacy. Coping strategies such as distraction, positive self-talk, and increasing activity levels are associated with adjustment to chronic pain (Jensen, Turner, Romano, & Karoly, 1991) and may promote psychological health following limb loss. In addition, individuals who can find some positive meaning from the amputation may have less depression and increased activity levels and better adjustment (Dunn, 1996; Gallagher & MacLachlan, 2000b). Therefore, interventions aimed at finding positive meaning, increasing positive self-talk, and stimulating activity may be beneficial in amputation rehabilitation (Ehde & Wegener, 2008; Wegener et al., 2008).

Medications: A wide range of medications may offer relief from symptoms of psychological distress associated with amputation; no randomized clinical trials provide data for their efficacy specifically in the limb loss population. A comprehensive discussion of medications that may be appropriate is beyond the scope of this chapter; psychologists working in the biopsychosocial model should seek appropriate medical consultation regarding medication as part of a comprehensive treatment approach (Wegener et al., 2008).

Pain Management: Sherman (1997) reported that despite some sixty different types of treatment being used with phantom limb pain (PLP) - physical, pharmaceutical or psychological – evidence for their efficacy was lacking. While there have been some advances in pharmacology and augmented reality treatments, no treatment has well supported efficacy. Conventional pain management techniques may effectively treat stump pain, but fail to address the confusion and distress that patients may experience as a result of pain or sensation in the part of their body that has been removed. Although there is still no treatment for PLP that is reliably effective, contemporary interventions used by psychologists include transcutaneous nerve stimulation (TENS), biofeedback, relaxation therapy and hypnotherapy (see Ehde & Wegener, 2008; McIver & Lloyd, 2010). Recently there has also been considerable interest in the use of mental imagery, virtual and augmented reality (e.g. Brodie, Whyte, & Niven, 2007; Cole, Crowle, Austwick, & Henderson Slater, 2009; Desmond, O'Neill, de Paor, Mac Darby, & MacLachlan, 2006; Murray, Patchick, Caillette, Howard, & Pettifer, 2006). Based on the assumption that PLP may arise due to a conflict between the visual and proprioceptive experience of an amputated limb, Ramachandran and Rogers-Ramachandran (1996) suggested that illusionary movement of an amputated limb might alleviate pain by aligning the experiences, or by helping to replace a remembered image of a painfully twisted limb with an image in a more relaxed posture. They were able to demonstrate pain relief for some patients, not for others, but spurred great interest in the area. Although subsequent research has shown some promise (Darnall, 2009; MacLachlan, McDonald, & Waloch, 2004) there have also been reports of the procedure being distressing and painful for some. For instance, Chan, Witt, Charrow et al. (2007) reported that pain reduction was greater in their mirror therapy group, compared with a covered-mirror control group, or an imagery comparison group. However, two of the six patients in the mirror therapy group reported brief grief reactions on viewing their ‘intact amputated limb’; in the covered-mirror group three of six patients reported worsening pain; and in the imagery group four of six reported worsening pain. Based on the same principles, the use of augmented reality (using computer simulation) has also had mixed results. For example, Desmond, O’Neill, de Paor et al. (2006) found that one of three participants reported a temporary reduction in pain, one no change at all, and one a worsening of pain. In summary, illusory visual representations of missing limb (through imagery, virtual or augmented reality techniques) appear to have salience for the pain experience of at least some people with PLP. Larger scale studies that report long-term follow-up are needed, but until then clinicians should be aware of the potential for such interventions to cause distress and increase pain for some patients, whilst offering the possibility of pain relief - although perhaps only transitory - for others. See Ehde and Wegener (2008) for a review of pain management after limb loss.

Next Steps in Treatment: Programs and services that empower patients and consumers to become active participants in their life-long care are needed to meet the increasing demands placed on them by the evolving health care systems that hold both consumers and their providers accountable for successful outcomes. Furthermore, development of the continuum of care beyond the acute time period is needed. Several lines of research suggest approaches that may enhance outcomes and expand the continuum of care. The development and evaluation of programs utilizing peer mentors may be helpful in assisting individuals with new impairments with successful adaptation. Motivational interviewing techniques have been developed and shown to be efficacious in increasing participation in a variety of health behaviors (see Rubak, Sandbæk, Lauritzen, & Christensen, 2005, for review). Finally, it is well recognized that computer-based health information and support systems can be used to disseminate information, link people to needed resources, connect people on-line who are facing similar challenges and develop communities of individuals with common interests, aspirations and needs. While such innovation is relatively recent, these programs and services have the potential to be successfully utilized by patients with a variety of chronic illnesses, including individuals in underserved populations (Wegener et al., 2008).

Future directions

There is an increasing body of research investigating and describing the consequences and implications of limb amputation from a psychosocial perspective. Nonetheless, relative to other rehabilitation areas, it remains a nascent area of research and continued efforts are required to advance understanding, to influence practice and to improve person-centered care. As noted previously the efficacy of interventions for persons with limb loss lacks a strong evidence base; randomized controlled interventions with adequate power and long term follow up remain scare in the context of amputation.

Given the incidence and prevalence of limb amputation and the concomitant need for prosthetic interventions, optimizing the prescription and use of prosthetic devices is a priority area. For example, two recent parallel studies provided a forum for patients and service providers to voice their opinions on what they believe to be the important predictors and outcomes involved in successful rehabilitation following upper and lower limb loss (NiMhurchadha, 2010; Schaffalitzky, 2010). These factors provide a guide for rehabilitation professionals in appropriately assessing individuals with limb loss/absence and identifying the important core areas to target in rehabilitation with the hope of improving fitting rates and user satisfaction, and reducing the waste of resources.

Outcome measurement in prosthetic prescription currently encompasses a number of different outcomes and measurement is carried in a number of different ways (see Hebert et al., 2009; Lindner, Nätterlund, & Hermansson, 2010). This makes it difficult to compare and evaluate different interventions and prosthetic components. By identifying the most important outcomes, to both prosthetic users and service providers, we can progress in standardizing outcome measurement to allow comparison and synthesis across studies. Furthermore, we are better equipped in understanding why and when prosthetic technology should be provided (Schaffalitzky et al., 2010).

Despite the potential for increased risk of cognitive impairment following amputation due to associations with vascular disease and older age, and its apparent importance in the rehabilitation process, there is a dearth of research regarding the prevalence and impacts of cognitive impairment amongst individuals with limb loss. Greater clarity regarding the prevalence of cognitive impairment and which cognitive abilities or limitations are important in determining outcomes should be prioritized (O'Neill & Evans, 2009).

The World Health Organization International Classification of Functioning and Health (ICF: World Health Organization, 2001) is an important framework through which our understanding of the interactions between people and their environment, participation and activities can be enhanced (Gallagher et al., 2011). Recognition of the growing importance of the ICF in the field of amputation and prosthetics is evident in the 2011 special edition of *Prosthetics and Orthotics International* and in the recent work to develop a core set, based on the ICF, for persons following an amputation as means of specifying function (Kohler et al., 2009). Continued efforts are required, however, as a greater understanding of the impact of amputation and type of prosthesis on activity, participation, and environmental barriers is important in terms of facilitating improved management and planning at an individual, service and societal level (Gallagher et al., 2011).

Research on the impact of amputation on families is lacking although it is clear that families play critical roles and take substantial responsibility in post-amputation care and recovery. Many individuals will experience significant changes in their own lives as a consequence of their family member’s amputation. Nonetheless investigation of the impacts of amputation, be they negative and/or positive, on the family is lacking. Finally, as noted above, research on sexuality in amputation is severely limited and much needed.

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