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Psychosocial adjustment to lower-limb amputation: A review

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Abstract

Purpose: To review the existing literature on the social and psychological challenges faced by people with an amputation and to provide a detailed analysis of the literature examining psychological adjustment to these challenges across time.

Method: Existing papers on psychological adjustment to amputation were analysed according to their results, methodology, and conclusions.

Results: Although depression and anxiety are relatively high up to 2 years post-amputation, they appear to decline thereafter to general population norms. However, social discomfort and body-image anxiety have also been found among some people with amputations, and these have been associated with increased activity restriction, depression, and anxiety. Factors associated with positive adjustment to limb loss include greater time since amputation, more social support, greater satisfaction with the prosthesis, active coping attempts, an optimistic personality disposition, a lower level of amputation in the case of lower limbs, and lower levels of phantom limb pain and stump pain.

Conclusion: The majority of studies on adjustment to amputation are cross-sectional in design and have used non-comparable measures. Furthermore, they have neglected to study many important areas of rehabilitation, including immediate reaction to amputation, adjustment during and shortly after the rehabilitation period, and development of a changed sense of self and identity. In order to address these concerns, more longitudinal and qualitative research is called for. We end by outlining the components of a descriptive phased model of the rehabilitation process.

Introduction

This paper seeks to review the existing literature on the social and psychological challenges faced by people with a lower limb amputation, and to provide a detailed analysis of literature examining psychologi-

cal adjustment to these challenges. Psychological adjustment to amputation is reviewed by considering depressive and anxious reactions, body-image anxiety, social functioning and social discomfort, sense of self and identity, and its relationship to physical limitations. Factors associated with adjustment are then discussed in terms of amputation-related factors, sociodemographic factors, and personality attributes and coping styles. Finally, studies examining reactions and responses to amputation are examined and discussed in terms of a phased model of adaptation to amputation.

Psychological Adjustment to Amputation

DEPRESSION

One measure of psychosocial adaptation to amputation that has been used extensively is depression. During the period shortly after amputation, depression has been reported by some patients as being the reason for decreased use of their prosthesis¹ and lower levels of mobility.² Amongst people with long-term amputations, depression has also been associated with higher levels of activity restriction,³ increased feelings of vulnerability,⁴ and poorer self-rated health.⁵

Research examining the prevalence of depression in people with amputations has yielded mixed findings. While some studies have found no evidence of increased levels of depression,^{6–8} others have concluded that individuals with an amputation have a particular vulnerability to developing depressive symptomatology.^{9,10} In examining the literature, it is difficult to draw any firm conclusions with regard to these findings. Most studies examining this issue have been cross-sectional in design, thus utilizing responses from people who have had their amputations at different ages, for different lengths of

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time, and for different reasons.⁴ In addition, as prevalence and symptoms of depression can vary across different age-groups,¹¹ determining the occurrence of depression amongst cross-sectional samples is also confounded with age-related issues. Furthermore, authors across studies have varied in their methods of assessing depressive symptomatology, with the result that many studies are, therefore, not comparable. To complicate matters further, those studies that have used the same instrument to assess depression have provided different norm figures for rates in the general population, thus making their conclusions non-comparable across studies using similar methodologies. In view of these difficulties, then, and for the purpose of this review, we have grouped studies examining the prevalence of depression in people with amputations on the basis of the mean time since respondents had their amputation(s).

Depression up to 2-years post-amputation

Relatively few studies have examined rates of depression amongst people shortly after amputation. Amongst younger people, some depressive symptoms have been observed during the post-amputation hospitalization period.^{12, 13} Amongst older participants, high levels of depression have been found at the beginning of a rehabilitation programme and substantially lower rates have been found at discharge from rehabilitation.^{14, 15}

In cross-sectional studies, people who were, on average, 18 months to 2 years post-amputation showed some depressive symptoms.^{16–18} One early study,¹⁷ for example, described 58% of their 12 participants as depressed 18 months post-amputation. A more recent study¹⁶ reported that on the Beck Depression Inventory, 30% scored above the cut-off score for depressive symptoms. Somewhat contradictory findings were reported by Thompson and Haran,¹⁸ who examined psychosocial functioning in people with newly acquired and established amputations who had been prosthesis wearers for 1 to 2 years. These authors found that although only 13% of their sample reported feeling depressed following their amputation, almost half were at risk of psychiatric illness according to their General Health Questionnaire (GHQ) scores. Interestingly, several researchers have commented on this phenomenon,^{15, 18–20} suggesting that individuals are likely to ‘deny’ the emotional impact of their limb loss. For example, Thompson and Haran¹⁸ suggested that participants in their study showed a ‘heroic cheerfulness’ and a tendency to deny their emotional problems.

Depression 2 to 10 years post-amputation

Compared to the 1- to 2-year depression rates discussed above, many cross-sectional studies examining depression amongst people who have had their amputations between an average of 2 to 10 years did not find elevated rates of depression amongst these individuals. In fact, only two studies reported higher rates of depression amongst people with amputations compared to the general population.^{3, 21} With both studies using the Center for Epidemiological Studies Depression Scale (CES-D) as an indicator of depressive symptomatology, the proportion of those scoring above the cut-off point was 23²¹ and 21%.³ The fact that the only two studies in this period that found higher rates of depression both used the CES-D requires some comment. A study conducted to investigate the validity of the CES-D among older people¹¹ reported that 27% of the sample scored above the cut-off score for depression, even though a clinical interview found that only 3.5% of the sample was actually depressed. It is therefore possible that studies using the CES-D have overestimated depression in their samples.

The remainder of the studies with participants who had their amputation an average of 2 to 10 years and using such scales as the Millon Clinical Multiaxial Inventory, Beck Depression Inventory, the Symptom Checklist-90 and the Hospital Anxiety and Depression Scale did not show particularly high rates of depression.^{6, 22–24}

Depression 10 to 20 years post-amputation

Contrary to the findings above, only two studies^{7, 8} have found low rates of depression in cross-sectional studies of people who were 10 to 20 years post-amputation. The remaining four studies that have examined rates of depression in people who were an average of 10 to 20 years post-amputation have indicated somewhat higher rates of depression.^{4, 5, 9, 25} However, three of these studies used the CES-D, reporting rates of depression that ranged from 22.4 to 28%.^{4, 5, 17} The remaining study⁹ using the GHQ-28 found that 30% exceeded the cut-off for moderate to severe levels of distress, which is higher than reported GHQ-28 norms of 24 and 8% amongst unmarried and married older men, respectively.²⁶

Depression 20 to 30 years post-amputation

There are few studies examining rates of depression amongst people with long-term amputations. To date,

two cross-sectional studies have looked at rates of depression amongst people who had their amputations an average of 20 to 30 years previously and both of these reported rates that were consistent with those of the general populations.^{2, 27}

Depression: Conclusion

In reviewing these studies of depression in people with amputations, a somewhat clear picture emerges. Studies of those with newly acquired amputations indicate that a depressive reaction is quite common in the initial post-amputation phase, although it could be argued that this may also be a normal reaction to losing a limb, rather than a depressive reaction *per se*. Following the initial post-amputation stage, comparatively high levels of depression have also been found in people who have lost their limb for an average of 2 years. However, rates of depression appear to decrease again between 2 and 10 years post-amputation, with only those studies using the CES-D indicating increased rates. Between 10 and 30 years post-amputation, findings are mixed, with some studies indicating elevated rates of depression and others indicating normal rates of depression. In interpreting these findings, again, it is interesting to note that most of those studies that have found elevated rates of depression have used the CES-D, an instrument that has been shown to have high false-positive rates of depression amongst older individuals. In conclusion, then, if one discounts studies using the CES-D, depression in people with an amputation appears to be high immediately and between 1 to 2 years post-amputation. Following this, however, rates of depression appear to decrease to what is found in the general population.

To date, therefore, research examining rates of depression amongst individuals with an amputation is predominantly cross-sectional in nature, utilizing samples of people with amputations of varying ages and of varying etiologies. Furthermore, very little longitudinal research has been conducted on rates and levels of depression amongst people immediately post-amputation and throughout the years following limb loss and rehabilitation. Finally, the literature to date suggests that different measures of depression are likely to yield substantially different results and rates of depressive symptomatology. Therefore, in order to clarify adjustment to amputation, in terms of depression, further longitudinal studies using well established and validated instruments, samples of similar ages and with amputations of similar etiologies are required.

ANXIETY

Anxiety is another potential measure of psychosocial adjustment to amputation. Unlike the mixed findings that have been reported in terms of the prevalence of depression in people with amputations, the findings regarding anxiety appear to be more straightforward. Studies on people up to 1 year post-amputation suggest that levels of anxiety are raised during this period.^{12, 13} Randall *et al.*,¹² for example, reported that using Rorschach tests, 67% of the 100 soldiers in their study had free-floating anxiety. Similarly, Shukla *et al.*¹³ reported that 53% of their younger participants indicated symptoms of anxiety shortly after amputation and during hospitalization.

The remaining cross-sectional studies that have examined anxiety in people who had their amputation an average of 2 to 20 years have found no difference between these individuals and the general population in levels of anxiety.^{6-8, 16, 23, 24, 28} In summary, therefore, it would appear that anxiety is likely to be somewhat increased in the period immediately after and up to 1 year post-amputation. After this, however, anxiety levels appear to fall to those that are observed in the general population.

BODY IMAGE ANXIETY

Adaptation to a changed body image is another potential measure of psychosocial adjustment to amputation. Body image may be defined as 'the combination of an individual's psychological experiences, feelings and attitudes that relate to the form, function, appearance and desirability of one's own body which is influenced by individual and environmental factors'.²⁹

In the amputation literature, earlier papers briefly described the occurrence of body-image anxiety in people who have had an amputation.^{22, 30, 31} Subsequent papers have since indicated that body-image distortion³² and body image anxiety^{5, 7, 8} occur among some people who have an amputation. Moreover, such anxiety has been found to be associated with depression,^{7, 8} poorer perceived quality of life,^{5, 8} lower levels of self-esteem,⁸ and higher levels of general anxiety.⁷

SOCIAL FUNCTIONING AND SOCIAL DISCOMFORT

Social functioning is another potential measure of psychosocial adjustment to an amputation. In addition to having to cope with physical limitations and the impact that these can have on social functioning,³³ individuals have to adjust to the fact that they appear

'different' from other people. In the eyes of people who do not have an amputation, they may now appear 'disabled' and, in the words of Goffman,³⁴ members of a 'stigmatized' group. Such perceptions of 'stigma' can sometimes lead to disabled people being treated differently by non-disabled people because the latter may make assumptions, on the basis of the disability, about all aspects of the individual's personality and functioning.³⁴ For example, people without a disability can sometimes make the erroneous assumption that a disability is the core aspect of the person's personality and functioning, rather than just one facet of his or her life.³⁵ In addition, people without an amputation are liable to assume that the occurrence of the amputation was a negative occurrence for the individual.³⁶ In view of this, it has been reported that many people without disabilities ignore those with disabilities for fear of saying the wrong thing or because of experiencing general anxiety and unease in their presence.³⁷

In support of this, experimental studies^{38, 39} have indicated that people with simulated disabilities, specifically, a simulated amputation, are treated differently by those without any visible impairment. For example, in Kleck's³⁹ study students were required to teach Origami to a confederate either with or without an 'amputation'. Those who appeared to have an amputation were given significantly greater social distance by the students on the first trial, but not on the second trial. Interestingly, students in the study formed a more positive impression of the 'disabled' confederate than of the non-disabled confederate. According to Kleck,³⁹ the formation of a more positive impression may have been due to the tendency in society to be kind to 'disadvantaged' individuals. According to some writers,⁴⁰ such 'kindness' may actually be an attempt on the part of non-disabled people to reduce anxiety upon seeing a disabled person and to establish a sense of dissimilarity from the latter.

In view of these findings that individuals without a disability are likely to treat those with a disability differently, it is no surprise that people with an amputation have also reported such experiences.^{20, 22, 41} In one qualitative study, for example, participants remarked that other people often appeared embarrassed upon realizing that they had an amputation.²² In support of Dunn's³⁵ assertion that non-disabled individuals are likely to over-emphasize the role of the disability in the individual's life, Furst and Humphrey also found that individuals naïve with respect to an amputation rated people with amputations as being highly misfortunate compared to themselves, while individuals with an amputation rated themselves as being only marginally less fortunate after their amputation than before.²²

Participants in another qualitative study⁴¹ remarked that at times, other people had reacted to their amputation with shock and sometimes patronising behaviour.

In view of the fact that people with amputations are functionally restricted³³ and sometimes treated differently by others,⁴¹ the findings regarding the impact of an amputation on social functioning have been mixed. Some studies have found that amongst people of all ages, no significant differences in social functioning or levels of social discomfort have been found between those with and without amputations.^{28, 42-44}

Contrary to the above findings, however, some social problems amongst people with an amputation have been reported.⁴⁵⁻⁴⁹ For example, amongst older people difficulties were found in participating in social activities⁴⁵ and social isolation.⁴⁶ Amongst younger people with amputations, one study⁵⁰ found that almost half of the participants visited friends and relatives less frequently since their amputation and that approximately two-thirds were less likely to go to the cinema, theatre, sport events, library, dances, and shows. In addition, other studies^{47, 48} reported that individuals scored significantly poorer on Social Functioning, as assessed by the SF-36, than the general population.

Although it is difficult to assess the relative contributions of functional limitations, social discomfort, and perceived social stigma to overall social functioning, one study did find a direct association between activity restriction and social discomfort.⁵¹ In this study, older people who experienced a sense of public self-consciousness were significantly more likely to report being restricted in caring for others, doing household chores, going out shopping, visiting friends and maintaining friendships. This finding was observed regardless of gender or age.⁵¹ The relationship between social discomfort and decreased social functioning could also be mediated by depression. Two studies have found that perceived social stigma and social discomfort are significantly associated with increased levels of depression amongst people with amputations.^{5, 21} Since depression is associated with increased physical disability in older adults,^{52, 53} social discomfort and perceived stigma could therefore impact on reduced physical and social activities indirectly as well as directly.

IDENTITY, SELF, AND LIMITATIONS

Following an amputation, individuals must adapt to changed physical and social functioning and incorporate these changes into a new sense of self and self-identity. In this way, changes in physical functioning, limitations, and self-identity are closely related. In his paper examin-

ing the psychological similarities between bereavement and limb loss, Parkes¹⁹ briefly discussed this topic. He remarked that in the early phases, a person with an amputation feels mutilated, empty and vulnerable. As time passes, however, the individual discovers how well he or she can cope with the newfound limitations and restrictions. This ongoing process of discovery and accomplishment is what influences the person's final view and sense of him/herself. Despite Parke's¹⁹ comments, to date there has been no research conducted on the relationships among functioning, limitations, and identity in people with amputations. However, the general literature on adjustment to illness and disability suggests that disability focuses attention on physical activities and bodily functions that were previously taken for granted⁵⁴ and that the person faces the task of building a new concept of self around his or her new found limitations.⁵⁵ Ultimately, the person who has acquired a disability has learned to 'live with the altered self'.⁵⁶ This is an area deserving of much more research within the context of limb amputation.

Factors associated with psychological adjustment

AMPUTATION RELATED FACTORS

Cause of amputation

As a potential mediator of psychological adjustment to amputation, differences in reaction between those who have lost their limb as a result of trauma and those who have lost their limb due to vascular disease have been anecdotally described.⁵⁷ According to these reports, people with trauma-related amputations are more likely to display denial, while people with vascular-related amputations are more likely to show anger and hostility immediately after the amputation.⁵⁷ Despite such anecdotal reports, only one study² has indicated that 'cause' of amputation, in the sense of being convinced as to the necessity of amputation, was associated with lower levels of depression post-amputation. The remaining studies examining the relationship between cause of amputation and psychosocial outcome have found no effect of amputation cause on psychiatric symptoms,¹³ anxiety,²⁸ depressive symptoms,^{10, 21, 25} activity restriction,⁵¹ or social discomfort.²⁸

Level of amputation

Amputation level appears to be an important factor in predicting successful rehabilitation.^{33, 58-62} For example,

one study⁶² found that prosthesis use decreased as level of amputation increased. These findings are likely due to the fact that significantly more energy is required to operate an above-knee (AK) prosthesis than a below-knee (BK) prosthesis.^{63, 64} It is perhaps no surprise, therefore, that in examining levels of activity amongst middle-aged and older people with amputations, individuals with AK amputations are significantly more likely to be restricted in daily activities than those with a BK amputation.^{3, 51} Interestingly, however, when public self-consciousness is also included in these analyses, high levels of this variable is a stronger predictor of activity restriction than is amputation level.⁵¹

Despite the fact that AK amputations are associated with poorer rehabilitation outcomes and higher levels of activity restriction, AK amputations have not been found to be associated with increased levels of anxiety,²⁸ social discomfort,²⁸ general psychiatric symptoms,¹³ depression,⁴ or adjustment to amputation.⁶⁵ Interestingly, the one study that did find a relationship between amputation level and psychological outcome revealed that individuals with a BK amputation were more likely to be depressed than those with an AK amputation.⁶⁶ In explaining this finding, it was suggested that because individuals with BK amputations are less severely disabled in terms of functioning than those with AK amputations, they may be in a better position to compare their functional abilities with their premorbid abilities and, as a result, be more sensitive to the differences between themselves and able-bodied individuals.⁶⁶

Time since amputation

Time since amputation is another factor that could mediate the relationship between amputation and psychological adjustment. Several studies have reported no relationship between time since amputation and depressive symptoms^{4, 21} or general psychiatric symptoms.¹⁸ When an effect of time since amputation has been found, the findings have indicated that increased time since amputation is associated with a more favourable outcome.^{5, 67} Frank *et al.*²⁴ reported an interesting interaction between age and time since amputation: while older people tended to improve in psychological functioning (assessed by the Beck Depression Inventory and the SCL-90), with increasing time since amputation, younger people tended to worsen.

In examining the relationship between *body image* and time since amputation, one study⁸ reported no such relationship while qualitative studies on body-image following physical disability generally^{29, 68} and amputation⁴¹ in particular, have indicated that acceptance of a changed

body-image increases over time. In one longitudinal study,⁶⁸ for example, it was found that individuals who had experienced a significant change in physical appearance or function, including amputation, went through three phases in adapting to a changed body-image over the course of 18 months: initially 'shock', followed 'wishing for restoration' (in which they engaged in efforts to disguise their changed shape and altered functioning), and then 'reimaging the self'. In this latter stage participants realized the implications of their loss, recognized their altered body-image, and incorporated the physical changes into their lives and into a changed definition of identity and self-image.⁶⁸

Phantom limb pain

Another potential mediator of psychological adjustment to amputation is phantom limb pain. Early psychodynamic explanations of phantom limb pain perceived it as evidence of psychopathology in people with amputations.⁶⁹⁻⁷² As part of these earlier psychogenic theories, it was argued that phantom limb pain may be more likely to occur in amputated parts that were of greater importance to the individual's body image⁷³⁻⁷⁵ and that it constituted 'denial through activity'.⁷¹ However, recent theories of phantom limb have argued that phantom limb pain is *not* a sign of denial or psychological dysfunction in people with amputations. In his review, for example, Katz⁷⁶ outlined several reasons as to why phantom limb pain could not be due to denial of limb loss, including the fact that phantom pain can occur in individuals who have not lost their limbs⁷⁷ and that individuals who appear to have successfully adapted to their amputations continue to experience phantom limb pain for years afterwards.⁷²

Throughout the literature, phantom pain has been cited as being responsible for the occurrence of *body image anxiety* following amputation.⁷⁸ However, only two studies have actually reported any significant relationship between body image anxiety and PLP.^{79, 80} Without speculating as to the precise direction of the relationship, one study⁷⁹ found that participants with phantom pain were significantly more likely to draw intact body image drawings than were participants without phantom pain. In addition, a second study⁸⁰ found that body image anxiety items from the Beck Depression Inventory accounted for 16% of the variance in phantom pain intensity.

Besides body image anxiety, phantom limb pain has also been associated with several other cognitive and/or emotional outcomes post-amputation. A relationship

between phantom limb pain and the occurrence of stress has been established.⁸¹⁻⁸⁸

Although the above findings indicate some relationship between stress and phantom limb pain, the findings relating anxiety and/or depression to phantom pain have been mixed. Some cross-sectional studies^{78, 80, 89} have found an association between duration or occurrence of phantom pain and depression. However, others have found no difference between those with and without such pain and levels of anxiety⁶ or depression.^{6, 90, 91} These mixed findings indicate the difficulties in determining the precise nature of the relationship between phantom pain and psychological distress. The general literature on pain and psychological functioning has reported a positive association between chronic pain and depression,⁹²⁻⁹⁴ a finding which researchers of phantom limb pain have tended to support.^{78, 95} Furthermore, although most studies have not reported high levels of depression and anxiety amongst the general population of people with an amputation,^{6-8, 24} the general depressive reactions experienced by some individuals shortly after having an amputation^{10, 12, 13, 17, 31, 96} make it difficult to assess the unique role of normal or depressive reactions to having an amputation, in the occurrence and intensity of PLP. In conclusion, people with an amputation have the same level of psychological functioning as the general population⁹⁵ and that chronic phantom limb pain is affected by stress, anxiety and depression in much the same way as are other chronic pain syndromes.⁸⁷

Stump pain

Another potential mediator of psychological adjustment to amputation is stump pain. In general, there are two possible mechanisms whereby stump pain could be associated with psychological well-being. In the first instance, stump pain could be directly associated with depression. In support of this, the general literature on pain and psychological well-being indicate that pain and depression tend to co-occur.^{92, 97}

Another mechanism whereby stump pain could impact on psychological well-being is via its impact on activity levels. In general, it has been observed that stump pain is associated with a less satisfactory outcome in rehabilitation.^{23, 42, 84, 98-101} As a result of the negative impact of stump pain on mobility and rehabilitation and the resulting activity restriction, individuals could become frustrated, depressed, and/or anxious. In the general literature on disability, a relationship between activity restriction and depressed affect has been found.^{102, 103} In the literature on people with amputa-

tions, it was found that activity restriction mediated the relationship between depression and the number of hours a day the prosthesis was worn, income adequacy, and satisfaction with social contacts.³ Although no study has examined the mediating effect of activity on stump pain and depression, the above findings would appear to suggest that as stump pain severely restricts adjustment to limitations and mobility,^{101, 102} the resulting activity restriction could act as a mediator between stump pain and psychological well-being.

Prosthesis

Another potential mediator of psychological adjustment to the amputation is the prosthesis. In adjusting to the physical limitations that the amputation brings, the prosthesis can help individuals regain mobility and independent functioning.¹⁰⁴ Since activity restriction and depression are interrelated,^{52, 53} the use of a prosthesis could be an important tool and mediator between disability and emotional well-being.

In adjusting to an altered body image, the prosthesis could also act as a buffer against body image anxiety. In 1947, Wittkower¹⁰⁵ suggested that in addition to serving functional needs, the prosthesis also acted as a tool to conceal the amputation and to restore a 'normal' or 'intact' body image to the individual.¹⁰⁵ Subsequent papers have verified these ideas qualitatively,^{41, 68} quantitatively,^{106, 107} and anecdotally.³⁰ For example, in their study of 44 lower-limb prosthesis users, Murray and Fox¹⁰⁶ found that amongst women, increased body-image anxiety was associated with lower levels of satisfaction with their prosthesis, in terms of overall ratings, aesthetic aspects, and weight as measured by the Trinity Amputation and Prosthesis Experience Scales (TAPES). Amongst men, increased body-image anxiety was associated with decreased use of the prosthesis and lower levels of prosthesis satisfaction in terms of overall ratings, functional aspects, and weight.

SOCIODEMOGRAPHIC FACTORS

Gender

One sociodemographic factor that could be associated with outcome following amputation is gender. In terms of *psychological well-being* following amputation, however, most studies have found no difference in the psychosocial outcome of men and women.^{4, 13, 21, 25, 51, 65, 108} Where effects of gender on psychological outcome have been found, they have tended to be in favour of men rather than women. These

studies have reported that women are more likely to experience depression,¹⁰ to score significantly poorer on emotional adaptation to role changes,⁴⁷ and to perform more poorly on a measure that includes an assessment of emotional adaptability.⁶⁶

In terms of *body-image* anxiety, the effect of gender is inconclusive. Although only one study suggested that women may be more prone to body-image anxieties following amputation than are men,²² the remainder of the studies that have examined body-image anxiety in people with an amputation have not assessed differences by gender, or reported no differences when it was measured.¹⁰⁶

Age

Another potential mediating factor in psychological adjustment to amputation is age. In examining the relationship between age and *psychological well-being* post-amputation, findings have been mixed. Using the CES-D, Rybarczyk *et al.*²¹ and Behel *et al.*⁴ found no relationship between age and depressive symptoms. Using the Diagnostic and Statistical Manual Version II (DSM-II) diagnostic categories, another study¹³ also reported that age had no effect on a range of psychiatric symptoms, including depression and anxiety. However, where age effects on psychological well-being have been found, the direction tends to be in favour of older people rather than younger people.^{3, 7, 24, 109} According to Dunn,²⁷ the relationship between age and depression may be mediated by activity restriction. In support of this, Williamson and Schulz¹⁰² found that restriction of routine activities because of pain and illness was relatively more distressing in younger cancer patients than in older cancer patients. If this is the case, then younger people with amputations could also become more distressed as a result of activity restrictions than older people with amputations.

In terms of the impact of age on *body image*, anecdotal reports indicate that adolescents often report feeling self-conscious about their body image and are upset and bothered when people stare at them or ask them questions about their amputation.⁶⁵ However, empirical studies of body-image in people with amputations have found no relationship between younger age and body-image anxiety.^{7, 8} In terms of *activity restriction*, while only one study⁵¹ found no relationship between age and this factor several other studies have implicated age as an important factor in determining rehabilitation outcome at 5 months, 1-year, and 5-year follow-up.^{33, 60, 61, 100, 109–112}

Other potential variables that could mediate the relationship between amputation and psychological adjustment are educational level, socio-economic status, and income level. Although Shukla *et al.*¹³ found no relationship between education level and the occurrence of psychiatric symptoms in their participants, another study found that amongst younger people, having a high school education was associated with greater levels of bodily pain than having lower levels of education.⁴⁷ In addition, having a college-level education was associated with a significantly better outcome on physical role functioning than was a lower level of education.⁴⁷ Interestingly, although socio-economic status has not been found to be related to the occurrence of psychiatric symptoms¹³ or child and adolescent adjustment to amputation,⁶⁵ income adequacy has been found to be significantly related to activity restriction.³ That is, individuals with lower levels of income were more likely to be restricted in their activities.³ Despite this, however, income level of people with amputations has not been found to be related to depressive symptoms.⁴

Marital status/social support

Social support may be considered to consist of three theoretically distinct constructs.¹¹³ support network resources, supportive behaviour, and support appraisals. Of particular interest in the rehabilitation context are the latter two aspects; supportive behaviour and supportive appraisals. Supportive behaviours are defined as those acts generally recognized as helping efforts on the part of others,¹¹⁴ while support appraisals are the subjective evaluations of an individual's supportive relationships.¹¹⁴ Interestingly, while helping behaviours tend to be deleterious in adjusting to disability, support appraisal is associated with more favourable outcomes.

In the amputation literature, it was found that in addition to coping responses, solicitous spouse responses at 1 month post-amputation were associated with increased levels of depression and phantom limb pain interference, while perceived social support was found to have the opposite effect.¹¹⁵

To date, the vast majority of studies that have included social support as a potential mediator between amputation and psychological outcome have tended to measure perceived social support (i.e., support appraisals). These studies have all drawn similar conclusions regarding its beneficial effects. In young children and adolescents, social support was found to have a direct effect on general adjustment

to amputation.⁶⁵ In one qualitative study,²² participants remarked that one of the factors promoting a successful rehabilitation post-amputation was the existence of family support. Several quantitative studies have found that increased social isolation and lower levels of perceived social support are associated with lower perceived quality of life⁵ and higher levels of depressive symptomatology.^{3, 5, 18, 21, 51} The general literature on the mechanism by which social support enhances psychological well-being has tended to revolve around two theories: the *buffer effect* model claims that social support mediates the relationship between stressful life events and psychological distress, and the *direct effect* model states that social support has a positive effect on psychological well-being regardless of the stress process.¹¹⁴ To date, however, there have been no studies examining the mechanism by which social support assists adjustment to amputation.

PERSONALITY ATTRIBUTES AND COPING MODES

Personality

Surprisingly, very few studies have examined the impact of personality factors on psychological adjustment to amputation. Although the role of motivation in adapting to the physical sequelae of an amputation has been discussed,^{17, 98} the impact of motivation on adjusting to psychological sequelae has not been empirically investigated. Nevertheless, several pre-amputation personality factors have been found to be important in determining rehabilitation success.^{2, 27} For example, Gerhards *et al.*² found that being a risk taker and an extrovert prior to the amputation was associated with lower levels of depression. In addition, having been socially active and an extrovert before the amputation was associated with better levels of social integration post-amputation.² Moreover, Dunn²⁷ noted that having an optimistic disposition and a higher level of perceived control over the disability were associated with lower levels of depression and higher levels of self-esteem. This finding was explained by the fact that respondents who were high in dispositional optimism would be more likely to search for a positive meaning in their amputation. Upon finding such meaning in the amputation, these individuals would gain a greater sense of control over the event and over the ensuing disability. Such control over the event and the disability would subsequently lead to a greater sense of coherence and self-esteem²⁷.

Coping

Coping is another potential mediator of outcome following amputation. The majority of studies examining coping with amputation have focused on its relationship with phantom limb pain.^{79–89, 115–117} Detailed analyses of coping with phantom limb pain have been conducted by Hill⁸⁹ and by Jensen *et al.*¹¹⁵ Using the Coping Strategies Questionnaire, Hill⁸⁹ found that amongst younger people with trauma-related amputations, catastrophizing responses to pain significantly contributed to the variance in pain reported and psychological distress. Further support for the role of catastrophizing was provided by Jensen *et al.*,¹¹⁵ who found that catastrophizing at 1 month post-amputation was associated with depression, pain intensity, and pain interference at this time and with depressive symptoms and pain interference 5 months later.

The remaining papers on coping with amputation have examined the relationship between coping and general adjustment to amputation. Some researchers have focused on particular coping scales to examine their association with psychological outcomes.^{67, 118, 119} In general, it was been concluded that the coping efforts of people with amputations are not meaningfully different from those used by people without any type of physical disability.¹¹⁸ Thus, people with an amputation tend to have coping responses that reflect three general dimensions including: (a) Active/confrontive coping versus passive/avoiding, (b) Optimistic/positivistic versus pessimistic/fatalistic, and (c) Social/emotional versus cognitive.¹¹⁸ Relationships between similar coping strategies and psychological well-being have been reported.^{67, 119}

Other researchers examining coping with amputation have based their investigations on major theories from the general literature on the use of reality negotiation, positive illusions and social comparisons in coping with health and illness.^{120–123} According to these researchers, negative life events, including trauma and illness, frequently lead the person to look for a positive meaning in the event and to rely on positive illusion, or reframing, to cope with the event outcome.¹²⁰

To date, two studies^{27, 124} have utilized these ideas in examining how people cope with their amputation and its psychosocial sequelae. For example, Dunn²⁷ found that finding positive meaning following the amputation was related to lower levels of depressive symptomatology.²⁷ Gallagher and MacLachlan¹²⁴ similarly found that perceiving something positive to have happened as a result of the amputation was associated with significantly higher self-ratings of health and physical capabilities,

better adjustment to limitations, and lower levels of athletic restrictions (as measured by the TAPES).

Reactions and responses to amputation

REACTION TO AMPUTATION: A PHASED MODEL

Overall, individuals with an amputation are faced with adapting to several losses and changes to their lifestyle, social interactions, and identity. One of the biggest changes that people have to adjust to following an amputation is loss of physical function and independence. In the early post-amputation stage, people with lower limb amputations are faced with difficulties in mobility¹²⁵ and in carrying out activities of daily living.¹ At the same time, they have to adapt to an image of themselves without the amputated limb while reconciling three images of their body: before the amputation, without a prosthesis, and with a prosthesis.³⁶ It has also been suggested that following an amputation, the individual loses a sense of him or herself as a complete intact person with an immutable body boundary, and is faced with the realization that he or she has a disrupted, violated body image.¹⁹

In addition to coping with these changes in physical function and body-image, individuals may also have to face the fact that they may now be seen as 'disabled' and part of a 'stigmatized' group in society.³⁴ The general literature to date has indicated that individuals with a physical disability often experience negative reactions from others, with the result that they may begin to avoid social contact.^{126, 127} Common reactions of people with amputations to the various functional, physical, and psychological challenges that confront them, have been described during the pre-operative period,^{15, 27, 108} immediately post-operatively,^{12, 15, 19, 30, 41, 108, 128} during rehabilitation,^{12, 15, 19, 30, 108, 128} and long-term.^{19, 22, 129, 130}

In the *pre-operative phase*, just after individuals have been told that an amputation is required, several reactions have been observed. According to Friedmann,²⁷ most people who require an amputation because of an injury or accident often experience little reaction to being told that this is the case. At this stage, they are not aware of their situation or surroundings and are not in a position to process the information given to them. On the other hand, people who need an amputation as a result of vascular disease or on-going illness often show signs of relief that a solution to their suffering has been proposed and that their pain is coming to an end. Nevertheless, other writers^{15, 108} have indicated that even though most vascular patients are in extreme pain at this time, an anticipatory grief reaction is

common amongst these individuals. Furthermore, concerns about the future and about coping with an amputation are also frequently observed¹⁰⁸ and as many as 40% of participants in one particular study have regarded the pre-operative phase as the most upsetting time of the amputation process.¹⁵

In the *immediate post-operative phase* reactions have been mixed. Participants in one qualitative study remarked that this period was marked by feelings of devastation and distress.⁴¹ On the other hand, participants in another qualitative study were thought to be demonstrating emotional numbness and a strong tendency to deny the emotional impact of their amputation. At the same time, some pining for what they had lost was observed.¹⁹ Amongst people who had lost a limb due to war conflicts, high levels of optimism have been reported.¹² In this way, they have been found to remark feeling lucky to be alive and, for the most part, showing few worries about the future. Similarly, it has been found that immediately post-amputation, many older people in one particular study admitted to being euphorically optimistic and encouraged about their futures. In fact, only 23% of their participants felt that the immediate post-operative stage of the amputation was the most upsetting phase of their ordeal.¹⁵

An *intermediate rehabilitation phase* has been observed amongst those who are selected for prosthetic fitting and rehabilitation. According to MacBride *et al.*,¹⁵ it is during this phase that the reality of their situation and losses begin to dawn upon patients. Upon being given a prosthesis to walk on, individuals realize that doctors' predictions that they would be 'as good as new' after a prosthesis were overly optimistic. Randall *et al.*¹² reported similar findings amongst their younger, military sample. During the rehabilitation phase, their study participants revealed newly-formed doubts and uncertainties about their futures. Worries about adjusting to an amputation and others' reactions to them also surfaced during this phase. In their review of the literature, Bradway *et al.*¹⁰⁸ remarked that denial of the emotional and physical impact of the amputation is replaced by the beginnings of a grief reaction and pining for the losses that they are now beginning to recognize.

Following discharge from regular visits to the rehabilitation centre, a *long term adaptation phase* ensues^{12, 108, 128} where the person with an amputation must adapt to their new life context, without substantial support from rehabilitation clinicians. Despite the fact that many writers recognise the existence of this phase, to date, there has been no literature on the immediate post-rehabilitation period. Although one study¹⁰⁸ has

remarked that the harsh realities of the disability are imposed upon the person with an amputation at this stage and that a marked decrease in supportive help is experienced, it cites Parkes¹⁹ and Randall *et al.*¹² in support of this, both of whom do not give an in-depth discussion of the immediate post-rehabilitation phase in their studies.

Conclusion

In reviewing psychological adjustment to amputation, the following conclusions can be drawn. Although depression and anxiety appear to be relatively high up to 2 years post-amputation, it appears to decline thereafter to what is found in the general population. Despite these findings, social discomfort and body-image anxiety have been found among some people with amputations, and these have been associated with a poorer adjustment in terms of greater activity restriction, depression, and anxiety. Factors associated with a better adjustment to limb loss include increased time since amputation, higher levels of social support, higher levels of satisfaction with the prosthesis, higher levels of active coping, an optimistic personality disposition, lower levels of amputation, and lower levels of phantom limb pain and stump pain. Although most research has found no association between sociodemographic factors and adjustment to limb loss, those studies that have observed a relationship between the two have indicated that older age or male gender are associated with a better outcome than younger age or female gender.

Overall, however, these findings are based upon studies that are predominantly cross-sectional in nature, utilizing samples of people with amputations of varying ages and of varying etiologies. Furthermore, the literature to date suggests that specific measures of adjustment may yield substantially different results. For example, different instruments used to measure depression are likely to yield varying levels of depressive symptomatology across samples. In addition, measures of body-image anxiety in people with amputations have not been validated for use amongst different age groups and amongst people with amputations of different etiologies. While much research has focused on negative outcomes associated with amputation, we call for research that more broadly addresses patient's quality of life (positive and negative), from within a psychosocial perspective.^{131, 132}

Moreover, certain areas of adjustment to amputation have been neglected in research to date. These include the nature of the reaction to limb loss as a stress or grief

response, the manner in which individuals adapt to the social changes and limitations they are faced with in the first few years following limb loss, and the way in which people who have lost a limb develop a changed sense of self and identity in the light of the challenges faced throughout the months and years following an amputation.

The advent of increasingly sophisticated enabling technologies and the opportunities they represent for alternative forms of embodiment for people with amputations^{133, 134} is deserving of more research interest.

In order to address and explore the concerns we have highlighted in the extant literature on adjustment to amputation, more longitudinal research is needed to examine adjustment amongst people immediately post-amputation and throughout the first few years following their limb loss and rehabilitation. Due to the large number of factors that have been found to influence the process of adjustment, and the importance of understanding the meaning of these for the individuals concerned, we recommend that both qualitative and quantitative research designs be used in examining the nature of their interrelationships.

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