

## Positive meaning in amputation and thoughts about the amputated limb

P. GALLAGHER and M. MacLACHLAN

*Trinity Psycho-Prosthetics Group, Department of Psychology, Trinity College, Dublin, Ireland*

### Abstract

The majority of research conducted on the aftermath of amputation understandably concerns itself with its most distressing aspects. This research aimed to explore whether and how people think about their amputated limb, and whether and if they considered anything good had emerged from their amputation. One hundred and four (104) people completed the Trinity Amputation and Prosthesis Experience Scales (TAPES) and two open-ended questions. The majority of participants were young and had traumatic amputations. Fifty-six percent (56%) of people thought about their amputated limb. People with bilateral or a trans-femoral amputation were more likely to think about their amputated limb than people with a trans-tibial amputation. Forty-eight percent (48%) considered that something good had happened as a result of the amputation. Furthermore, finding positive meaning was significantly associated with more favourable physical capabilities and health ratings, lower levels of Athletic Activity Restriction and higher levels of Adjustment to Limitation. Future research and clinical implications are discussed.

### Introduction

Amputation of a limb is an irrevocable physical phenomenon that can present a plethora of physical and psychosocial challenges to the person involved. The most immediate challenge facing the person who has had an amputation is acquiring an artificial limb and becoming

proficient in its use. Consequently, the majority of research is concerned with the ensuing physical adjustment, the prosthesis and factors that impede and facilitate this adjustment process (e.g. Pohjolainen and Alaranta, 1991; Hagberg *et al.*, 1992; Pernot *et al.*, 1997; Sherman, 1997; Kent and Fyfe, 1999). In contrast to the physical aspects, the issue of what psychosocial experiences are involved in adjusting to amputation remains comparatively unresearched.

The majority of psychosocial research on the effects of lower limb amputation has almost exclusively focussed on the negative impact the event has on the person's life and well-being, e.g. depression, anxiety, grief, body image disturbances, and social discomfort (Parkes, 1972; Shukla *et al.*, 1992; Frierson and Lippman, 1987; Hill *et al.*, 1995; Rybarczyk *et al.*, 1992 and 1995; Fisher and Hanspal, 1998; Livneh *et al.*, 1999; Gallagher and MacLachlan, 1999). While this research is important for eliciting the potential sequelae to amputation, and consequently has implications for clinical and treatment purposes, there is the danger of presenting a one-sided picture of amputation as an inevitably overwhelming negative event from which the person is unlikely to recover. Recently, there has been an attempt to redress this balance by identifying factors that promote positive adjustment. Dunn (1996) examined the salutary effects of finding positive meaning in a disabling experience, being an optimist, and perceiving control over disability on self-esteem and depression after lower limb amputation. Finding positive meaning following amputation was linked to lower levels of depressive symptomatology but not to self-esteem. Furthermore, it was concluded that the most

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All correspondence to be addressed to Dr. Malcolm MacLachlan, Department of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2, Ireland. Tel: (+353) 1-6081453; Fax: (+353) 1-6712006; E-mail: mlachlan@tcd.ie

important point was construing positive meaning and not the form it took. However, the paucity of research related to positive experiences necessitates future research to enhance our understanding of what, if any, salutary effects occur after amputation and their association with adjustment.

Anecdotal evidence from limb fitting clinics and the authors' previous research using focus groups to explore amputees' experience and concerns (Gallagher and MacLachlan, 2001) indicates that people, who have had an amputation, are often curious about their amputated limb. Such curiosity is another aspect of trying to understand, and perhaps find meaning in the relationship between the "physical self" and "psychological self". However, of necessity, the majority of time spent in the prosthetist's office deals with the mechanical issues of the prosthetic fit and there is little opportunity to deal with thoughts and feelings relating to personal meanings and identity. Thus, the aim of this research was twofold. Firstly, to gain a greater understanding of what thoughts people have about their amputated limb and to investigate whether these are associated to adjustment following the amputation of a limb. Secondly, to investigate whether people consider that there are any beneficial outcomes after amputation, what these benefits might be and whether they are associated with adjustment following the amputation of a limb.

## Method

### Questionnaire

*Trinity Amputation and Prosthesis Experience Scales (TAPES)* (Gallagher and MacLachlan, 2000):

This consists of three psychosocial subscales, General Adjustment (e.g. I have adjusted to having an artificial limb), Social Adjustment (e.g. I don't mind people asking about my artificial limb) and Adjustment to Limitation (e.g. Being an amputee means that I can't do what I want to do). Each of these subscales contains five items, which are measured along a five-point rating scale (*Strongly Disagree, Disagree, Neither Agree nor Disagree, Agree, Strongly Agree*). Scores range from 5-25 with higher scores indicating greater levels of adjustment. The TAPES also contains three activity restriction subscales, Functional

Activity Restriction (e.g. walking 100 yards), Social Activity Restriction (e.g. visiting friends) and Athletic Activity Restriction (e.g. sport and recreation). Each of these activity restrictions subscales contain 4 items, which are measured along a three-point scale (*Not at All Limited, Limited a Little, Limited a Lot*). Scores range from 3-12 with higher scores being indicative of greater activity restriction. There are also three satisfaction with the prosthesis subscales, measured along a five-point scale (*Very Dissatisfied, Dissatisfied, Neither Dissatisfied nor Satisfied, Satisfied, Very Satisfied*). The Functional Satisfaction subscale contains five items (e.g. reliability) with a potential score range from 5-25. There are four items in the Aesthetic Satisfaction subscale (e.g. colour) with a potential score range from 4-20. As Weight Satisfaction contains only one item, scores in this subscale range from 1-5. Higher scores in each of the satisfaction subscales are indicative of greater satisfaction with the prosthesis. Each of the psychosocial, activity restriction and satisfaction scales demonstrate high internal reliability using Cronbach's alpha (range from .75 to .89) and good face, content, construct and predictive validity (Gallagher and MacLachlan, 2000). The TAPES also looks at the experience of phantom limb pain, stump pain, other medical problems not related to the amputation and the person's rating of their health and physical capabilities. (The TAPES is available from the authors free of charge).

### Good and Thinking Questions:

Respondents were asked two open-ended questions. The first requested information on "whether something good had happened as a result of the amputation and if so, to please describe what this was". The second question addressed "whether they ever thought about their amputated limb and if so, to describe what these thoughts were".

### Procedure

Hospital charts of potential participants attending the Limb Fitting Clinic in Cappagh National Orthopaedic Hospital, Dublin, Ireland, were reviewed. The pre-selection criteria included a requirement that the participants be at least 18 years old and have had a lower limb amputation. One hundred and eighty-four (184) patients met these inclusion criteria. A covering

letter, the questionnaire and a stamped address envelope were posted to each person. A short reminder card was sent two weeks after the initial mailing.

### Sample

Fourteen (14) people were excluded because they no longer lived at the address or were deceased. In all, 170 potential respondents constituted the sample, and of these, 104 (61%) completed the questionnaire. The characteristics of the sample are outlined in Table 1. As can be seen, the sample was predominantly male with the prevalent cause of amputation being trauma/accident. In addition, the most common type of amputation was trans-tibial.

### Statistical analysis

Initially a frequency count was performed on each of the 'good' and 'think' questions to determine how many people considered that something good had happened as a result of their amputation and how many people thought about their amputated limb. Subsequently, the

descriptive responses for these two questions were analysed thematically. Chi-square tests were employed to investigate whether there was a difference in considering that something good had happened as a result of the amputation and in thinking about the amputated limb, depending on gender, cause of amputation, type of amputation, and the experience of stump pain, phantom limb pain and other medical problems. T-tests were utilised to investigate whether differences arose depending on age, length of time with prosthesis, average daily prosthetic use, health and physical capabilities ratings, satisfaction (TAPES subscales – Functional, Aesthetic and Weight Satisfaction), activity restriction (TAPES subscales – Functional, Social and Athletic Activity Restriction) and psychosocial adjustment (TAPES subscales – General, Social and Limitation Adjustment). Only significant effects are reported here.

### Results

#### *Has anything good happened as a result of your having an artificial limb?*

Of the 104 respondents, 50 people (48%) indicated that nothing good had happened, 48 people (46%) said that something good had happened, and 6 people (6%) did not specify. All 48 people, who indicated that something good had happened, provided an explanation of the way in which they had benefited. Table 2 describes the main themes that emerged from responses, the number and percentage of times each theme emerged and relevant examples.

As illustrated in Table 2, 16 people (33% of those who considered that something good had happened as a result of the amputation) considered the *independence* that the amputation and the prosthesis gave them, as a positive benefit. Eight (8) people (17%) specified that the subsequent change in their *attitude to life* was beneficial. Nine (9) respondents considered that the amputation was *character building* (19%). Others felt that the experience had endowed them with improved *coping abilities* (6, 12.5%). Five (5) respondents (10%) referred to the direct *financial benefits*, which occurred as a result of their amputation, and a further 5 people (10%) mentioned the *elimination of pain*, which was facilitated by the amputation, as something good that had happened. While all responses referred indirectly to a *better way of life*, 4 people (8%)

Table 1. Sample characteristics.

	n	%
Gender		
Males	78	75
Females	26	25
Cause of amputation		
Congenital	7	6.7
Cancer	24	23.1
Accident	51	49.0
Other <sup>1</sup>	20	19.3
Not specified	2	1.9
Type of amputation		
Trans-tibial	54	51.9
Trans-femoral	44	42.3
Bilateral	6	5.8
	Mean (SD)	Range
Age	45.3 years (18.9)	18-84 years
Length of time with prosthesis	8.3 years (9.9)	2 months - 58.25 years
Daily prosthetic use	12.9 hours (3.88)	0-19

<sup>1</sup>Other causes include peripheral vascular disorder (n=9), diabetes, polio, infection of the bones, TB, osteomyelitis, secondary Raynards disease, and ulcers.

Table 2. Predominant themes of good things that happened as a result of the amputation.

Themes	N	%	Examples ( <i>Direct quotes in italics</i> )
Independence	16	33	<ul style="list-style-type: none"> <li>• Greater activity and mobility</li> <li>• <i>“Being able to walk without crutches”</i></li> <li>• The ability to lead a normal active life – learning to drive, returning to work and spending more time with their family</li> <li>• <i>“Without my limb I can do nothing. It has given me back some of my independence”</i></li> </ul>
Character building	9	19	<ul style="list-style-type: none"> <li>• Being happier and more content in life</li> <li>• Having an increased sense of confidence and greater sensitivity to the problems of others</li> <li>• <i>“Learning to sit and have patience”</i></li> <li>• <i>“Working harder to obtain goals”</i></li> </ul>
Attitude to life	8	17	<ul style="list-style-type: none"> <li>• Realising life is too short for worry</li> <li>• <i>“An acute appreciation of life”</i></li> <li>• <i>“To look at life and people much more clearly”</i></li> <li>• <i>“It has given me a very positive outlook on life. In fact when people meet me they are surprised how unaffected I am. I just feel that there could be a lot worse wrong with me”</i></li> </ul>
Coping abilities	6	12.5	<ul style="list-style-type: none"> <li>• Providing a tougher mental attitude</li> <li>• Being more resilient and better able to cope</li> <li>• <i>“In a sense it makes life more challenging and any problem that may arise can be overcome. It helps you to adjust”</i></li> </ul>
Financial benefits	5	10	<ul style="list-style-type: none"> <li>• Compensation from the accident</li> <li>• Exemptions on car tax</li> </ul>
Elimination of pain	5	10	<ul style="list-style-type: none"> <li>• <i>“I have not the terrible pain I had in my knee and I had very bad ulcers. I can get a night’s sleep now”</i></li> </ul>
Better way of life	4	8	<ul style="list-style-type: none"> <li>• Importance of the prosthesis in restoring normality back into life</li> <li>• <i>“Well seeing that I had cancer and if I did not have my leg amputated I would not be filling out this form. I found as a first-time user an artificial limb to be magnificent”</i></li> </ul>
Meeting people	3	6	<ul style="list-style-type: none"> <li>• Meeting people that they would not have met but for the amputation.</li> </ul>

explicitly stated that life had improved since the limb had been amputated and the prosthesis had been fitted. Finally, 3 people (6%) indicated that *meeting people* that they would not have met but for the amputation was something good that had happened.

#### **Factors associated with considering something good happened as a result of the amputation**

There was a significant difference in patients’ ratings of their health ( $t(96)=-2.69$ ,  $p<.008$ ) and

physical capabilities ( $t(96)=-2.73$ ,  $p<.008$ ) between those who did not consider that something good had happened as a result of the amputation. The health and physical capabilities ratings for those who did consider that something good had happened were (mean 3.7, SD 0.86) and (mean 3.1, SD 0.9) respectively and for those who did not consider that something good had happened (mean 3.1, SD 1.0) and (mean 2.5, SD 1.1) respectively. This indicates that those who considered that

Table 3. Predominant themes of thoughts regarding the amputated limb.

Themes	N	%	Examples ( <i>Direct quotes in italics</i> )
Activity restriction	10	18	<ul style="list-style-type: none"> <li>• <i>"All I can't do since I lost it. Doing the things I used to"</i></li> </ul>
Prosthesis	10	18	<ul style="list-style-type: none"> <li>• Wanting improvements to the design and appearance of the prosthesis</li> <li>• <i>"A more flexible foot so that it can be bent normally"</i></li> <li>• Weight, comfort and noise of the prosthesis</li> </ul>
Positive consequences	8	14	<ul style="list-style-type: none"> <li>• <i>"Good riddance to bad rubbish"</i></li> <li>• <i>". . . happy to have had it removed, as my life has changed all round"</i></li> <li>• <i>"Of course, I think about my leg because I have to put on an artificial one, but it has become a way of life and now it's just like putting on your shoes. But I only think good about my leg"</i></li> </ul>
What happened to the limb?	8	14	<ul style="list-style-type: none"> <li>• <i>"If the person who carried it away from the table had any thoughts about it"</i></li> <li>• <i>"Was it incinerated or just dumped? If it was dumped. I would have liked to have buried it myself"</i></li> <li>• Was it used in research and had it contributed to anything worthwhile?</li> </ul>
What life would have been like	8	14	<ul style="list-style-type: none"> <li>• <i>"What it would be like if the accident hadn't happened – where would I be now?"</i></li> </ul>
Missing their limb	8	14	<ul style="list-style-type: none"> <li>• <i>"Missing the sensation of both feet touching the ground when I step out of bed in the morning"</i></li> <li>• <i>"How large, complicated and beautiful the section of my leg I have lost was and how it will never return again"</i></li> <li>• <i>"How unaware of how I needed my limb I was. How precious it was and how little I valued it"</i></li> <li>• Grieving for the limb like an old friend</li> </ul>
Emotions	7	12	<ul style="list-style-type: none"> <li>• <i>"Negative thoughts each morning when the alarm goes off"</i></li> <li>• Annoyance at not being able to play sport and <i>"at a part of me being dead and buried"</i></li> <li>• Regret, helplessness and vulnerability</li> </ul>
Wishful thinking	6	11	<ul style="list-style-type: none"> <li>• Wishing that the limb was back or that the accident had not happened</li> </ul>
Why me?	4	7	<ul style="list-style-type: none"> <li>• <i>"Why me? Why do most other people have perfect limbs and seemingly perfect lives?"</i></li> </ul>
What the future holds	4	7	<ul style="list-style-type: none"> <li>• Problems that might arise with increasing age</li> </ul>
Employment	2	4	<ul style="list-style-type: none"> <li>• Difficulty in finding work as a result of the limb loss</li> </ul>
What if . . .	2	4	<ul style="list-style-type: none"> <li>• <i>"If it were nowadays – could my amputated limb have been grafted back on?"</i></li> <li>• <i>"Could they have tried harder to save it?"</i></li> </ul>

something good had happened as a result of their amputation rated their health and physical capabilities more favourably than those who did not consider that something good had happened.

There was also a significant difference ( $t(94)=-2.49$ ,  $p<.01$ ) in Athletic Activity Restriction on the TAPES between respondents who indicated that nothing good had happened as a result of losing a limb (mean 6.18, SD 1.92) and those who indicated that something good had happened (mean 5.16, SD 2.09). Furthermore, there was a significant difference ( $t(96)=-3.63$ ,  $p<.001$ ) in Adjustment to Limitation on the TAPES between those who indicated that something good had happened (mean 15.39, SD 4.04) and those who said nothing good happened (mean 12.18, SD 4.68). Thus, overall on the TAPES, respondents who indicated that something good had happened as a result of losing a limb were found to have lower levels of Athletic Activity Restriction and higher levels of Adjustment to Limitation than those who said that nothing good had happened.

#### ***Do you ever think about your amputated limb?***

Of the 104 respondents, 43 people (41%) indicated that they did not think about their amputated limb, 58 people (56%) said that they did, and 3 people (3%) failed to specify. Of the 58 people who indicated that they thought about their amputated limb, 57 gave an insight into what thoughts they had. Table 3 summarises these thoughts by identifying common themes, the number and percentage of times each theme emerged and relevant examples.

As illustrated in Table 3, a prevalent theme mentioned by 10 people (18% of those who thought about their amputated limb), related to the subsequent loss of mobility and *activity restriction*, which arose as a result of the loss of a limb. A related issue that emerged included thoughts about the *prosthesis*, which resulted from the loss of the limb (10 incidents, 18%). Many responses contained both positive and negative overtones. However, an analysis of the 57 responses revealed that 8 (14%) appeared to be solely positively based. Another prevalent theme that arose was the question, *what happened to the amputated limb?* Eight (8) occurrences (14%) of this question arose. There were also people who questioned *what life would have been like* if they had not lost a limb (8 occurrences, 14%). Eight (8) people (14%)

also indicated that they *missed* their old limb. Some thoughts about the amputated limb evoked specific *emotions* (7 occurrences, 12%). Some people also expressed a *wish* that they did not have an artificial limb, that they had their limb(s) back or that the accident had not happened (6 occurrences, 11%). Also evident in some replies was the question of "*why me?*" (4 occurrences, 7%). Other common themes that arose included a concern about *what the future held* as a result of having a limb amputated (4 incidents, 7%) and concern about *getting employment* (2 occurrences, 4%). Finally, there were a couple of "*what if*" incidents (4%).

#### ***Factors associated with thinking about the amputated limb***

The only significant association occurred with type of artificial limb. Whether a person thought about their amputated limb, differed depending on the type of artificial limb that they had ( $\chi^2(2)=8.93$ ,  $p<.01$ ). More individuals with a bilateral amputation and a trans-femoral amputation thought about their amputated limb(s) than individuals with a trans-tibial amputation (see Table 4). In this sample, 100% of people with a bilateral amputation, and 67.4% of people with a trans-femoral amputation thought about their amputated limb as compared to 46.2% of people with a trans-tibial amputation.

#### **Discussion**

This is the first study, which has investigated whether people think about their amputated limb and whether they find anything positive resulting from their amputation, in a general sample of people who have had an amputation. Forty-nine percent (49%) of the sample indicated that something good had happened as a result of their amputation. Furthermore, this was associated with more favourable health and physical capabilities ratings, higher Adjustment

Table 4. Thinking about the amputated limb and type of artificial limb.

Type of artificial limb	Do you think about your amputated limb?	
	Yes	No
Trans-tibial	46.2%	53.8%
Trans-femoral	67.4%	32.6%
Bilateral	100%	0%

to Limitation and lower Athletic Activity Restriction. Dunn (1996) reported a higher percentage (77%) of people who considered that something good had arisen from their amputation. However, her sample consisted of members of an amputee golf organisation. Their membership of this organisation may have predisposed them to have adjusted better to their amputation and to consider that something good had happened.

The present study has shown that people construct positive meanings using a variety of attributional strategies that are similar to those outlined by Dunn (1996). For example, making favourable social comparisons, re-evaluating the event as positive, redefining the amputation in one's life, finding side benefits, and imagining worse situations or forgetting negative aspects of their situation. This social comparison view (Festinger, 1954; Rosenberg and Kaplan, 1982) is based on the premise that self-concept is formed through comparisons with similar others. Taylor and Lobel (1989) have reported that engaging in downward social comparison, that is considering oneself as fortunate compared to others who have had greater misfortune, facilitates adjustment to a range of negative events. Dunn (1996) has indicated that side benefits and reappraisals of life are representative of the way in which the disability has been advantageously assimilated into the person's life. Furthermore, subordinating physical aspects relative to other values (e.g. personality) has been hypothesised to be strongly related to acceptance of disability as non-devaluating and to facilitate a positive reframing of disability (Wright, 1983). These data illustrate that finding something positive, irrespective of the form it takes, is beneficial for the person. Furthermore, it may be worthwhile for clinicians and health professionals working with people who have had a lower limb amputation to encourage individuals, who may independently attribute positive meaning to their amputation, to develop these attributions. It is also noteworthy that considering that something good had happened as a result of the amputation did not vary with gender, age, cause of amputation or type of amputation, indicating that finding positive meaning is independent of these variables.

It was found in the thematic analysis of the "think" responses, that activity restriction in

everyday activities and problems with the prosthesis were prevalent issues. This is consistent with a previous study (Gallagher and MacLachlan, 2001) that illustrated similar issues, having obtained the perspectives of individuals, who had a lower limb amputation, using focus group methodology. It is interesting that a general concern was what happened to the limb after it was amputated. This is an issue, which could be readily dealt with through simple communication procedures. Overall, the responses demonstrate that people do think about their limb and mourn the loss, which is consistent with the theory put forward by Parkes (1975). Interestingly, the more of a limb that was lost, the more likely that participants were to "think" about their amputated limb. This may refer to the fact that the more of a limb that is lost the greater is the difficulty in restoring physical functioning (e.g. Helm *et al.*, 1986; Pohjolainen and Alaranta, 1991; Hagberg *et al.*, 1992; Stewart and Jain, 1993).

Consequently, it may be easier to assimilate a trans-tibial prosthesis into one's lifestyle when it does not interfere as much as a bilateral amputation or a trans-femoral amputation. As a result, there may be less necessity to think about the amputated limb.

One of the study's most intriguing results is the association between finding something positive in the experience of amputation and being fitted with a prosthesis on one hand, and higher Adjustment to Limitation and ratings of personal health and physical capabilities, and lower Athletic Activity Restriction on the other. The design of the present study does not permit identification of the primary causal factor in this association, but it is worthy of speculation and future research. Is it the case that those with a propensity to make positive attributions achieve better adjustment post-amputation, or is it that those who adjust well post-amputation are more inclined to find something positive in their situation? A longitudinal strategy is required to resolve the issue of causality and to clarify the relationship between well-being and positive attributions post-amputation. A final note of caution refers to the sample. The sample in this study is skewed towards younger adults who have had a traumatic amputation, whereas the majority of amputations arise from peripheral vascular causes and occur primarily in the elderly (>65 years of age) (e.g. Pernot *et al.*,

1997). Furthermore, this study does not include people with an upper limb amputation. Thus, further research with larger and varying samples is also required to verify whether the findings may be generalised.

## Conclusion

Research into what promotes optimal adjustment has only recently been initiated and this is the first account of what people may think about their amputated limb. There is, therefore, great scope to expand the research in this area. For example, whether varying attributional strategies or thoughts have differing effects on adjustment. In addition, further studies are needed to explore what promotes optimal adjustment. It is important that research does not solely concentrate on the difficulties of having an artificial limb, what the person cannot do, and the problems that weigh the person down, but the challenge for meaningful adaptation and change, and the individual having abilities that have intrinsic value. The relationship between positive outcome and positive meanings attributed to amputation reflects the importance of the meaning attributed to disability. Furthermore, the use of meaning can serve as evidence that amputation and physical disability need not be envisaged as inevitably distressing or predictive of maladjustment. The condition, as seen by others, can be separated from the way it is experienced by the person. The individual's perception may have only a modest correlation with its medically defined characteristics. Finally, the degree to which it is a source of distress will depend on the individual's personal and social resources.

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