A Prospective Study of the Role of Hope in Predicting Adjustment in New Lower Limb Amputees

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Abstract

The amputation of a lower limb represents a significant physical, practical and emotional challenge for the amputee, their family and services aiming to assist them. Previous research has indicated that psychosocial variables such as satisfaction with social support and active coping may be of importance in facilitating adjustment to amputation. However, studies published to date have been almost exclusively cross sectional and have framed adjustment in negative terms (e.g., the absence of depression). The current study aims to build on previous research by examining prospectively demographic, amputation-related and psychosocial variables. Adjustment is conceptualized as subjective and is positively framed. Furthermore, the role of hope, a cognitive model from the field of positive psychology, is examined for its unique contribution to adjustment over other variables. Ninety-nine lower limb amputees were recruited and completed measures of social support, active coping and hope at the beginning of rehabilitation. At six-month follow up participants completed measures of positive affect and subjective adjustment. Analyses of the data confirm the importance of psychosocial variables in predicting adjustment to lower limb amputation. Social support, active coping and hope were all significantly correlated with outcome. Hope made a unique contribution to the prediction of positive mood in lower limb amputees. Conclusions are drawn concerning the clinical implications of the findings and suggestions made for future research.

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1 Introduction

The amputation of a lower limb is a physical, emotional and social challenge for the patient, their family and services aiming to assist them. The differing ways that individuals meet the issues they face post-amputation will affect their well-being over time. The current study aims to improve on existing research in this area by examining prospectively the variables that may influence adjustment to lower limb amputation. The research draws on a positive psychology perspective to identify factors relating to well-being following amputation. It is hoped that the findings will aid rehabilitation services in their efforts to facilitate optimum patient adjustment to lower limb amputation.

As an introduction to the study, the incidence and causes of lower limb amputation are described. An exploration is made of the concept of 'adjustment' to lower limb amputation and the various documented effects of amputation in terms of physical, emotional and social consequences are discussed. A narrative review of the predictors of adjustment to amputation is presented. Psychological models of adjustment to illness and disability from a positive psychology perspective are briefly examined and related to the reviewed studies. Conclusions are drawn about the quality and coherence of psychological research relating to adjustment in lower limb amputees and suggestions

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made for future work in this area. The rationale for the current study is discussed and the main research questions are presented.

1.1 Lower limb amputation

Lower limb amputation is defined as the complete loss of any part of the lower limb for any reason (Global Lower Extremity Amputation Study, 2000). Limb amputations occur for a variety of reasons including trauma, cancer, congenital deformity or vascular disease, often as a complication of diabetes. The incidence of amputation rises with age; most amputations occurring in patients over 60 years old. The incidence is higher in men, and diabetes is associated with between 25 and 90 per cent of amputations (Global Lower Extremity Amputation Study, 2000). The Global Lower Extremity Amputation Study (2000) collected data from ten centres around the world, including four in the UK. The UK data show an age-adjusted incidence of 14.5 new amputations per 100,000 men and 6.3 per hundred thousand women in the UK on average.

The average age of lower limb amputees and the presence of other conditions mean that the mortality rates post operatively are relatively high. A Swedish study found 23% mortality at 30 days post-operatively and 56% at two years (Kald, Carlsson & Nilsson, 1989), although cause of death was not recorded. A large American study found that the median survival time after a below knee amputation was 52 months and after an above knee amputation was 20 months (Subrananiam, Pomposelli, Talmor & Park, 2005). Long term survival after lower

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extremity amputation has significantly improved in the last decade (Sandnes, Sobel & Flum, 2004).

1.2 Adjustment

The amputation of a lower limb renders a person both disabled and disfigured. It follows that research efforts and service provision should focus on understanding and fostering adjustment and quality of life for amputees. The concept of adjustment, like that of 'quality of life' is difficult to define and measure (Garske & Turpin, 1998; Pain, Dunn, Anderson, Darrah & Kratochvil, 1998). Bishop (2005, p5) notes that despite decades of research on psychosocial adaptation to illness there is 'a surprising lack of conceptual clarity and limited consensus about such fundamental questions as the nature of the process…and the appropriate conceptualisation of outcome…there is little evidence that… theory has effectively translated into clinical intervention'.

Definitions and measurement of adjustment outcome in disability research to date have mostly been uni-dimensional and negatively framed, for example focussing on depression or physical problems, and have failed to account for the subjective and multi-dimensional nature of quality of life from a patient's perspective (Pain, Dunn, Anderson, Darrah & Kratochvil, 1998; Bishop, 2005). Early simplistic models of adjustment relating outcome to the degree of physical impairment have been recognised as incomplete and unsupported by evidence (Williamson, Schulz, Bridges & Behan, 1994). More recent conceptualizations of

adjustment incorporate a range of variables which influence outcome, such as social, disability related, psychological and environmental factors (Livneh & Antonak, 1997), but do not explain the process of movement towards adaptation nor do they adequately conceptualise adjustment outcomes (Elliott, Kurylo & Rivera, 2002). The assumption is made by researchers and clinicians that adjustment is a positive and important outcome for people with acquired disability (for example, Ward & Higgs, 1998).

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Studies relating to research identifying a range of adjustment outcome factors in lower limb amputation will be discussed. Following this, variables that predict adjustment outcomes for lower limb amputees will be reviewed. Conclusions will be drawn regarding variables that constitute 'adjustment' and what is currently known regarding the prediction of those outcomes for lower limb amputees.

1.3 Outcomes in lower limb amputation

1.3.1 Mobility

Perhaps the most obvious and immediate effect of lower limb amputation is the impact on a person's mobility. A ten-year review of the rehabilitation literature for lower limb amputations recommended that efforts should be focused on improving mobility problems as these were the major contributor to poor quality of life in amputees (Geertzen, Martina & Rietman, 2001). About half of Hagberg and Branemark's

(2001) sample of 97 non-vascular amputees stated that using public transport was a problem. Only 35% of the sample reported regularly walking the 600 metres or more required to be considered an 'independent community ambulator'. Vascular amputees generally have worse mobility outcomes (van Velzen, van Bennekom, Polomski, Slootman, van der Woude et al., 2006). In a recent systematic review of walking ability after lower limb amputation, van Velzen et al. (2006) found strong evidence for a reduction in walking velocity and symmetry. Nissen and Newman's study (1992) of factors influencing reintegration to normal living after amputation recommended that more attention be paid to community mobility, such as the ability to drive or use public transport.

Mobility is clearly an important factor in amputees' quality of life. Despite the importance of mobility in rehabilitation outcomes, Rommers, Vos, Groothoff and Eisma (2001) had to conclude, following a systematic review of scales, that there is 'no real consensus' about the measurement of this variable in lower limb amputees.

1.3.2 Employment

There have been three studies published regarding return to work following lower limb amputation. A British study found 66% of patients successfully returning to work following lower limb amputation (Fisher, Hanspal & Marks, 2003). Their sample comprised 100 patients of working age who were one year post amputation. They found that return to work was related to mobility, time since amputation and Handicap

Scale score (Fisher, Hanspal & Marks, 2003). Age, comfort of the prosthesis, level and cause of amputation, type of work and other medical problems did not predict return to employment. A second study of 322 Dutch patients, working at the time of amputation, followed up after two years, found 79% successfully returning to work (Schoppen, Boonstra, Groothoff, van Sonderen & Groeken et al., 2001). Somewhat in contrast to the British sample, they found that age, comfort of the prosthesis and type of work were important predictors of return to employment. Finally, a survey of 315 Scottish amputees found that 75% were in employment prior to the amputation and only 43.5% following amputation (Whyte & Carroll 2002). Unemployed amputees reported a higher intensity of phantom limb pain and lower levels of prosthesis use.

The three studies described above sampled differing populations (established prosthesis wearers, orthopaedic workshop patients and patients registered with artificial limb services who reported phantom limb pain), using a variety of methods (interview and self report, standardised and non standardised assessments). As such firm conclusions in this area are premature. However, it is clear that a proportion of working age amputees may be at risk for unsuccessful return to work.

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1.3.3 Body Image

Amputees, by definition, have to adjust to a changed 'body image'. Body Image has been described by Pruzinsky and Cash (1990) as pertaining

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to the perceptions, thoughts and feelings about the body and bodily experience. A number of researchers have looked at the effect of amputees' body image on other variables such as mood and quality of life. For example Rybarczyk, Nyenhuis, Nicholas, Cash and Kaiser (1995) found that body image predicted depression, quality of life and prosthetist ratings of adjustment. However, the study was cross sectional, rather than prospective and the body image measure was devised for the study and not validated. The 11 item questionnaire comprised all negative items, such as 'I thought my prosthesis was ugly' and amputees were asked to rate the frequency of the thought from 'never' to 'all the time'. As depression is characterised by frequent negative thoughts, a high correlation between the measure and depression would be expected. A similar critique can be made of a cross sectional study by Breakey (1997) who also developed a body image measure for amputees and found significant correlations with self-esteem, anxiety and depression.

Fisher and Hanspal (1998) used a body image questionnaire adapted from eating disorders research to examine whether a prosthesis can restore positive body image in amputees who are established limb wearers. Interestingly they found that there was little evidence of body image problems or distress in this group and that these variables were unrelated to mobility except in young patients with traumatic amputations. These results are supported by Murray and Fox (2002) who conducted an internet survey and found moderate to high negative correlations between body image disturbance (using Breakey's measure)

and prosthesis satisfaction for males and females. A more recent cross sectional survey of 67 lower limb prosthesis users by Atherton and Robertson (2006) using the Appearance Schemas Inventory (Cash and Labarge, 1996) found distress and psychosocial adjustment were associated with appearance related beliefs.

Although all the studies looking at body image are cross sectional (and therefore conclusions about the relationship with adjustment cannot be firmly drawn) this variable does seem to be an important factor in understanding the experience of lower limb amputees. Further research relating to the occurrence, causes and effects of body image problems for lower limb amputees is warranted. There is also a dearth of research concerning psychosexual issues for lower limb amputees which are likely to be related to body image concerns (Ide, 2004).

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1.3.4 Pain

Phantom limb pain (painful sensations experienced in the missing part of the limb) is now widely accepted as a common consequence of amputation (Hanley, Jensen, Ehde, Hoffman, Patterson et al., 2004). It is thought to result from central cortical re-organisation ('take-over' of the representation zone for the limb in the cortex by adjacent neuronal input; e.g., Flor, 2003) and can persist for many years. Phantom limb pain is reported to occur in between 60 and 85% of amputees and can have adverse affects on mood, mobility, employment and social activities (Hanley et al., 2004). A Scottish study found 77.5% of their sample of

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amputees had phantom limb pain or sensations, 10% of patients were moderately or severely limited by pain (McCartney, Charles, Cooper, Chambers & Smith, 1999). Hanley at al. (2004) found that good perceived social support at one month post amputation was associated with better outcomes in terms of pain and depression at one year follow up.

Residual limb pain (painful sensations in the remaining part of the limb), back pain and non painful phantom sensations are also common and are thought to affect between 20 and 75% of amputees (Rudy, Lieber, Boston, Gourley & Baysal, 2003). Rudy et al. (2003) showed that patients with chronic pain had decreased endurance for physical tasks compared to pain free individuals with comparable disabilities. Pain intensity and pain cognitions were highly predictive of performance, as were self-efficacy and perceived functioning.

Painful sensations are a common experience following amputation. The factors predicting pain outcomes and the relationship of pain to adjustment in lower limb amputees warrant further prospective investigation.

1.3.5 Anxiety

Although few studies have specifically studied anxiety in amputees and none have looked prospectively at this issue, it appears that anxiety may be raised shortly after amputation but that this is not maintained after one

year post operatively (Horgan & MacLachlan, 2004). It is a common finding that anxiety is associated with surgery and hospitalisation (Salmon, 1992).

1.3.6 Depression

Depression has been more extensively studied as a measure of adjustment to amputation, but the results are equivocal (Horgan & MacLachlan, 2004). Gallagher and MacLachlan (1999) report that rates of clinical depression in amputees range from 21% to 35%. Cansever, Uzun, Yildiz, Ates and Atesalp (2003) found 35% prevalence in a traumatic amputee group and 51% in a surgical group using the Hamilton Depression Rating Scale. However, Dunn (1996) found 18.2% of her sample with a score in the 'at risk' range of the Center for Epidemiological Studies Depression Scale (CES-D). The mean score for the sample was in the general population range. The sample was a little unusual in that it was taken from the Eastern Amputee Golf Association in the USA. Oaksford, Frude and Cuddihy (2005) also found no evidence of depression in their small sample from an artificial limb centre in the UK on the Hospital Anxiety and Depression Scale.

Studies of depression and amputation have been cross sectional and have employed a variety of measures and populations. Horgan and MacLachlan (2004) point out that most studies finding high rates of depression employed the CES-D, an instrument known for high false positive rates amongst older individuals. Discounting these studies led

them to conclude that two years post amputation, rates of depression in this population decrease to what is found in the general population, a conclusion similar to that for anxiety in amputees.

1.3.7 Quality of Life

'Quality of life' concerns a patient's perception of their social, physical and psychological well being and the effects that their condition has on their daily life. Bishop (2005) argues that because adaptation to disability is fundamentally subjective and multidimensional then quality of life must be defined and measured in those terms. Hagberg and Branemark (2001) found that a quarter of their sample of 97 non-vascular amputees considered themselves to have 'a poor or extremely poor overall situation'. Problems included pain, mobility and prosthesis issues. De Godoy, Braile, Buzatto, Longo and Fontes (2002) also concluded that the quality of life of their sample of lower limb patients was prejudiced. Compared to a control group they rated themselves as significantly worse off physically, socially, emotionally and in relation to pain. A large study by Demet, Martinet, Guillemin, Paysant and Andre (2003) of 539 amputees found quality of life, as measured by the Nottingham Health Profile (NHP), as most impaired in relation to physical disability, pain and energy. They conclude that 'in terms of NHP scores, people with limb amputations could be compared to patients before heart-lung transplantation or with neurological diseases such as multiple sclerosis, parkinsons disease or hemiplegia'. Young age and traumatic rather than vascular cause were associated with better quality of life.

Gallagher and MacLachlan (2004) have recently developed a brief self-administered inventory of adjustment to a prosthetic limb- The Trinity Amputation and Prosthetic Experience Scale (TAPES), which is based on quality of life principles and is multi-dimensional. In contrast to Demet et al. (2003) they did not find an association between quality of life and cause of amputation or age.

Although the predictors of quality of life in amputees are not yet reliably established there is broad agreement that as a whole this group are likely to experience significant concerns in a number of domains affecting their well being and daily lives. The concepts of adjustment and quality of life are clearly related. Adjustment comprises a subjective sense of well-being whereas quality of life is a broader concept including a number of life domains such as mobility and pain. It is likely that adjustment and quality of life will affect each other both positively and negatively. For example, a high subjective sense of well-being may lead to a lesser pain experience or contrastingly reduced mobility may lead to a reduced sense of well-being (Ward & Higgs, 1998).

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1.3.8 Conclusions

Lower limb amputation represents a significant challenge. Amputees have a range of problems to contend with, for example in relation to mobility and pain. Despite this it appears that the majority of amputees adjust in terms of mood within two years. Studies are lacking which take

a holistic, patient-centred view of adjustment as comprising outcomes in relation to mood and subjective adjustment. A further important distinction is that research has focussed on poor adjustment outcomes (low mood, body image problems, reduced Quality of Life and pain) and its correlates, as opposed to aspects of good adjustment and functioning following amputation. No previous studies have been found investigating predictors of positive adjustment following lower limb amputation. Studies of adjustment to chronic stressors have found that positive emotions can co-occur with negative ones (Folkman & Moskowitz, 2000) and are often more important in long term outcomes (Folkman, 2008). It is proposed in this study that positive mood measures and subjective ratings of adjustment would represent an improved conceptualisation of adjustment outcomes to amputation and perhaps other acquired disabilities.

1.4 Predictors of adjustment to amputation

Studies specifically relating to variables that predict and correlate with the various adjustment domains in lower limb amputation discussed above are explored in the following section. A comprehensive search was made of Medline and Psychlit from 1970 onwards using the terms 'lower limb amputation' and 'adjustment'. No studies were excluded from consideration as there is a lack of research in this area. Fourteen studies are discussed below in relation to findings relating to the predictors of adjustment in lower limb amputees.

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1.4.1 Age and gender

The findings regarding the influence of age and gender on adjustment to amputation are equivocal (Horgan & MacLachlan, 2004). Pernot, de Witte, Lindeman and Cluitmans (1997) found, not surprisingly, that younger age was related to better levels of daily functioning. Demet et al. (2003) also found that younger age was related to better quality of life. However, Williamson et al. (1994) found that younger amputees were more depressed. Other studies have found no relationship between age and depression (e.g., Fisher & Hanspal, 1998). It may be that age has varying influences on different aspects of adjustment to amputation, mediated by other factors such as the time elapsed since the amputation, cause and level of the amputation, pain, body image and gender, for example.

There is even less evidence concerning the role of gender in adjustment. Horgan and MacLachlan (2004) conclude that there is little evidence for gender being a major correlate of psychological well-being following amputation. No studies to date have examined prospectively the role of age and gender in influencing the various adjustment domains in lower limb amputation. A prospective study of adjustment examining the role of age and gender would be an important contribution to this area so that this question can be clarified.

1.4.2 Cause and level of amputation

It seems reasonable to hypothesise that the cause of an amputation (vascular or traumatic for example) may influence aspects of future adjustment. Traumatic amputations are a 'one off' event, whereas vascular amputees often face further deterioration and surgery. However, there seems little evidence to date from cross-sectional studies that this is the case (Horgan & MacLachlan, 2004). Larner, van Ross and Hale (2003) found that the level of amputation and the Kendrick Object Learning Test could predict whether amputees admitted to an inpatient rehabilitation ward would learn to use a prosthetic limb with 81% accuracy but they only looked at this one outcome variable. Above knee amputations are, as one would expect, associated with greater activity restrictions (Williamson et al., 1994) but generally not with worse emotional adjustment (Horgan & MacLachlan, 2004). A prospective study examining the role of cause and level of amputation to adjustment would be an important contribution to this field to clarify further this issue.

1.4.3 Social support

A number of cross sectional studies have found that higher levels of perceived social support are associated with lower levels of depression after amputation (e.g., Williamson et al., 1994; Rybarczyk et al., 2002). There has also been one prospective study of social support and adjustment to amputation in the U.S.A. (Williams, Ehde, Smith, Czerniecki, Hoffman et al., 2004). Williams et al. (2004) found that

perceived social support as measured by the Multidimensional Scale of Perceived Social Support (MSPSS: Zimet, Dahlem, Zimet & Farley, 1988) predicted mobility and occupational functioning 6 months post amputation, controlling for demographic and amputation related factors. Reporting on the same study, Hanley et al. (2004) found that higher perceived social support was related to less pain interference and fewer depressive symptoms after two years.

The importance of social support in adjustment to amputation warrants further prospective investigation to confirm its relationship with outcomes such as mood and self-rated adjustment.

1.4.4 Coping style

Coping refers to the range of strategies that people use to minimise or overcome perceived stressful circumstances. Folkman (1991) defines coping as 'the changing thoughts and acts that the individual uses to manage the external and/or internal demands of a specific person environment transaction that is appraised as stressful' (p.5). There have been a few cross sectional studies of coping styles in amputees. Gallagher and MacLachlan (1999) reported a postal survey of 44 adult amputees. Using the Coping Strategy Indicator which contains three sub-scales (problem solving, seeking social support and avoidance), they found that avoidance and a tendency not to seek social support were linked with more stump pain. Avoidance was also linked to higher levels of emotional distress. Livneh, Antonak and Gerhardt (1999) found

in a study of 61 amputees using the COPE inventory (Carver, Scheier and Weintraub, 1989) that active problem solving was associated with lower levels of depression and, importantly, to adjustment and acceptance of disability. Cognitive disengagement showed the opposite associations. In another report of the same study (Livneh, Antonak & Gerhardt, 2000), they concluded that coping efforts of individuals with amputations are not meaningfully different from the coping efforts of those who are not disabled. Coping strategies such as active problem solving, finding positive meaning and perceiving control over the disability are cited as areas which clinicians may wish to bear in mind in their assessment and rehabilitation efforts. Oaksford, Frude and Cuddihy (2005) report a qualitative cross sectional study of 12 lower limb amputees exploring positive coping and growth. Participants identified seeking support, using humour, acceptance and practical coping as helping their adjustment. Nearly all of the participants reported benefits and positive aspects of their amputation experience, such as now being pain free, feeling emotionally stronger etc.

The contribution of active coping strategies to adjustment outcomes in lower limb amputation warrants prospective investigation as such studies are currently lacking and are potentially a stepping stone to more effective interventions in this area.

1.4.5 Optimism

There has been one cross sectional study of optimism and adjustment to amputation. Scheier and Carver (1985, 1992) define optimism as a generalized expectancy that one will experience good outcomes in life. Dunn (1996) examined the salutary effects of optimism, positive meaning and perceived control on depression and self esteem in 138 amputees. Optimism, meaning and control were all linked to lower levels of depression. Optimism and control were linked to higher self esteem. Dunn's sample was a little unusual as, already mentioned above, it comprised members of an amputee golf association, who may not be representative of the general lower limb amputation population.

The role of cognitive factors in adjustment to lower limb amputation requires further research.

1.4.6 Conclusions

To summarize, there is some evidence that social support predicts aspects of adjustment outcomes in amputation over time. Also active/positive coping is associated with better outcomes in cross sectional studies. One could hypothesise that individuals who are more optimistic use more positive coping strategies and actively seek out the social support they need which in turn improves adjustment over time. Mosher, Prelow, Chen and Yackel (2006) found that optimistic black students in the USA were better adjusted and that this relationship was

mediated by coping style and social support. The role of age, gender, cause and level of amputation is less clear and therefore warrants further study if only to confirm that these variables are not of central importance in understanding the adjustment process. A major weakness in the research into adjustment to amputation to date is the dearth of prospective studies. There have been no prospective studies of positive adjustment following lower limb amputation published to date. The full range of possible predictors (demographic, amputation factors and psychosocial variables) have not been studied together to examine their relative contributions to adjustment outcomes for amputees. Other issues include the negative and uni-dimensional conceptualisation of adjustment. A further issue is a lack of studies relating to known models of adjustment to disability which take into account the importance of cognitive factors. These are issues which are common in research relating to quality of life and adjustment to chronic illness and acquired disability (Bishop, 2005). Psychological models of adjustment to illness and disability will be considered in the following section.

1.5 Psychological models of adjustment to illness and disability

A number of psychological concepts and models have been proposed to account for individual differences in adjustment to disability, illness and general adverse life circumstances. It is now widely accepted that adjustment is a recurrent as opposed to linear stage process differing across individuals and time depending on the coping resources available to them (Kendall & Buys, 1998). Folkman and Greer (2000) emphasise

the importance of understanding the coping processes that support well-being, as a compliment to the traditional focus on psychiatric symptoms and problems, in helping patients with serious illness. The question then becomes which psychological factors drive and predict a successful adjustment process? The last few years have seen a growth in interest in positive psychology which has been broadly defined by Seligman (2005) as the study of positive emotions, character traits and enabling institutions. Dunn and Dougherty (2005) have highlighted the potentially important contribution of positive psychology ideas to the field of rehabilitation psychology and the distinct contrast it provides to the negative disease model that dominates not only medicine but also psychology. Naidoo (2006) puts in a nutshell positive psychology's potential contribution to disability and rehabilitation as 'directing researchers and practitioners to the aim of building, reinforcing and extending disabled individuals' strengths and capacities in order to optimize their functioning in all areas of life, and thereby promote wellness'. Psychological variables that have been shown to promote 'wellness' and adjustment to illness and disability are discussed in the next section.

1.5.1 Control beliefs

Taylor and Brown (1988) have suggested that individuals who are able to respond to difficult circumstances with a belief in personal efficacy and an optimistic sense of the future will adjust better to those circumstances over time. Research suggests that personal control beliefs are adaptive

in patients with cardiac disease, cancer and AIDS (Taylor, Helgeson, Reed & Skokan, 1991). Partridge and Johnstone (1989) found that internal recovery locus of control was prospectively associated with faster recovery in stroke and wrist fracture patients. There is thus support for the idea that a sense of personal control over circumstances is an important psychological factor in successful coping and adjustment in illness and disability.

1.5.2 Optimism and Active coping

Scheier and Carver (1985, 1992) have studied extensively the importance of optimism (the expectation of positive outcomes) on psychological and physical well-being. They suggest that the positive effect of optimism on both psychological and physical adjustment is mediated, in part, by the use of positive coping strategies such as active coping and seeking support. Folkman and Moskowitz (2000) also identify goal-directed problem focused coping as related to the occurrence of positive affect in the context of chronic stress. Scheier and Carver (1992) emphasise the role of self-efficacy or personal agency beliefs (Bandura, 1977) in individuals achieving specific adaptive behaviours, for example taking more exercise. Thus, not only a sense of optimistic personal control over circumstances but an 'action' component of certain coping behaviours appears important in successful adjustment.

1.5.3 Hope theory

Snyder (2002), a major contributor to the field of positive psychology, proposes what he terms 'hope theory' to account for findings relating both to a sense of personal control and goal directed coping in adjustment to adverse circumstances including physical illness and disability. Hope theory, perhaps better termed a model, proposes that individuals have 'enduring, self-referential thoughts about their capabilities to produce routes to goals and their capabilities to find the requisite motivations for those goal pursuits'. Individuals with a more positive belief in their abilities to plan and pursue their goals will have higher hope. Hope theory, essentially a cognitive model, has also been summarised as 'the will and the ways' (Magaletta & Oliver, 1999), that is to say hope comprises an individual's sense of personal agency and the ability to generate and follow pathways to reach a desired future.

Snyder (2002) proposes that high hope is consistently related to better outcomes in health, psychological adjustment and psychotherapy. He further describes studies that demonstrate that hope, whilst related to optimism, self-efficacy, coping and problem solving has discriminant validity beyond these other correlates of adjustment (Snyder, Harris, Anderson, Holleran, Irving et al., 1991). Although similar to personal control ideas, hope places greater emphasis on trait like, cross-situational goal and pathways thinking. In terms of the relation to coping, Snyder (2002) proposes that goal directed agency and pathways thinking drive coping efforts.

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Elliott, Witty, Herrick and Hoffman (1991) found that high 'agency' and 'pathways' thinking related to adjustment to spinal chord injury. Jackson, Taylor, Palmatier, Elliott and Elliott (1998) found that hope correlated with sociable and confident coping and mediated the relationship between this and perceived functional ability in their sample of blinded veterans. Low hope was associated with depressive symptoms. Hope remained a statistically significant predictor of functional ability when entered into the analysis simultaneously with coping.

Snyder (2002) proposes that hope, as described by the proposed model, is a stable attribute, relatively uninfluenced by circumstances. It would be important to confirm this stability in a prospective study for the assessment of hope to be of use in clinical settings.

1.5.4 Summary

Hope, as conceptualised by Snyder (2002), appears to account in a parsimonious manner for findings related to adjustment to disability, illness and adverse circumstances. The model gives equal importance to a person's sense of 'agency' and their ability to produce goal directed behaviour, both of which have been shown previously to be important in successful adjustment to adverse circumstances, including acquired disability. Hope has convergent validity when compared to optimism and self-efficacy, which are important contributors to adjustment, but also discriminant validity yielding unique variance (Snyder, 2002; Magaletta &

Oliver, 1999). It seems reasonable to hypothesise that hope may be a useful variable in understanding the process of adjustment to lower limb amputation which presents patients with a range of practical and emotional challenges.

1.6 Conclusions

Evidence has been presented to illustrate the multiple challenges of adjustment for lower-limb amputees. Adjustment has been described as subjective and potentially positively framed, comprising positive mood and positive self-rated adjustment. A dearth of prospective studies examining a range of possible predictors, a negative and one-dimensional conceptualisation of adjustment and a lack of coherence from a psychological perspective in research in this area to date have all been highlighted. Age, gender, cause, level of amputation, social support and active coping in adjustment to lower limb amputation all warrant prospective investigation. Research on adjustment in health settings has demonstrated the importance of a positive sense of personal control over circumstances and the ability to generate active coping behaviours as important predictors of outcome in illness and disability. Hope (Snyder, 2002) has recently emerged as a parsimonious model to account for these factors and hence, successful adjustment. The role and stability of hope in the process of adjustment to lower limb amputation warrants further investigation and particularly whether this concept is more predictive of outcome than the 'traditional' predictors of active coping and social support. Such research would have valuable

clinical applications in helping rehabilitation teams to 'triage' individuals likely to need additional support at an early stage and in the potential design of successful intervention strategies to improve adjustment.

1.7 The current study

The aim of the current study is to address some of the weaknesses that have been identified in previous research relating to adjustment to lower limb amputation. Adjustment will be conceptualised as subjective and will be positively framed. A range of variables which have been previously shown to be potentially important in predicting adjustment will be measured. The study takes into account current theoretical models of adjustment to disability and will examine the role and stability of hope (Snyder 2002), a concept from the field of positive psychology, in accounting for variance in individual outcomes. The study will be prospective and comprise a consecutive clinical sample of adequate size to have appropriate statistical power and to have generalisability to other clinical amputee populations.

In the design of the study the researcher has taken an empirical positivist position. It is assumed that the hypothesised variables in the study such as 'hope' and 'adjustment', although subjective, can be measured objectively in a robust, meaningful, reliable and valid way.

1.7.1 Main research question:

What proportion of the variance in adjustment to lower limb amputation can be attributed to hope when previously implicated factors have been controlled for?

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1.7.2 Subsidiary questions:

What proportion of the variance in adjustment to lower limb amputation can be attributed to previously implicated factors?

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What evidence is there for the stability of trait hope over time?

1.7.3 Hypotheses:

1. Age, gender, cause of amputation and level of amputation will not be significantly associated with positive mood and adjustment in new amputation patients at 6 months

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2. Social support and active coping will correlate significantly with positive mood and adjustment in new amputation patients at 6 months follow up.

3. Hope will correlate significantly with positive mood and adjustment in new amputation patients at 6 months.

4. Hope will explain additional variance in positive mood and adjustment in new amputation patients at 6 months when the variance contributed by social support and active coping has been accounted for.

5. There will be no significant difference between hope scores at time 1 and time 2.

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2 Method

The study design, participants, instruments and procedures used in the current study are described.

2.1 Study design

2.1.1 Overview

The study comprised a quantitative prospective study of new amputation patients at two time points. The first time point was at the beginning of rehabilitation (around 8 weeks post amputation) and the second at 6 months later (around 8 months post amputation). Following an examination of the data, the correlations between continuous predictor and outcome variables were examined using Pearson's *r* or Spearman's *rho* as appropriate. The association between categorical demographic variables and outcome variables was examined using Mann Whitney tests. The contributions of predictor variables to the prediction of outcome variables were examined using a linear multiple regression model. Variables were entered in theoretically justified blocks; demographic and amputation variables (age, gender, cause and level of amputation), followed by previously indicated psycho-social factors (social support and coping) and finally, hope. Block entry allowed the contribution to the explanation of the variance of each block to be independently assessed. The dependent variables were positive mood and subjective adjustment.

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A repeated measures t test was used to assess the stability of hope over time.

2.1.2 Sample size considerations

A medium effect size was assumed from previous studies of psychosocial variables and adjustment in amputees (e.g., Williams et al., 2004). If at least 7 predictors are entered into the model with a medium effect size (0.15) and a power of 0.8 then a total sample of 103 participants is needed (G*Power version 3.0.5). This is also sufficient for the case: predictor variable ratio to be robust. As a general rule the case: predictor ratio should be at least 10:1. In this case more than 70 participants are needed.

2.1.3 Practical and ethical considerations

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Participants were recruited as a consecutive sample of new referrals to a large Disablement Services Centre (DSC) based in a teaching hospital in the UK. The DSC is referred patients from a large geographical area in the NW of the UK who need artificial limbs or wheelchairs because of limb loss or incapacity due to any cause. Referred patients are those well enough medically to benefit from prosthetic or cosmetic limbs. The mortality rate following amputation surgery, particularly in older, vascular patients means that only a proportion of all amputees are subsequently referred for limb fitting. Typically, patients were six to ten weeks post

operative at recruitment. Data collection took around 24 months (including follow up), allowing for exclusions, non consenting patients and those not completing measures at follow up.

The research was planned in collaboration with the lead consultant and specialist nurse, the research review panel and the patient (limb user) group of the service in question. The study received approval from a local research ethics committee (25th January 2006; REC reference number 05/Q1309/14) and the hospital's Research and Development department. A successful bid was made to the Trust Research and Development Department as part of their 'seedcorn' initiative. The Trust provided a grant of approximately £10,000 to support the extra specialist nurse time needed for consenting and data collection over the course of 24 months.

The researcher was unaware of the patient's rehabilitation progress as she took no clinical role at the service where the research was planned. Arrangements were made in collaboration with the Psychology Service in the hospital for patients to receive appropriate psychological assessment and intervention if centre staff became concerned for their emotional state as a result of issues raised by taking part in the study.

2.2 Participants

2.2.1 Recruitment

All new lower limb amputees referred to the DSC over the age of 18 who met the inclusion criteria, as judged by the specialist nurses were approached to participate in the study. Information sheets and letters of invitation to take part in the study were included with the patients' first appointment information letters (appendices 1 and 2). Patients with significant cognitive impairment, as defined by the Hodkinson's Mental Test (Kane and Kane, 1985), administered and scored by the specialist nurses, were excluded. Furthermore, it was agreed that where individuals could not complete the questionnaires due to language issues, they would be excluded as the measures have not been widely translated. No patients were actually excluded from the study on the basis of language issues. No exclusion based on severe mental health problems was included in the study. It was agreed that emotional state would be monitored in the usual way by a specialist nurse. There were no problematic issues in relation to mental health symptoms during the course of the study.

Phase one of recruiting to the study took place over 18 months. During this time 205 new referrals were received by the DSC. Sixty four patients were excluded from the study. Nine of these patients were babies or children, 17 patients were upper limb amputees, 20 were transferred patients from other Centres, 16 were too ill for rehabilitation

or required further surgery, one patient was dysphasic and one had significant cognitive impairment. The patient's specialist nurse discussed the research with those meeting the inclusion criteria. Of the remaining 141 patients, 21 declined to take part in the study and 120 consented and completed the questionnaires (see appendices 3 and 4). Where reasons were given for declining to take part and noted by the nurses they included time pressures, feeling tired and being a private person.

During the follow up phase every effort was made by the nurses to schedule appointments to complete the follow up questionnaires around six months post recruitment (see appendix 5). The average follow up period between time 1 and time 2 was 6.8 months. Of the original 120 participants, 99 completed the follow up questionnaires and made up the study sample. Of those not followed up, four participants were deceased, six were unwell or needed further surgery, three declined to complete the questionnaires and eight patients could not be contacted or did not attend appointments. See figure 1 showing the recruitment process and participation.

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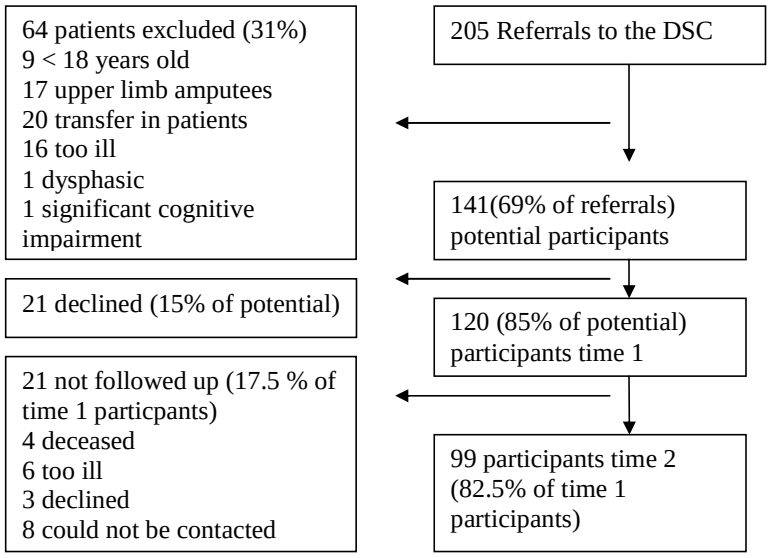

Figure 1 Recruitment process and participation rates

The mean age of the 21 participants not followed up was 62.90 years (SD = 10.8). This is similar to the mean age of the participant group of 60.7 years (SD = 13.3). An independent samples t-test confirmed that there was no significant difference in mean age of the two groups (t=-.711, df =118; p=.48). Of the participants not followed up, 4 were female (19%) and 17 were male (81%). This was similar to the participant group where 16 were female (16.2%) and 83 were male (83.8%). A Fisher's exact test confirmed that there was no significant difference between the groups in terms of gender (p =.75). Furthermore, of the participants not followed up 13 had a below knee amputation (61.9%) and 8 had an above knee amputation (38.1%) compared to 54 of the participant group having a below knee amputation (54.5%) and 45 having an above knee amputation (45.5%). A Pearson chi-square test

confirmed that there was no significant difference between the groups in terms of level of amputation (p =.54). It can be concluded that, in terms of age, gender and level of amputation, those not completing the study were comparable to those completing the study.

2.3 Instruments

2.3.1 Time 1 predictor variables

2.3.1.1 Social Support

Self reported levels of social support were assessed using the Multidimensional Scale of Perceived Social Support (MSPSS- Zimet, Dahlem, Zimet & Farley, 1988). The MSPSS was used in the one existing prospective study of social support and adjustment to amputation in the U.S.A. (Williams et al., 2004). In that study, social support was found to predict mobility and occupational functioning six months post amputation, controlling for demographic and amputation related factors, and less pain interference and fewer depressive symptoms after two years.

The instrument has good internal (alpha =.88) and test-retest reliability (.85) as well as moderate construct validity. Perceived support from family correlates inversely with depression (r =-.24, p<.01) and anxiety (r =-.18, p<.01) as measured by the Hopkins Symptom Checklist. The MSPSS is a brief 12-item inventory with a seven point rating scale from

'very strongly disagree' to 'very strongly agree'. Items cover social support from friends, family and significant others, for example 'I get the emotional help and support I need from my family'. Factor analysis confirms these as three separate dimensions (Zimet et al., 1988). The mean total scale score for a sample of undergraduates was 5.8 with a standard deviation of .86.

2.3.1.2 Coping

Coping was assessed using the Brief COPE inventory (Carver, 1997). This instrument is a 28-item self-report measure of coping efforts. Each statement is rated on a four point scale from 'I haven't being doing this at all' to 'I've been doing this a lot'. There are 14 subscales for which items were chosen due to strong loadings from previous factor analyses of a longer instrument. The subscales are self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion and self-blame. Internal reliability of each subscale exceeds .50 despite the fact there are only two items in each (Carver, 1997). The longer version of the instrument has convergent and discriminant validity with other concepts such as hardiness and optimism (Carver, Schier & Weintraub, 1989). Livneh, Antonak & Gerhardt (1999) found in a study of 61 amputees using the COPE inventory that active problem solving was associated with lower levels of depression and, importantly, with adjustment and acceptance of disability.

Jacobson (2006) recommends the use of three sub scales (positive coping, passive coping and negative coping) from a principal components analysis of her data from the Brief COPE and reports the reliability of each subscale as ranging from 0.75 to 0.82. Carver (1989) recommends using individual study data from the Brief COPE to determine higher order factors as different samples have different patterns of relations.

2.3.1.3 Hope

Hope was assessed using the Hope Scale (Snyder et al., 1991). The Hope Scale has 12 items which are self rated on an 8 point scale from 'definitely false' to 'definitely true'. Four items assess 'agency' (goal-directed determination), four assess 'pathways' (planning ways to meet goals) and four items are filler items. Factor analysis shows the agency and pathways components as related but not synonymous (Snyder et al., 1991). Internal reliability (alpha .74 to .84) and test-retest reliability (.73 to .85) for the Hope scale are high (Snyder et al., 1991). The scale has both convergent and discriminant validity with related constructs, such as optimism and hopelessness for example, in a number of studies (Snyder et al., 1991). Average full scores for the general population are approximately 24 when using a 4 point rating scale (Snyder, 1995). For the purposes of the current study the 8 point scale was used (Snyder et al., 1991).

2.3.2 Time 2 Outcome variables

2.3.2.1 Positive affect

Positive affect was assessed using the Positive and Negative Affect Scale (PANAS-Crawford & Henry, 2004). The scale consists of 20 words that describe both positive and negative emotions. These are self rated for how much they have been experienced in the last week on a five point scale from 'very slightly or not at all' to 'extremely'. The positive and negative scales are scored separately. The internal consistencies of the positive and negative affect scales are reported as .89 and .85 (Crawford & Henry, 2004). The PANAS has convergent validity with measures such as the Hospital Anxiety and Depression Scale but also accounts for unique variance particularly in relation to depression (Crawford & Henry, 2004). The positive affect mean in a general population sample is 31.3 (SD=7.7) and the negative affect mean is 16 (SD=5.9) (Crawford & Henry, 2004).

2.3.2.2. Subjective adjustment

The Trinity Amputation and Prosthetic Experience Scales (TAPES; Gallagher & MacLachlan, 2000) was used in full to assess quality of life but specifically subjective adjustment. The scale was selected as it was developed specifically for the population in question and covers a range of self-rated adjustment dimensions described below. The total number of items is 54 and it takes around 15 minutes to complete. There are 3

factor analytically derived subscales of 5 items each in the Psychosocial scale (general adjustment, social adjustment and adjustment to limitation), three factor analytically derived subscales with four items each in the activity restriction scale (functional, social and athletic restriction) and three factor analytically derived scales in the satisfaction with prosthesis scale (functional, aesthetic and weight satisfaction). The final section relates to pain experience. Patients rate the frequency, duration, intensity and interference of stump and phantom pain over the last week on five point scales. All of the subscales have high internal reliability (alpha range .75 to .89) (Gallagher & MacLachlan, 2004). The scale has good face, construct and predictive validity (Gallagher & MacLachlan, 2000) and can be used to evaluate changes in quality of life during rehabilitation. Permission was sought from the authors and granted, for use of the scale and to enlarge the original font size. Piloting of the scale had shown that some participants would struggle to read the original version.

2.3.2.3 Hope

The Hope Scale (Snyder et al., 1991) was used to re-assess hope, as described above.

2.4 Procedures

A letter informing patients about the research project was included with their first appointment letter from the DSC, along with an information sheet about the study (appendices 1 and 2). During the first appointment the research project was discussed with patients by a Specialist Nurse. If patients were willing to take part, written consent was sought following a full explanation of the study (appendix 3). Patients consenting to take part were provided with the first set of questionnaires to complete as self-report (appendix 4). The time taken to consent participants and for them to complete the questionnaires was between 30 and 50 minutes. Patients often had periods of waiting between seeing the nurse, consultant or prosthetist at the first appointment so had the opportunity to complete the questionnaires without having to extend their usual time in the centre. Any problems with completing the questionnaires could be discussed with the specialist nurse present. After six months, participants were approached at follow up appointments by the specialist nurse and asked to complete the second set of questionnaires (appendix 5). This typically took around 20 to 30 minutes. Where patients were not due for an appointment they were invited in to complete the questionnaires. If participants had moved away or were otherwise unavailable every effort was made to complete the questionnaires over the telephone by a specialist nurse at the DSC.

2.5 Statistical analyses

SPSS version 15.00 was used to analyse the data. Individual item scores for all measures were entered for each participant into the database.

2.5.1 Hypotheses 1, 2 and 3

1. Age, gender, cause of amputation and level of amputation will not be significantly associated with positive mood and adjustment in new amputation patients at 6 months

2. Social support and active coping will correlate significantly with positive mood and adjustment in new amputation patients at 6 months follow up.

3. Hope will correlate significantly with positive mood and adjustment in new amputation patients at 6 months.

Following the checking of the data Mann Whitney tests were used to check for the association of gender, cause and level of amputation with positive mood and subjective adjustment. Spearman's *rho* correlational analyses were used to examine the correlations between continuous predictor variables (age, social support total-MSPSS score, coping-active

coping sub-scale of the brief COPE and hope-total hope scale score) and outcome variables (mood-positive affect sub scale score on the PANAS and subjective adjustment-psychosocial sub scales of the TAPES).

2.5.2 Hypothesis 4

4. Hope will explain additional variance in positive mood and adjustment in new amputation patients at 6 months when the variance contributed by social support and active coping has been accounted for.

Predictor variables were entered into a linear multiple regression model in the following blocks; demographic/amputation variables (age, gender, cause of amputation and level of amputation), previously established predictors (social support, coping) and finally, hope.

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2.5.3 Hypothesis 5

5. There will be no significant difference between hope scores at time 1 and time 2.

The stability of hope scores was analysed using a repeated measures t-test.

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3 Results

3.1 Analysis

The analyses of the data undertaken to examine the study hypotheses are described. SPSS version 15.00 was used to analyse the data.

Initial data exploration confirmed that the necessary assumptions for regression analysis of the data were met (Field, 2005). The standardized residuals were normally distributed for both regression analyses (Shapiro-Wilk = .987, p =.51; Shapiro-Wilk = .986, p =.442). No transformations were performed. Variance inflation factors (VIF values) ranged between 1 and 1.5, indicating there was no multicollinearity in the data. The assumption of no independent errors was met (Durbin-Watson should not be less than 1 or greater than 3 and was 1.96 and 2.23 for the current data). All Cook's distances were less than 1, indicating that no individual cases were influencing the models. No data were excluded from the analysis. The final data set comprised 99 participants. Descriptive data are presented for the predictor and outcome variables.

Whether gender, level or cause of amputation influenced positive affect and subjective adjustment was examined using Mann-Whitney tests. Spearman's *rho* correlational analyses were conducted between continuous predictor variables (age, social support- total MSPSS score, coping-active coping sub-scale of the brief COPE and hope-total hope scale score time 1) and outcome variables (mood-positive affect sub

scale score on the PANAS and subjective adjustment-psychosocial sub scale of the TAPES). A non-parametric correlation was chosen as variables tended to be positively skewed. Predictor variables were entered in the regression model in the following blocks; demographic/amputation variables (age, gender, cause of amputation and level of amputation), previously established predictors (social support and coping) and finally, hope.

The stability of hope scores was analysed using a repeated measures t-test.

3.2 Sample characteristics

3.2.1 The sample

The final sample comprised 99 participants and is described below.

3.2.2 Predictor variables

3.2.2.1 Age

The mean age of participants was 60.7 years old (SD = 13.3). The range of ages was from 19 to 91 years old. A histogram of the age of participants is appended (appendix 6).

3.2.2.2 Gender

Of the participants, 16 (16.2%) were female and 83 (83.8%) were male.

3.2.2.3 Level of amputation

Fifty four of the participants (54.5%) had below the knee amputations and 45 (45.5%) had above the knee amputations.

3.2.2.4 Cause of amputation

Of the 98 participants for whom cause of amputation was recorded, 42 (42.4%) were due to peripheral vascular disorder, 26 (26.3%) were due to diabetes, 3 (3%) were due to cancer, 18 (18.2%) were due to accidents, 9 (9.1%) were due to other causes. For the purposes of the examination of the study hypotheses these categories were reduced to two; vascular and diabetic related amputations and those related to cancer, accidents or other causes. Sixty-six participants had vascular or diabetic related amputations (67.3%) and 32 (32.7%) had cancer, accident or other amputation causes.

3.2.2.5 Social support

The mean average total scale score for the participants was 5.6 (SD = 1.29), with a minimum score of 1.36 and a maximum of 7. Total scale scores were used for the purposes of further analyses, the mean being

61.7 (SD =14.2), with a minimum of 15 and a maximum of 77. These data are presented in table form below (table 1). A histogram of social support scores is appended (appendix 6). Cronbach's alpha for the MSPSS was .93.

3.2.2.6 Active coping

The mean active coping sub-scale score was 6.42 (SD = 1.7), with a minimum of 2 and a maximum of 8. These data are presented in table form below (table 1). A histogram of active coping scores is appended (appendix 6). Cronbach's alpha for the active coping sub scale of the brief COPE was .63 with an inter item correlation of .47.

3.2.2.7 Hope

The mean hope score for participants was 53.16 (SD = 9.07) with a maximum of 64 and a minimum of 14. These data are presented in table form below (table 1). A histogram of hope scores is appended (appendix 6). Cronbach's alpha for the hope scale was .89.

	Minimum	**Maximum**	**Mean**	***S.D.***
Social Support	15	77	61.56	*14.21*
Active Coping	2	8	6.42	*1.71*
Hope	*14*	*64*	*53.16*	*9.07*

Table 1 Descriptive data for predictor variables.

3.2.3 Adjustment variables

3.2.3.1 Positive Mood

The minimum, maximum, mean and standard deviations are shown below (table 2) for the positive and negative affect subscales of the PANAS. A histogram of positive affect scores is appended (appendix 6). Cronbach's alpha for the positive affect sub scale of the PANAS was .85.

	N	Minimum	Maximum	Mean	SD
Positive Affect	98	13	49	33.33	8.29
Negative Affect	97	10	37	18.03	7.35

Table 2 Descriptive data for the Positive and Negative Affect Scale

3.2.3.2 Subjective adjustment

The minimum, maximum, mean and standard deviations are shown below (table 3) for the adjustment subscales of the TAPES. A histogram of subjective adjustment scores is appended (appendix 6). Cronbach's alpha for the subjective adjustment scale was .84.

	N	Minimum	Maximum	Mean	S. D.
General Adjustment	95	7	25	19.61	4.28
Social Adjustment	94	10	25	21.76	3.31
Limitation Adjustment	92	5	25	12.46	4.75
Total Subjective Adjustment	91	38	75	53.73	8.79

Table 3 Descriptive data for the adjustment subscales of the TAPES

3.3 Mann Whitney & correlation analyses: hypotheses 1, 2 and 3

Hypotheses 1, 2 and 3 are re-stated below.

1. Age, gender, cause of amputation and level of amputation will not be significantly associated with positive mood and adjustment in new amputation patients at 6 months.

2. Social support and active coping will significantly correlate with positive mood and adjustment in new amputation patients at 6 months.

3. Hope will correlate significantly with positive mood and adjustment in new amputation patients at 6 months.

Mann-Whitney tests were carried out to examine the influence of gender and level of amputation on positive affect and subjective adjustment. No significant results were found (for gender p=.85, p=.81 respectively, or for level of amputation p=.31, p=.28 respectively). A Mann-Whitney test was carried out to examine the influence of cause of amputation on positive affect and subjective adjustment. A non significant result was found for positive affect (p=.88) but a just significant result for subjective adjustment (Z=-1.99, p=.046), indicating that amputations with an acute cause are associated with better subjective adjustment.

The table below (Table 4) summarises the correlations between continuous predictor and outcome variables. One tailed tests were used where specific predictions had been made (social support, active coping and hope). No significant associations were found between age and positive affect or subjective adjustment. Social support was strongly associated with positive mood and subjective adjustment (r =.343, p =.001; r =.365, p =.000). Active coping was associated with subjective adjustment (r =.297, p =.004). Hope was strongly associated with positive mood and subjective adjustment (r =.392, p =.000; r =.44, p =.000).

		Positive Affect	Subjective Adjustment
Age	Spearman's rho Correlation	.125	.035
	Sig. (2-tailed)	.221	.743
Social support	Spearman's rho Correlation	.343	.365
	Sig. (1-tailed)	**.001**	**.000**
Active coping	Spearman's rho Correlation	.152	.297
	Sig. (1-tailed)	.134	**.004**
Hope	Spearman's rho Correlation	.440	.392
	Sig. (1-tailed)	**.000**	**.000**

Table 4 Correlations between predictor and outcome variables

3.4 Multiple regression analyses: hypothesis 4

Hypothesis 4 is restated below.

4. Hope will explain additional variance in positive mood and adjustment in new amputation patients at 6 months when the variance contributed by social support and active coping has been accounted for.

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The multiple regressions of significant predictor variables with positive mood and subjective adjustment are described.

3.4.1 Positive mood

Social support and hope together predicted about 18% of the variance in positive mood following lower limb amputation. Hope contributes an additional 9% of unique variance in the prediction of positive mood over and above the 9% contributed by social support, representing an additional significant contribution (significant *F* change *p*=.001). The regression is summarised in table 5 below.

	B	**SE *B***	**Beta**
Step 1			
Constant	23.112	3.484	
Social Support	.169	.055	.300*
Step 2			
Constant	10.431	5.043	
Social Support	.117	.055	.207*
Hope	.298	.089	.324**

Note R^2 change step 1 = .09, step 2 =.096; for step 2 *p*=.001

**p*<.05; ***p*<.001

Table 5 Multiple regression analysis for positive mood

3.4.2 Subjective adjustment

Cause of amputation, active coping, social support and hope together predict 21% of the variance in subjective adjustment. Hope contributes 3% unique variance in the prediction of subjective adjustment to lower limb amputation over and above that contributed by cause of amputation, active coping and social support (non significant *F* change *p* =.063). The regression is summarised in table 6 below.

	B	SE *B*	Beta
Step 1			
Constant	48.396	2.731	
Cause	4.028	1.915	.219*
Step 2			
Constant	34.244	4.640	
Cause	3.769	1.831	.205*
Social support	.181	.066	.299*
Active coping	.539	.547	.109
Step 3			
Constant	27.950	5.666	
Cause	3.262	1.825	.177
Social support	.167	.065	.277*
Active coping	.125	.582	.025
Hope	.198	.105	.208

Note R^2 change step 1 =.048, R^2 change step 2 =.129, R^2 change step 3= .033 * p<.05

Table 6 Multiple regression analysis for subjective adjustment

3.5 T test for the stability of trait hope in this sample: hypothesis 5

Hypothesis 5 is re-stated below.

5. There will be no significant difference between hope scores at time 1 and time 2.

Table 7 below shows hope scores at time 1 and time 2.

	Mean	N	S. D.	S.E. Mean
Hope time 1	53.16	98	9.068	.916
Hope time 2	51.22	98	8.608	.870

Table 7 Hope scores at time 1 and time 2

There was no significant difference between hope at time 1 and time 2 (t=1.974, p=.051). However, there was a tendency for hope scores to reduce over time.

3.6 Post hoc analyses

Although it is important to exercise caution in conducting unplanned analyses, a number of additional observations from the data can be made. The relationship of phantom pain to adjustment was examined as previous studies have suggested that this variable is related to worse outcomes (e.g., Hanley et al., 2004). The correlates of negative affect were examined to see if this accorded with previous research (e.g., Folkman, 2008). The correlates of satisfaction with the prosthesis were examined as, in the experience of the researcher, this represents an important clinical question for rehabilitation services. Finally, coefficients from regression equations were examined to test for mediation of the relationship between hope and positive affect/ adjustment by social support and active coping. This final analysis was conducted to test a tentative model which has recently emerged in the literature in relation to these variables (Mosher et al., 2006; Folkman, 2008) and could be the focus of further research is this field.

3.6.1 Phantom pain intensity

Phantom pain was reported by 72 participants (72.7%). Participants varied in how they rated the experience, the majority reported that it was mild or discomforting, however about 20% of those giving a rating, rated the pain as distressing, horrible or excruciating. Interestingly though, phantom pain intensity at time 2 is not significantly correlated to either positive affect (r =-.07) or subjective adjustment (r =-.05). This suggests

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that it is possible to experience phantom pain and feel adjusted to the amputation.

3.6.2 Negative affect

Negative affect at time 2 was significantly correlated with the use of the coping strategies of denial (Spearman's *rho* =.327, *p* =.001), behavioural disengagement (Spearman's *rho* =.26, *p* = .01) and self blame (Spearman's *rho* = .323, *p* = .001).

3.6.3 Satisfaction with prosthesis

Satisfaction with the prosthesis (a TAPES sub scale) showed a significant positive correlation with social support (Pearson's *r* =.349, *p*=.001).

3.6.4 Does social support mediate the relationship between hope and adjustment?

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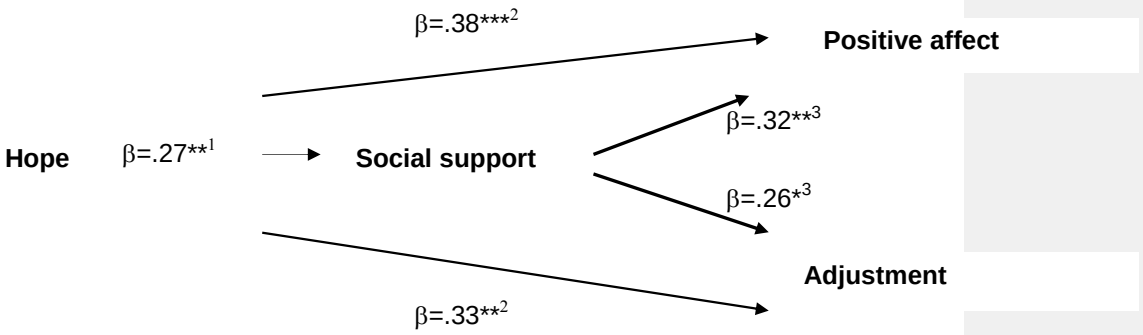
There is increasing evidence to suggest that adjustment to disability is a dynamic process involving a range of individual illness and social factors that interact over time (Elliott et al., 2002; Folkman, 2008). It is tentatively hypothesised that relatively stable cognitive factors may 'drive' certain coping strategies that in turn influence adjustment outcomes. A

greater understanding of such processes will underpin more effective triage and interventions in clinical settings.

The coefficients from regression equations were examined to test for mediation of the relationship between hope at time 1 and positive affect/ adjustment by social support (Baron & Kenny, 1986). To establish mediation, firstly hope must affect the mediator[1] (social support), secondly hope must affect positive affect/adjustment[2] and thirdly in a regression of positive affect/adjustment on both hope and the proposed mediator[3] (social support), the mediator must affect positive affect/adjustment. The effect of hope on adjustment must be less in the third regression than the second. All of these conditions were satisfied for social support to be considered a mediator of the relationship between hope and both positive affect or subjective adjustment. These relationships are shown in diagrammatic form below.



*p<.05, **p<.01, ***p<.001,

Figure 2 Regression coefficients for social support as a mediator of the relationship between hope and adjustment.

3.7 Summary

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The findings of the study confirm that demographic and amputation related variables have little or no effect on subjective adjustment and positive mood following lower limb amputation. Social support, active coping and hope were all highly correlated with subjective adjustment at follow up. Social support and hope were highly correlated with positive mood at follow up. Hope contributed 9% of unique variance to positive mood which represented an additional significant contribution after other variables had been accounted for. The findings will be discussed in detail in the following section and evaluated in terms of the study hypotheses, strengths and weaknesses of the study design, possible clinical implications of the findings and suggestions for future research in this area.

4 Discussion

The findings of the current study will be discussed in relation to previous research in this area and the study hypotheses. The study sample will be compared to previous studies and normative data for the study variables. The study hypotheses will be accepted or rejected in light of the findings. The current study will be critiqued in terms of its strengths and weaknesses. Subsequently, conclusions will be drawn concerning the study findings and their contribution to knowledge in this area. The possible implications for clinical practice will be delineated. Recommendations will be made for future studies of adjustment to lower limb amputation. Final conclusions will be drawn regarding the study.

4.1 Current findings in relation to previous studies

The findings of the current study with relation to the participants, predictor and outcome variables will be discussed and compared with previous research.

4.1.1 Participants

The average of age of participants in the current study was a little over 60 years old. This mean age is in line with that with that found in the Global Lower Extremity Amputation Study (2000). However, the mean age is somewhat elevated in comparison with other studies of adjustment in lower limb amputees. Hanley et al. (2004) report a mean

age of 45 years with a range of 16 to 89 in their sample of 70. Livneh et al. (2000) reported a mean age of 55 years with a range of 15 to 84. Gallagher and MacLachlan (1999) report a mean age of 54 with a range of 20 to 83 in their sample of 44 lower limb amputees. The higher mean age of the participants in the current study can be understood in relation to the differing recruitment methods of the above cited studies. Hanley et al. (2004) report the youngest mean age of lower limb amputees. The sample was recruited as consecutive admissions to a trauma centre for lower limb amputation and thereby comprised an under representation of amputation for causes such as diabetes associated with older age. Both Livneh et al. (2000) and Gallagher and MacLachlan's (1999) cross sectional studies used postal surveys. In the case of Livneh et al. (2000), participants were members of an amputee support service and in the case of Gallagher and MacLachlan (1999) were patients who had received artificial limbs from a national rehabilitation hospital. They had response rates of 32% and 27% respectively. This contrasts with the current study in a number of ways. In none of these three studies were participants recruited as a consecutive sample representative of the range of amputation causes. Sampling from trauma patients and cross-sectionally by post is likely to bias a sample to be younger than the true population of all lower limb amputees. It is proposed that the method of recruiting participants to the current study represents a more accurate sampling method with respect to age of new lower limb amputees.

In terms of the gender of the sample, the large majority of participants were male (over 80%). This proportion of male to female amputees is

typical (Global Lower Extremity amputation Study, 2000). In a study of 104 participants using the TAPES, Gallagher and MacLachlan (2000) reported 75% of the sample to be male and 25% female. Hanley et al. (2004) reported 73% of their sample of lower limb amputees was male. These proportions are similar to the current study.

Slightly more than half of the participants in the study had below knee amputations. This proportion of below knee to above knee amputations is similar to that reported by Gallagher and MacLachlan (1999). Hanley et al. (2004) report 67% of their sample had below knee amputations. However, as described above, their participants were recruited from a trauma centre and did not represent the full range of amputation causes.

The commonest cause of amputation in the participants was peripheral vascular disorder, followed by diabetes. Again this is similar to findings of other studies (e.g., Global Lower Extremity Amputation Study, 2000; Livneh et al., 2000). Hanley et al. (2004) and Gallagher and MacLachlan (1999) report a higher proportion of traumatic amputations in comparison to the current study. This can be understood in terms of the different recruitment methods used in the studies as previously discussed.

In terms of demographic and amputation factors, the study participants are comparable to the general population of lower limb amputees. Differences in the mean age and proportion of traumatic amputations between the current study and other studies of adjustment to lower limb amputation can be accounted for by differing recruitment methods. The

current study participants more closely resemble the total lower limb amputee population than previous studies in this area.

4.1.2 Study variables

Data from the current study in relation to the key variables will be compared to previously published normative data and where possible previous research with lower limb amputees.

4.1.2.1 Predictor variables

The psychosocial predictor variables in the study comprised satisfaction with social support, active coping strategies and hope. The data for each variable will be discussed.

In terms of social support, the mean total scale score for the participants in the study on the MSPSS was 5.6 with a standard deviation of 1.29. This is comparable to a mean total scale score for a sample of undergraduates reported by Zimet et al. (1988) which was 5.8 with a standard deviation of 0.86. This indicates that the current participants have a comparable level of satisfaction with their social support to a general population sample.

With regards to coping, Cronbach's alpha for the active coping sub scale of the brief COPE (Carver, 1997) for the current sample was .63. This is towards the low end of acceptability but is comparable to the .68

reported by Carver (1997). Livneh et al. (2000) used the brief COPE in their study of coping and amputation with a sample of 61 amputees. Although they do not report alpha coefficients for each sub scale separately they report a median co-efficient of 0.67 for 14 scales taken together.

The current study participants reported a mean total hope score of 53.16 at time 1 and 51.22 at time 2. This is comparable with mean normative sample scores of 51.28 reported by Snyder et al. (1991) for a college sample. Also Magaletta and Oliver (1999) report mean scores of 53 also for a student sample.

The current participants' ratings of social support, active coping and hope appear similar to both normative samples and other studies of amputees on these variables, where these data have been published.

4.1.2.2 Outcome variables

The outcome variables in the current study comprised positive mood and subjective adjustment to the amputation. The data for the current sample will be compared with previously published research.

The participants in the current study reported a mean score for positive affect of 33.33. Due to the preponderance (over 80%) of males in the current sample this can be compared to a mean score of 32.06 reported by Crawford and Henry (2004) for the male participants in their large

normative general population sample. It can be concluded that six months post amputation the participants are experiencing a similar level of positive emotion to that reported in a general population sample.

Although negative affect was not an outcome variable in the current study, it is interesting to note that participants reported higher levels of negative affect (mean score 18.03) in comparison to Crawford and Henry's (2004) sample (mean score 15.2).

The current sample reported means of 19.61, 21.76 and 12.46 for the general, social and limitation adjustment sub scales of the TAPES respectively. This can be compared to 18.87, 19.5 and 13.67 for Gallagher and MacLachlan's (2000) sample of 104 amputees studied during the development of the TAPES. The mean scores reported by the current sample for subjective adjustment are comparable to those reported by Gallagher and MacLachlan (2000) in a cross sectional sample 8 years post amputation on average.

The current participants are comparable to normative data for positive affect and to a sample of amputees for subjective adjustment.

4.1.3 Study findings

The relationships between predictor and outcome variables in the data will be discussed.

4.1.3.1 The role of demographic and amputation factors in outcome

The prediction was made that age, gender, level and cause of amputation would not be associated with positive affect and adjustment. Although the prediction was largely confirmed a correlation was found between cause of amputation and subjective adjustment that just reached statistical significance.

In previous cross sectional research looking at adjustment in lower limb amputees there have been contradictory and inconclusive findings in relation to the importance of demographic and amputation factors (Horgan and MacLachlan, 2004). The current findings are that gender, age and level of amputation are not associated with measures of positive mood or subjective adjustment at around 6 months post amputation. This is largely in accordance with Horgan and MacLachlan's (2004) conclusions after reviewing all current studies (up to 2004) relating to this issue. They concluded that a lower level of amputation was likely to be related to better adjustment. However, closer examination of the relevant studies shows that it is only in the area of activity restriction that above knee amputees are disadvantaged in relation to below knee amputees not in relation to psychological measures. This also accords with Larner et al. (2003) who found that above knee amputees were less likely to learn to use a prosthesis.

Cause of amputation has not been consistently found to be associated with adjustment in previous studies (Horgan and MacLachlan, 2004). In

the current data there is a weak but statistically significant correlation between cause of amputation and subjective adjustment. Amputees who have lost a limb due to cancer or accident tend to report better subjective adjustment than those with vascular or other chronic illness related causes. It is possible that the former group view their amputations as 'curative' and a one off event in comparison to the second group who not uncommonly have a deteriorating chronic condition. Ideally, patients with cancer, trauma and vascular conditions would be studied as separate groups but this was not possible within the confines of the current study. Ward and Higgs (1998) summarise research showing that chronic illness and conditions over which the patient has little control are more likely to lead to difficulties of adjustment. One previous study (Gerhards, Florin and Knapp, 1984) found that 'being convinced as to the necessity' of the operation was associated with lower levels of depression following amputation. Further prospective research on subjective adjustment to amputation in relation to the cause, perceived necessity and consequences of the operation would be of interest in this area due to the beneficial influence it could have on preparing potential amputees for surgery. An 'illness representation' approach (Weinman & Petrie, 1997), examining beliefs about amputation in terms of control and chronicity could be potentially informative in further research in this area. Further prospective studies that are adequately powered are also needed to replicate the link between cause of amputation and adjustment.

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4.1.3.2 The role of social support and active coping

It was predicted that social support and active coping would both be correlated with positive affect and subjective adjustment. The prediction was largely confirmed however active coping was not significantly correlated with positive affect.

The importance of social support in both positive mood and subjective adjustment following amputation is confirmed by strong correlations with both these outcome variables in the data. This supports previous cross sectional and prospective findings in this area (Horgan and MacLachlan, 2004; Williams et al., 2004). Social support remained a significant variable in predicting positive affect and subjective adjustment when entered into the regression with the other study variables. These consistent findings now need building into dynamic models of adjustment (Elliott et al., 2002).

The importance of active coping strategies in relation to subjective adjustment following amputation is confirmed by a significant correlation between these two variables. There have been no previous prospective studies in this field.

Interestingly, active coping strategies were not significantly correlated with positive affect in this study, nor did they remain as significant predictors in the regression analysis for subjective adjustment. Folkman (2008, p 11), in summarising the current research in this area, concludes

that although we know that positive emotions are a normative and restorative part of the stress process, 'less is known about the full range of coping processes…which are associated with the regulation of positive as opposed to negative emotions'. Recent findings suggest that values and goals are 'heavily implicated' in these processes (Folkman, 2008). Further research is needed regarding the specific coping strategies that underpin positive emotion and adjustment particularly in relation to amputation.

4.1.3.3 The role of hope

The predicted importance of hope in both positive affect and subjective adjustment post amputation is confirmed by highly significant positive correlations between hope and these variables. This finding adds further evidence to the importance of hope in adjustment to a range of adverse circumstances (Snyder 2002). The current data show that individuals who perceive themselves to be able to generate successful pathways to desired goals and have the self-belief to pursue those pathways will experience greater positive emotion and rate themselves as better adjusted to amputation.

It was predicted that hope would remain a significant predictor of positive affect and subjective adjustment over and above social support and active coping. The prediction was confirmed in relation to positive affect but not in relation to subjective adjustment. Hope contributed an additional 10% unique variance to positive affect and 3% unique

variance to subjective adjustment. Social support and hope are the main contributors to positive affect and together account for about 18% of the variance. Only social support remained significant in predicting subjective adjustment when entered into the multiple regression with cause, active coping and hope.

Folkman's (2008) revised stress and coping model would suggest that there is a process whereby positive emotion both underpins and results from successful coping and together these drive adjustment. It is possible that a longer follow up period would yield findings more in line with the original hypotheses and confirm a relationship between hope and subjective adjustment.

It was predicted that hope would remain stable over time. This was confirmed. The stability of hope over time lends support to Snyder's (2002) assertion that it is a trait like concept. Furthermore, if hope can be reliably measured and is related to outcomes, it could form part of a useful assessment protocol for patients with amputations or other acquired disabilities.

4.1.4 Post hoc analyses

4.1.4.1 Phantom pain

Previous findings suggesting that phantom pain is a common experience post amputation were confirmed by the current data. Phantom pain was not correlated with positive affect or subjective adjustment. These are

interesting findings and somewhat at odds with previous work using phantom pain as an indicator of adjustment (e.g., Hanley et al., 2004). The current findings suggest that the presence of phantom pain should not imply poor adjustment. This area would be useful to explore in future studies, perhaps using qualitative methods.

4.1.4.2 Negative affect

Previous studies suggesting that negative coping styles (denial, disengagement, self blame) are related to negative emotion (Folkman & Moskowitz, 2000) are afforded support by the current findings. Folkman (2008, p12) urges researchers and clinicians to now restore the balance of decades of 'exclusive concern' with negative emotions by exploring how clients generate and sustain positive emotions.

4.1.4.3 Satisfaction with the prosthesis

A frequent question asked by prosthetists, in the author's clinical experience, is why it is that, despite all their best efforts, there are a significant minority of patients who are never satisfied with their prosthesis? The current data suggest that, interestingly, satisfaction with social support is correlated with this variable. Those less likely to be satisfied with the prosthesis report themselves to be more isolated socially. This would also be an interesting area to explore in future studies.

4.1.4.4 Social support as a mediator of the relationship between hope and adjustment

Snyder and colleagues (1991) suggest that hope is a relatively stable individual difference and is a cognitive set derived from a sense of successful planning (pathways) and goal-directed determination (agency). Mosher et al. (2006) found that lower levels of depression in optimistic black students were mediated by coping and social support. It therefore seemed plausible to suppose that the relationship found in the current data between hope and positive mood may be mediated by social support. The utilisation of social support could be regarded as the action component arising from the underlying cognitive set of 'hopefulness' and resulting in more positive affect and a higher subjective sense of adjustment. This model would also be supported by Folkman (2008) who suggests that underlying beliefs support strategies that generate positive emotion and the progression towards adaptation.

The current data lend some support to this model and suggest that individuals high in hope are likely to use active coping strategies and to be happy with their support networks, presumably because they have taken an active part in constructing and nurturing them (this relationship could be a focus for further investigation). These strategies in turn generate higher levels of positive affect and subjective adjustment, in this case to the experience of having lost a lower limb. Researchers in this area are increasingly moving towards dynamic models to understand the iterative processes involved in driving adaptation and adjustment (e.g.,

Folkman, 2008; Elliott et al., 2002) in which they see positive emotion as central. Elliott et al. (2002) suggest that sophisticated statistical methods such as structural equation modelling can be usefully brought to bear in this area in the future.

4.1.5 Conclusions

In light of the data analysed it has been concluded that the current participants are broadly representative of the population of lower limb amputees and similar to participants in previous studies. In terms of social support, hope and positive mood participants are comparable to general population norms. In terms of subjective adjustment to the amputation the participants are similar to a cross sectional lower limb amputee sample. Demographic and amputation factors are not of key importance in predicting adjustment to lower limb amputation. Cause of amputation (particularly the distinction between acute and chronic causes) may have some influence but did not remain a significant predictor in the multiple regression analysis of subjective adjustment.

Satisfaction with social support is an important predictor of both positive mood and subjective adjustment following lower limb amputation, accounting for significant variance in outcome. Active coping was significantly correlated with subjective outcome but does not remain a significant predictor in the regression analysis when entered along with cause, social support and hope. Hope is strongly correlated with positive affect and remains a significant predictor of this variable alongside social

support. Although also strongly correlated with subjective adjustment, hope does not remain a significant predictor when entered alongside cause, social support and active coping. As suggested above, it is possible that a longer follow-up period would have yielded findings more in line with expectation as amputees' coping efforts impact on subjective adjustment. However, it is also possible that the longer follow-up period would show that hope scores were not stable over time, but that the trend in the reduction of scores had continued. In this case it is unclear if the anticipated relationship between hope and adjustment would remain. The strongest finding of the study is the large effect of perceived social support on both adjustment and positive mood and this certainly warrants further study.

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A post hoc analysis suggests that the relationships between hope and the outcome variables may be mediated by social support.

4.2 Methodological issues

The relative strengths and weaknesses of the current study will be explored in relation to previous studies, design issues and practical challenges of completing the research.

4.2.1 Strengths of the study

The study has several strengths in relation to previous research in this area. Most importantly, this is the first prospective study of adjustment in

a UK sample. A previous prospective study of adjustment (Hanley et al. (2004) has been conducted in the USA. Cross sectional studies are limited in the conclusions they can draw in relation to direction of relationships between variables studied. Furthermore, the identification of variables in which it may be possible to intervene to improve medium to long term outcomes must be an important goal of research in this area.

The second strength of the current research is that the participants are more closely representative of the lower limb amputee population. Hanley et al. (2004) recruited their sample from a trauma centre and other cross sectional studies will tend to favour younger more able amputees. Because the current participants were recruited as a consecutive sample then as many biases as possible were minimised.

A third strength of the study is the high completion rates for the consenting and follow up phases of the study. The data set had little missing data. This was achieved by close collaboration with the service and by the study protocols being embedded in the everyday running of the service for the duration of the study. This latter strength of the study also contributed to the ethical robustness of the research. The specialist nurses were able to monitor patients' possible distress and instigate their usual protocols should this occur. No patients were referred for additional psychological support as a result of distress during the course of the study. A positive 'side effect' of the study for the nurses was that completing the questionnaires with patients resulted in useful

conversations and information which they felt improved the level of care they could provide.

The study was adequately powered to address the stated hypotheses and this is in contrast to many other studies in this area which have tended to rely in smaller sample sizes. The prospective study reported by Hanley et al. (2004) comprised 70 participants and they state that the 'results would be strengthened by a larger sample size'.

Previous studies, including Hanley et al. (2004) have tended to study adjustment in negative terms (the absence of depression or phantom pain for example). Although these studies have been useful in highlighting possible correlates of outcome they only represent half the story. As the current data show, the majority of people experiencing lower limb amputation will fairly quickly adapt and adjust successfully to their situation. Furthermore the findings suggest that phantom pain is not a barrier to good subjective adjustment and positive mood. Clinicians will benefit by being able to support natural adjustment processes and encourage them in those who may be doing less well. Folkman (2008) provides up to date evidence that positive emotion has an important function in the stress process and also in supporting coping processes that are distinct from those involved with distress.

As is often the case in studies of adjustment to disability, previous research with respect to adjustment to amputation was largely conducted without reference to psychological theory. The current study was designed to examine the question of adjustment to amputation within a

positive psychology framework (to redress the previous negative bias) whilst also accounting for previous findings from cross sectional studies in relation to active coping and social support.

Finally, the study was designed to be of clinical relevance to lower limb amputees and the services trying to help them. Services need simple and effective ways of identifying individuals who may need extra support and also reliable ways of encouraging adjustment for everyone in their care.

4.2.2 Weaknesses of the study

Despite the fact that the study numbers were adequate and very close to the target of 103, the study would have been strengthened by more participants. This would have further reduced the possibility of type I and type II errors in the data (Wilson Van Voorhis & Morgan, 2007). The findings from the post-hoc meditational analysis must be viewed with caution due to the sample being smaller than planned and the resulting loss of power. During the 18 months in which time 1 and time 2 data were being collected there were three different consultants at the service. The first longstanding incumbent retired and was replaced by a locum and then a new permanent doctor. The centre only operated with one doctor and thus each change over resulted in a reduction in new patient assessments and follow up appointments. Research always has unforeseen challenges and these were largely well managed during the

current study. Ideally the study period would have been extended but the grant supporting the staff time had run out.

A further limitation of the study is the follow up period. Typically participants were about 8 to 10 months post operative at follow up. It would have been preferable to have a longer follow up period or be able to add another assessment point perhaps 18 months to two years post operative. Hanley et al. (2004) found stronger associations at two year follow up compared to one year for the psychosocial variables they studied (social support, perceived control, catastrophising) suggesting that the effect of these variables may be further amplified over time.

In terms of the methods used to measure some of the study variables, some improvements could be made in future studies. The active coping variable was studied using the brief COPE and comprises two questions. The internal reliability of this two item scale was on the low side and the range of scores was limited. Future research might usefully evaluate other measures of positive and active coping (e.g., the ways of coping checklist; Vitaliano, Russo, Carr, Maiuro & Becker, 1985) to identify the best method of rating this variable.

Subjective adjustment was studied using a subscale of the TAPES which was designed for amputees. This should be compared in future research to measures of subjective adjustment that have been developed for use with the general population (e.g., Ryff & Keyes, 1995). The measures of hope, social support and positive affect, whilst all useful, have a common

shortcoming and that is that people tend to rate themselves towards the top of the scales meaning data are positively skewed. For the purposes of the current study, because the residuals were normally distributed in the multiple regression, it was possible to proceed without transforming the data.

Despite significant results found in the regression analyses in the study only about 20% of the variance in adjustment is accounted for by the variables studied. A range of other individual, health and social factors will also influence adjustment and be subject to a degree of variability. Variables that were considered for inclusion in the study but which had to be excluded for practical, ethical and theoretical reasons could usefully be the focus of future studies. These include post-traumatic symptoms, body image and illness beliefs, for example.

4.3 Evaluation of the study findings

Following consideration of the strengths and weaknesses of the study it is possible to evaluate the study findings. It can be concluded that the current research adds to existing studies in this area in a number of ways. The prospective nature of the study and the incorporation of both previous findings and new research from positive psychology are particular strengths. The study confirms the relative un-importance of demographic and amputation variables in influencing adjustment outcomes in amputation. The importance of social support, active coping

and hope in promoting adjustment to amputation are leant strong support by the findings.

4.4 Practical and clinical implications of the study findings

The most striking finding in the current study is that in less than a year post amputation participants were on average experiencing as much positive affect as the general population and were subjectively adjusted to the amputation to the same extent as those on average over eight years post amputation (Gallagher and MacLachlan, 2000). Although a significant challenge, an amputation does not have to be conceived as a life long tragedy. This information can be usefully shared with patients at pre-amputation assessment or early in the rehabilitation phase to enhance hopefulness about the recovery phase.

Amputees do not appear to differ in terms of the adjustment process to people with other health conditions or adverse life events. The findings are largely in concordance with expectation. The implication follows that in disability services it behoves professionals to foster and encourage the importance of social support and active coping. This could be achieved in a number of formal and informal ways; support groups, 'buddy' schemes, resource sign posting, and collaborative goal setting for example.

Resources in a publicly funded health service are always going to be limited and professionals need to develop evidenced based ways of

targeting efforts where they are most needed. Models such as the 'stepped care' idea are becoming more widely accepted and are being increasingly recommended (e.g., NICE guidance for supportive and palliative care, 2004). The current findings suggest that the minority of patients who are low in hope, social support and active coping could helpfully be identified at assessment and more intensely monitored for the presence or development of mood disorders or other problems of adjustment. The protocol of the study has shown that routine assessment of these variables can be incorporated into a service with relative ease. Without the consenting process, completion of the hope scale and the MSPSS would take a few minutes and could be done at home by the patient before their first appointment. Previous screening efforts commonly screen for distress. However, this approach does not account for the fact that positive and negative emotion can co-exist and that the former is more predictive of long term adjustment (Folkman and Moskowitz, 2000). Distress in the early phases of a post surgical recovery is a common finding (Salmon, 1992). The challenge is to predict which individuals will struggle to adjust in the long term.

There is growing evidence that it is possible to provide interventions that will increase an individual's hopefulness (Linley & Joseph, 2004). Individuals identified as 'low hope' could perhaps be offered individual or group interventions to enhance their hope and thereby improve adjustment over time. Delehanty and Trachsel (1995) report a small study of a group intervention for amputees aimed at building coping

strategies. Treatment group members were less distressed than a comparison group awaiting the program.

Hope is a concept which is easily explainable to clinical staff not formally trained in psychology. The same is also true for social support and active coping. As such they are potentially easily incorporated into a service philosophy and easily supported by a psychologist offering an input to a team or service.

These developments should be the subject of further clinical effectiveness research in this field.

4.5 Recommendations for further research

The current study is the first prospective study of adjustment to amputation in the UK and is also unique in studying positive outcomes. As such it would be important for future studies that are prospective and also studying similar outcomes to replicate the current findings, preferably with a larger sample. A longer follow up period should be included in future studies. It may be possible with the agreement of the service and suitable ethical permissions to follow up the current sample after two years and this possibility will be pursued.

The current study was inevitably limited in scope and the result was that variables of interest were not studied. Future studies could usefully examine further the relationships between hope, social support and body

image. The area of post-traumatic stress disorder in non-combat amputees is also under researched to date and the relationship of such symptoms to phantom pain would be of interest.

The relationships between adjustment and both phantom and stump pain are of interest. Hanley et al. (2004) found that psychosocial variables were related to phantom limb pain intensity at follow up but did not study stump pain. Also phantom pain is a common experience following amputation. Given the current study findings, it seems likely that a large proportion of individuals with phantom pain are still able to adjust satisfactorily to their situation. In fact, a study also carried out at the same service as the current research found that phantom sensations are not always viewed in a negative light by patients (Tomasini, Kacperek & Bray, 2006).

As researchers and clinicians we need to challenge our assumptions about adjustment. The presence of pain and distress are not necessarily the best indicators of adjustment from a patient perspective. Further qualitative research on the components of subjective ratings of adjustment would be informative in this regard.

A more detailed exploration of social support and the mechanism by which it appears to facilitate adjustment to amputation is also warranted. The importance of social support in well being is now well documented. Lower limb amputation can result in individuals struggling with mobility issues which will inevitably impact on their relationships with previous

social networks. The current findings suggest that certain people are more equipped to overcome and adjust to these barriers.

The post hoc analyses suggesting that social support and active coping mediate the relationship between hope and adjustment could be the potential focus of further research both in amputation and other adjustment research aimed at building better models to account for the dynamic nature of the process. Closer examination of the relationships between variables influencing adjustment will allow researchers and clinicians to build more accurate models of adjustment to illness and disability. Such models would have wide ranging benefits for the provision of services for the increasing numbers of people living for extended periods facing such challenges.

A further interesting study from a clinical point of view would examine the relationship between hope and social support and non-adjustment at follow up. The aim would be to identify a 'cut off' score for low hope or social support which would signal to teams that an individual is likely to need more than 'routine' support in the rehabilitation phase. These individuals could be offered additional support and monitoring and potentially be referred for individual or group psychological intervention where necessary.

4.6 Conclusions

The current study aimed to build on previous research in adjustment to lower limb amputation. A prospective study using a positive and subjective conceptualisation of adjustment was conducted to examine the roles of demographic and amputation variables, social support, active coping and hope in adjustment. The findings confirm the importance of satisfaction with social support, use of active coping strategies and hope in positive subjective outcomes. The clinical implications and possible future studies in this field were discussed.

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6 Appendices

Appendix 1:

Patient information sheet for the study

Information Sheet

Study Title:
A Prospective Study of Adjustment in New Lower Limb Amputees

Researcher:
Jennifer Unwin, Consultant Clinical and Health Psychologist

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information and discuss it with others if you wish. Ask us if you would like any more information.

About the study
We know that having an amputation can be a difficult experience and that some people find it hard to adjust or 'get back on track' afterwards. There have been no studies following new amputation patients and seeing which factors make a difference to their adjustment over time. We have looked at previous research and will be asking people about factors that may affect their adjustment. After six months we will look at how people are getting on. In that way, we will be able to look at what helps people to do better.

We hope that what we learn will mean we can help patients to cope better with their amputation.

Why have I been chosen?
We are asking all new lower limb amputation patients referred to the Disablement Services Centre (DSC), xxxxxxxxx Hospital to take part in this study and hope to study around 100 people.

Do I have to take part?
It is up to you to decide if you want to take part. If you decide to take part you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw at any time. A decision not to take part or to withdraw at any time will not affect the standard of care you receive.

What will happen if I decide to take part?
You will be asked to complete a questionnaire, which will take around 30 minutes. You will be able to ask the Specialist Nurse if you have any questions. Then six months after this we will contact you either at the Centre when you come for an appointment or by post to ask you to fill in a questionnaire which will take about 20 minutes.

Occasionally, people can be upset when thinking about what has happened. If you need to talk to someone about your amputation please contact Lynn Kacperek or Kathy Greenwood on telephone number xxxxxxx or e mail lynn.kacperek@xxxx.nhs.uk

Confidentiality
All information that is collected about you during the study will be kept strictly confidential. Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised from it. If you decide to take part in this study will we let your GP know of your involvement.

What will happen to the results of the research?
The study is due for completion in April 2008. It is our aim to publish the results of the study. Information about the results of the study will automatically be sent to you if you take part in the study. A full copy of the final report will be available on request. You will not be identified in any way in any publications or presentations.

Who has monitored the research?
The study is supervised by Hull University. xxxxxxxx Teaching Hospitals NHS Foundation Trust Research and Development Directorate is funding the research. The study has been reviewed by the local research ethics committee and approved by the DSC research committee.

What next?
If you have any questions about the research please telephone Lynn Kacperek on xxxxxxxxx or e mail lynn.kacperek@xxxx.nhs.uk . You will be asked if you wish to take part at your appointment and given a consent form to sign before completing the questionnaires.
If you decide not to take part we thank you for reading this information and wish you well.

Version 3
09/02/2006

Appendix 2:

Letter of invitation to take part in the study

Dear

A study to look at coping with lower limb amputation

You will soon be coming to the Disablement Services Centre at the xxxxxxxx Hospital for your first appointment following your lower limb amputation. At the moment we are carrying out a study at the Centre looking at how people cope with their amputation. We are asking all new patients if they are willing to take part in a study. Taking part would involve filling in some questionnaires at your first appointment. This takes about 30 minutes. Then we will ask you to fill in some other questionnaires in six months time and this takes about 20 minutes.

The study will help us to understand how people cope with amputation so we can provide the best possible care to patients. All questionnaires will be anonymous. Everyone who takes part will receive a written summary of what we learn from the study and will be invited to a talk about the study. If you decide not to take part in the study your care will not be affected in any way at all.

We enclose an information sheet giving you more details about the study. When you come for your appointment the Specialist Nurse will discuss with you

whether you wish to take part and answer any questions you have. If you would like to know more about the study before your appointment please ring Lynn Kacperek or Kathy Greenwood on telephone number xxxxxxxxxxx.

Yours sincerely,

Jennifer Unwin, Consultant Clinical and Health Psychologist

Lynn Kacperek and Kathy Greenwood, Specialist Nurses in Rehabilitation

Version 1 27/10/05

Appendix 3:

Consent form for the study

Patient Identification Number:……

CONSENT FORM

Title of Project: A Prospective Study of Adjustment in New Lower Limb Amputees

Name of Researcher: **Jennifer Unwin, Consultant Clinical and Health Psychologist**

Please initial boxes

☐ I confirm that I have read and understand the information sheet and have had the opportunity to ask questions

☐ I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, this will not affect my medical care or legal rights.

☐ I understand that my GP will be informed of my involvement in the above study

☐ I agree to take part in the above study

…….	……..	
Name of Patient	Date	Signature
…….	……..	
Name of Researcher	Date	Signature

1 copy for patient; 1 copy for researcher; 1 copy to be keep with hospital notes

Version 1
27/10/05

Appendix 4:

Time 1 measures

Patient No…….

Questionnaires for the Lower Limb Amputation Study.
Version 2 Jan 12th 2006

1) We are interested in how you feel about the following statements.
Please circle the appropriate number on the scale.

a) There is a special person who is around when I am in need.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

b) There is a special person with whom I can share my joys and sorrows.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

c) My family really tries to help me.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

d) I get the emotional help and support I need from my family.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

e) I have a special person who is a real source of comfort to me.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

f) My friends really try to help me.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

g) I can count on my friends when things go wrong.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

h) I can talk about my problems with my family.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

i) I have friends with whom I can share my joys and sorrows.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

j) There is a special person in my life who cares about my feelings.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

k) I can talk about my problems with my friends.

1	2	3	4	5	6	7
Very strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildy Agree	Strongly Agree	Very strongly Agree

2) These items are about how you have been coping. Please circle the appropriate answer for you.

a) I've been turning to work or other activities to take my mind off things

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

b) I've been concentrating my efforts on doing something about the situation I'm in.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

c) **I've been saying to myself 'this isn't real'**.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

d) I've been using alcohol or other drugs to make myself feel better.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

e) I've been getting emotional support from others.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

f) **I've been giving up trying to deal with it**.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

g) I've been taking action to try to make the situation better.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

h) I've been refusing to believe that it has happened.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

i) I've been saying things to let my unpleasant feeling escape.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

j) I've been getting help and advice from other people.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

k) I've been using alcohol or other drugs to help me get through it.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

l) **I've been trying to see it in a different light, to make it seem more positive**.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

m) I've been criticising myself.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

n) I've been trying to come up with a strategy about what to do.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

o) I've been getting comfort and understanding from someone.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

p) I've been giving up the attempt to cope.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

q) I've been looking for something good in what is happening.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

r) I've been making jokes about it.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

s) I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

t) I've been accepting the reality of the fact that it has happened.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

u) I've been expressing my negative feelings.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

v) I've been trying to find comfort in my religion or spiritual beliefs.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

w) I've been trying to get advice or help from other people about what to do.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

x) I've been learning to live with it.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

y) I've been thinking hard about what steps to take.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

z) I've been blaming myself for things that happened.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

aa) I've been praying or meditating.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

bb) I've been making fun of the situation.

1	2	3	4
I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot

Go to the next page

3) Please circle the number that best describes YOU.

a) **I can think of many ways to get out of a jam.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

b) **I energetically pursue my goals**.

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

c**) I feel tired most of the time.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

d) **There are lots of ways around any problem**.

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

e) **I am easily downed in an argument.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

f) **I can think of many ways to get the things in life that are most important to me.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

g) **I worry about my health.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

h) **Even when others get discouraged, I know I can find a way to solve a problem.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

i) **My past experiences have prepared me well for my future.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

j**) I've been pretty successful in life.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

k) **I usually find myself worrying about something.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

l**) I meet the goals I set for myself.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

Thank you for taking the time to fill in the questionnaires and help us with the study. Please place them in the envelope provided and return this to the Nurse.

Appendix 5:

Time 2 measures

Patient No……

Questionnaires Lower Limb Amputation Study Follow up
version 1 23 August 2006

1) The following items are a number of words that describe different feelings and emotions. Indicate to what extent you have felt like this in the last week **by circling the appropriate number on the scale.**

a) Interested

Very slightly or not at all	**A little**	**moderately**	**quite a bit**	**extremely**
[1]	[2]	[3]	[4]	[5]

b) Irritable

Very slightly or not at all	**A little**	**moderately**	**quite a bit**	**extremely**
[1]	[2]	[3]	[4]	[5]

c) Distressed

Very slightly or not at all	**A little**	**moderately**	**quite a bit**	**extremely**
[1]	[2]	[3]	[4]	[5]

d) Alert

Very slightly or not at all	**A little**	**moderately**	**quite a bit**	**extremely**
[1]	[2]	[3]	[4]	[5]

e) Excited

Very slightly or not at all	**A little**	**moderately**	**quite a bit**	**extremely**
[1]	[2]	[3]	[4]	[5]

f) Ashamed

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

g) Upset

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

h) Inspired

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

i) Strong

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

j) Nervous

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

k) Guilty

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

l) Determined

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

m) Scared

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

n) Attentive

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

o) Hostile

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

p) Jittery

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

q) Enthusiastic

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

r) Active

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

s) Proud

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

t) Afraid

Very slightly or not at all	A little	moderately	quite a bit	extremely
[1]	[2]	[3]	[4]	[5]

2) Please circle the number that best describes YOU.

a) **I can think of many ways to get out of a jam.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

b) **I energetically pursue my goals**.

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

c**) I feel tired most of the time.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

d) **There are lots of ways around any problem**.

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

e) **I am easily downed in an argument.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

f) **I can think of many ways to get the things in life that are most important to me.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

g) **I worry about my health.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

h) **Even when others get discouraged, I know I can find a way to solve a problem.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

i) **My past experiences have prepared me well for my future.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

j**) I've been pretty successful in life.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

k) **I usually find myself worrying about something.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

l**) I meet the goals I set for myself.**

1	2	3	4	5	6	7	8
Definitely False	Mostly False	Somewhat False	Slightly False	Slightly True	Somewhat True	Mostly True	Definitely True

Trinity Amputation and Prosthesis Experience Scales

The Trinity Amputation and Prosthetic Experience Scales (TAPES) was produced in 2000 at the Department of Psychology, Trinity College, Dublin. It may be freely copied and downloaded for teaching, clinical and/or research purposes (www.tcd.ie/psychoprosthetics). Salient psychometric data are published in Gallagher, P. & MacLachlan, M. (2000) Development and psychometric evaluation of the Trinity Amputation and Prosthesis Experience Scales (TAPES). *Rehabilitation Psychology*, 45, 130-154.

Preliminary information on using the TAPES with people with acquired upper limb amputation is available in 'A guide to the TAPES' (p7) and in: Desmond, D. M., & MacLachlan, M. (2005). Factor structure of the trinity amputation and prosthesis experience scales (TAPES) with individuals with acquired upper limb amputations. American Journal of Physical Medicine & Rehabilitation, 84(7), 506-513.

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This is a questionnaire designed to investigate different aspects of having an amputation / artificial limb.

Please answer every item as honestly as you can. There are no right or wrong answers.

Your responses will remain confidential.

Are you male.... [ ]
female..[ ]

What age are you?
_____ years

How long have you had your artificial limb?
_____ years _____ months

4. What type of artificial limb do you have? *(Please tick the appropriate box)*
Below-Knee [ ] Through-Knee [ ]

Above-Knee [ ]
Other (please specify) _____

What was your amputation a result of? *(Please tick the appropiate box)*
Peripheral Vascular Disorder [ ]
Diabetes [ ]
Cancer [ ]
Accident [ ]
Other (please specify) _____

Part I

Below are written a series of statements concerning having an artificial limb. Please read through each statement carefully. Then ***tick the box*** beside each statement, which shows how strongly you agree or disagree with it.

		Strongly disagree	Dis-agree	Neither agree nor disagree	Agree	Strongly agree
1.	I have adjusted to having an artificial limb .	[1]	[2]	[3]	[4]	[5]
2.	As time goes by, I accept my artificial limb more	[1]	[2]	[3]	[4]	[5]
3.	I feel that I have dealt successfully with this trauma in my life	[1]	[2]	[3]	[4]	[5]
4.	Although I have an artificial limb, my life is full	[1]	[2]	[3]	[4]	[5]
5.	I have gotten used to wearing an artificial limb	[1]	[2]	[3]	[4]	[5]
6.	I don't care if somebody looks at my artificial limb	[1]	[2]	[3]	[4]	[5]
7.	I find it easy to talk about my artificial limb	[1]	[2]	[3]	[4]	[5]
8.	I don't mind people asking about my artificial limb	[1]	[2]	[3]	[4]	[5]
9.	I have difficulty in talking about my limb loss in conversation	[5]	[4]	[3]	[2]	[1]
10.	I don't care if somebody notices that I am limping	[1]	[2]	[3]	[4]	[5]
11.	An artificial limb interferes with the <u>ability</u> to do my work.....	[5]	[4]	[3]	[2]	[1]
12.	Having an artificial limb makes me more dependent on others than I would like to be.....	[5]	[4]	[3]	[2]	[1]
13.	Having an artificial limb limits the <u>kind</u> of work that I can do	[5]	[4]	[3]	[2]	[1]
14.	Being an amputee means that I can't do what I want to do.....	[5]	[4]	[3]	[2]	[1]
15.	Having an artificial limb limits the <u>amount</u> of work that I can do	[5]	[4]	[3]	[2]	[1]

The following questions are about activities you might do during a typical day. Does having an artificial limb limit you in these activities? If so, how much? *Please tick the appropriate box.*

	Yes, limited a lot	**Limited a little**	**No, not limited at all**
(a) Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports..... .	[2]	[1]	[0]
(b) climbing several flights of stairs.....	[2]	[1]	[0]
(c) running for a bus.....	[2]	[1]	[0]
(d) sport and recreation	[2]	[1]	[0]
(e) climbing one flight of stairs.....	[2]	[1]	[0]
(f) walking more than a mile	[2]	[1]	[0]
(g) walking half a mile.....	[2]	[1]	[0]
(h) walking 100 yards.....	[2]	[1]	[0]
(i) maintaining friendships.....	[2]	[1]	[0]
(j) visiting friends	[2]	[1]	[0]
(k) working on hobbies	[2]	[1]	[0]
(l) going to work.....	[2]	[1]	[0]

Please *tick the box* that represents the extent to which you are satisfied or dissatisfied with *each* of the different aspects of your artificial limb mentioned below:

		Very Dis-satisfied	Dis-satisfied	Neither Dis-satisfied nor Satisfied	Satisfied	Very Satisfied
(i)	Colour.	[1]	[2]	[3]	[4]	[5]
(ii)	Shape	[1]	[2]	[3]	[4]	[5]
(iii)	Noise	[1]	[2]	[3]	[4]	[5]
(iv)	Appearance	[1]	[2]	[3]	[4]	[5]
(v)	Weight	[1]	[2]	[3]	[4]	[5]
(vi)	Usefulness	[1]	[2]	[3]	[4]	[5]
(vii)	Reliability	[1]	[2]	[3]	[4]	[5]
(viii)	Fit	[1]	[2]	[3]	[4]	[5]
(ix)	Comfort	[1]	[2]	[3]	[4]	[5]
(x)	Overall Satisfaction . . .	[1]	[2]	[3]	[4]	[5]

Part II

(For the following questions, please tick the appropriate boxes)

1. On average, how many hours a day do you wear your prosthesis?

_____ **hours**

2. In general, would you say your health is:

Very Poor [1] Poor [2] Fair [3] Good [4] Very Good [5]

3. In general, would you say your physical capabilities are:

Very Poor [1] Poor [2] Fair [3] Good [4] Very Good [5]

4(a) Do you experience **residual limb (stump) pain** (pain in the remaining part of your amputated limb)?

No [0] .... (If no, go to question 5)
Yes [1] .... (If yes, answer (b), (c), (d) and (e))

(b) During the last week, how many times have you Experienced stump pain? _____

(c) How long, on average, did each episode of pain last? _____

(d) Please indicate, the average level of stump pain experienced during the last week on the scale below by ticking the appropriate box:

Excruciating	Horrible	Distressing	Discomforting	Mild
[5]	[4]	[3]	[2]	[1]

(e) How much did stump pain interfere with your normal lifestyle (eg. work, social and family activities) during the last week?

A Lot	Quite a Bit	Moderately	A Little Bit	Not at All
[5]	[4]	[3]	[2]	[1]

5. (a) Do you experience **phantom limb pain** (pain in the part of the limb which was amputated)?

No [0] .... (if no, go to question 6)
Yes [1] .... (If yes, answer (b), (c), (d), and (e))

(b) During the last week, how many times have you Experienced phantom limb pain? _____

(c) How long, on average, did each episode of pain last? _____

(d) Please indicate the average level of phantom limb pain experienced during the last week on the scale below by ticking the appropriate box:

Excruciating	Horrible	Distressing	Discomforting	Mild
[5]	[4]	[3]	[2]	[1]

(e) How much did phantom limb pain interfere with your normal lifestyle (e.g. work, social and family activities) during the last week?

A Lot	Quite a Bit	Moderately	A Little Bit	Not at All
[5]	[4]	[3]	[2]	[1]

6. (a) Do you experience any **other medical problems** apart from stump pain or phantom limb pain?

No [0]
Yes [1] (If yes, answer (b), (c), (d), (e),(f) and (g))

(b) Please specify what problems you experience

_____

(c) During the last week, how many times have you suffered from these medical problems? _____

(d) How long, on average, did each problem last? _____

(e) Please indicate the level of pain experienced as a result of these problems during the last week on the scale below by ticking the appropriate box:

Excruciating	Horrible	Distressing	Discomforting	Mild
[5]	[4]	[3]	[2]	[1]

(f) How much did these medical problems interfere with your Normal lifestyle (e.g. work, social and family activities) during the last week?

A Lot	Quite a Bit	Moderately	A Little Bit	Not at All
[5]	[4]	[3]	[2]	[1]

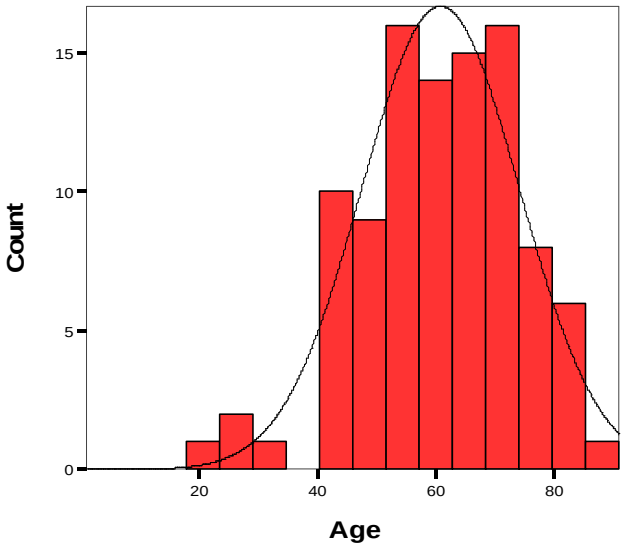
(g) Do you experience **any other pain** that you have not previously mentioned?

No [0]
Yes [1]
If yes, please specify

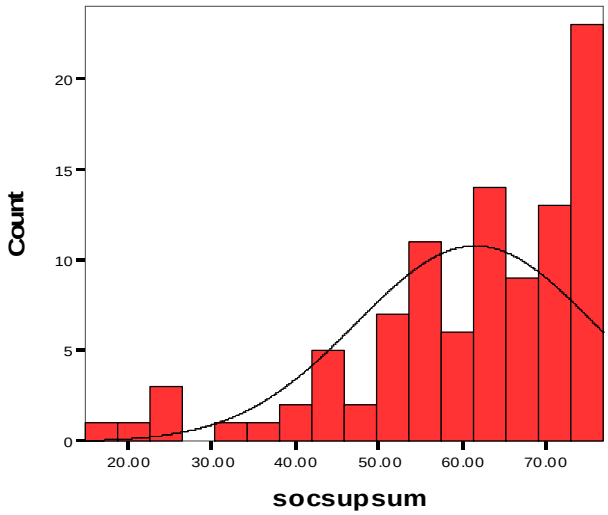
Please check that you have answered all the questions.
Thank you for all your help.

Appendix 6

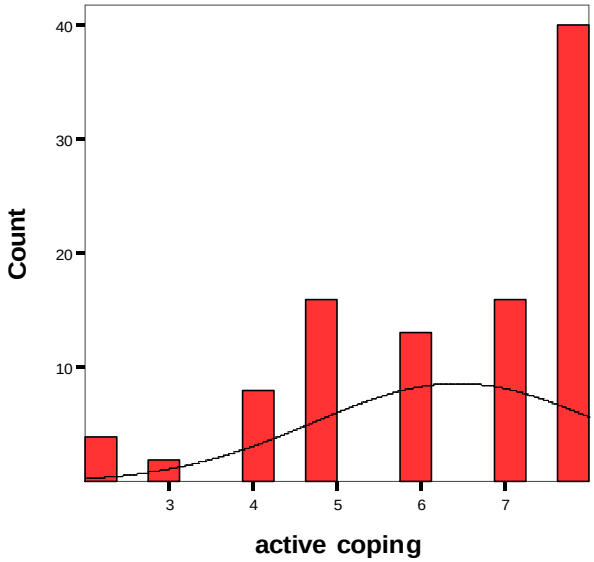
Histograms for age, social support, active coping, hope, positive affect and subjective adjustment data



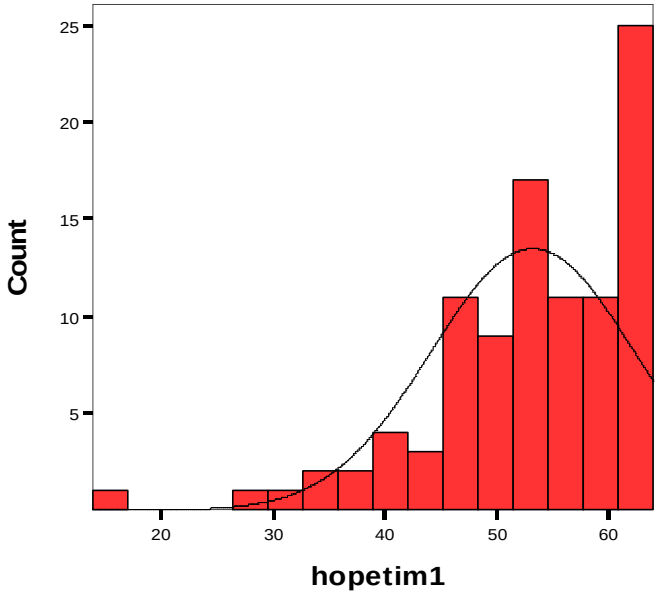
Histogram for age of participants



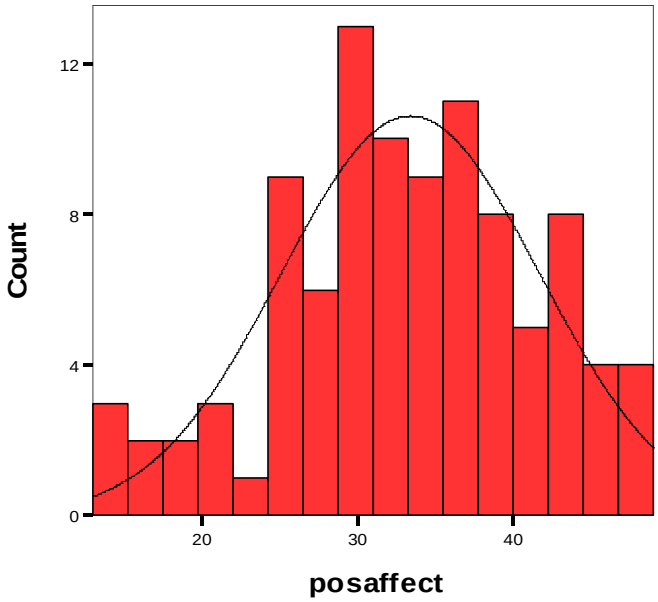
Histogram for MSPSS scores for participants



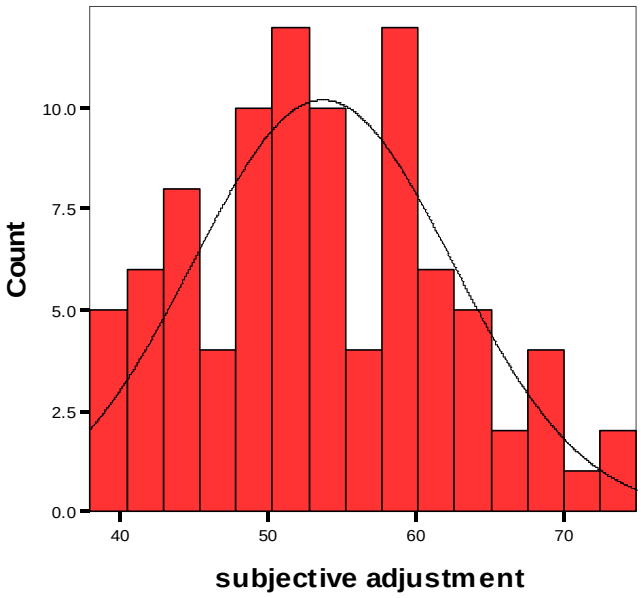
Histogram for active coping sub-scale scores for participants



Histogram for Hope Scale scores for participants



Histogram for positive affect sub-scales scores for participants



Histogram for subjective adjustment sub-scale scores for participants