

## Coping with the loss of a leg

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### Abstract

This study sets out to examine the physical and psychological effects of amputation on marriage and family life; assess the extent to which the needs of the younger amputee are being met from current rehabilitation resources, and to ascertain how the non-disabled regard amputation and its consequences.

Interviews were conducted with a group of 19 amputees and a group of 40 non-disabled individuals within the same age range and the results are reported.

### Introduction

How do people react to sudden misfortune? There is no simple answer, since individual reactions are sufficiently varied to limit the usefulness of general rules. Our knowledge of human variation is greater for some kinds of misfortune than for others—for example, bereavement (especially loss of a spouse) has attracted much more research than loss of a limb. Yet the latter is by no means a rare event, and we would like to report some findings from a small-scale but intensive study of amputees traced through a limb fitting centre in the United Kingdom.

About 5,000 lower limb amputations are performed annually in England and Wales. The reason for most of these operations is vascular or metabolic disease, injury accounts for only 10% of cases (perhaps surprisingly), and malignant disease for only 5%. Men outnumber women by a ratio of 2: 1, and 70% of patients are older than 60 (Department of Health and Social Security, 1981). We ourselves are particularly interested in

the younger amputee, yet loss of a leg is typically a geriatric problem.

Level of amputation in the individual case is clearly a matter of clinical judgement, but the prospect of successful rehabilitation is much better when the knee joint has been conserved. The majority of amputees are given the opportunity to be fitted with an artificial limb at a specialized centre; and where a leg has been lost (much the most common form of amputation) they will usually receive training in the use of an artificial leg. The waiting period is dependent on the healing process, which is usually more complex after an accident (where there may be a delay of several months before the stump is considered sound enough to bear weight). In general, the sooner walking practice can begin the more favourable the outlook, although accident victims do at least tend to have youth on their side.

Beattie, a lecturer in psychology, has published (Beattie, 1979) a moving account of his wife's experience in losing an arm. He complained that personal factors, such as attitude to disablement and disfigurement, were virtually ignored by the attending physician in his excessive concern with mechanical factors. However, a psychologist can hardly be taken to represent the general public, least of all when married to another psychologist. Discussions with staff members soon made us aware that technical competence does not preclude sensitivity to the individual, yet equally it did not take long to find evidence of an unmet need for psychological guidance among both patients and staff. Our observations may help to put the Beatties' experience in perspective.

Interviews were conducted by one of us (LF) with 19 amputees who had responded to a postal questionnaire sent to a larger group of patients

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aged 20–60 who had lost a leg one to five years earlier but were otherwise in good health. All but four were married (or in one instance cohabiting), and their partners were also included in the home visit. None of those approached had refused to take part. Our aims were broadly threefold:

1. To look at the physical and psychological effects of amputation (which was mainly below the knee) and its impact on marriage and family life;
2. To assess how far the needs of the younger amputee were being met from current rehabilitation resources; and
3. To ascertain how the non-disabled "man in the street" (who might be the amputee of tomorrow) regarded amputation and its consequences for the individual.

For this last purpose we recruited a group of 40 married individuals within the same age range who were attending the casualty department of a teaching hospital with minor injuries. Again, all of those approached agreed to be interviewed after the nature of the project had been explained to them. Since this was an exploratory study, with few guidelines from the literature, we could not hope to rely on quantitative measures. Instead we made use of a brief structured interview but spent long enough with our subjects (usually at least two hours) to allow them to talk freely of their experience.

### **Knowledge of amputation**

How much can we expect the layman to know? We had predicted, partly on the basis of our own previous ignorance, that he or she would be poorly informed as compared with the patient's spouse. However, we were surprised to find how little these two groups differed in their level of apparent knowledge. Only in their recognition of the importance of the knee joint were the spouses of amputees better informed. Annual incidence of leg amputation was underestimated by one in two of our informants when asked to choose between four alternatives (50, 500, 5,000, 10,000). Again, four out of five thought of accidents as the main cause, and this even applied to five of the spouses of six patients with vascular disease. Similarly, the age of the average amputee was underestimated by around 40 years in each case. This was an unexpected misconception among the spouses, all of whom

had at some time visited the Limb Fitting Centre where the elderly amputee is conspicuous (and most were able to acknowledge this when reminded). But perhaps we should not have expected too much sophistication from a group who on the whole were neither scholars nor scientists. After all, there are probably not too many relatives of sick or disabled people who are inspired to learn all they can about a condition merely through personal experience of it.

### **Functional impairment**

Next, let us consider the functional limitations imposed by loss of a leg below the knee. One of us in his youth was hard put to match the skill of such a person on the tennis court, but most of our naive informants had never met an amputee. Our list of activities, mainly relating to mobility, self-care and use of transport, yielded a maximum score of 25. The mean score obtained by our amputees was 17.9, with only the more vigorous sporting pursuits reported as out of range. This fell to 12.5 when responses to the same questions were drawn from our naive informants, who were asked to imagine what the average amputee could do. Thus, as we had predicted, the naive group showed a marked tendency to exaggerate the physical handicap of losing a leg. Doubtless the public's horror of disablement springs partly from conceiving the consequences as even worse than they really are. The professional literature is of little help here since it relates primarily to the older patient whose difficulties are compounded by the ageing process if not also by concurrent illness. Loss of a limb or even part of a limb is a traumatic experience at any age, but up to the age of 60 most people in our experience seemed to have adapted to it well enough, at least from a physical standpoint.

What of the psychological effects? A good physical recovery is certainly no guarantee of a smooth personal adjustment, and we shall review the emotional aspects of amputation under the following headings: attitude to handicap, self-consciousness, and mourning of the absent limb.

### **Attitude to handicap**

To estimate the amputee's sense of misfortune, we used two techniques. First, we followed Dembo et al (1956) in asking our subjects to place themselves (with reference to

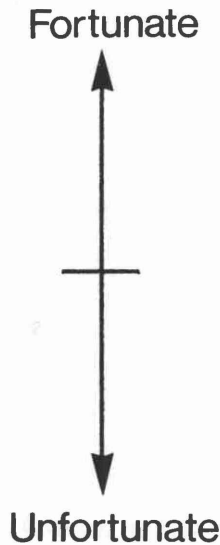


Fig. 1. Self rating scale.

the immediate present) on a vertical scale of 60mm, the top of which indicated the position of the most fortunate person in the world, while the bottom indicated the most unfortunate. The distance from the midpoint could be read off to the nearest millimetre, with scores ranging from +30 to -30 (Fig. 1). Our results are shown in the accompanying Table. Evidently the amputees thought that they would have rated themselves as only marginally more fortunate before the operation, and few saw themselves as unfortunate now.

Table 1.  
Inter-group comparison of fortune scale ratings

Group	Mean
Amputees:	
Now	20.2
Before amputation	21.4
Naive subjects:	
Self-rating	14.4
Imagined state of amputee	-5.9
Spouses:	
Self-rating	16.8

The naive group could not quite match the amputees in level of self-rated good fortune, but the striking feature was the discrepancy (as measured by a gap of 26mm) between how the amputees saw themselves and how they were seen by their non-disabled peers. The spouses' self-rating was intermediate between the two other groups. In the absence of norms from the

population at large one cannot attach too much weight to the comparison, but casual enquiry of relatives and friends suggests that most people are reluctant to declare themselves as unfortunate even in the most harrowing circumstances. Perhaps there are mechanisms of denial and self-protection that work to the disabled person's own advantage, up to a point anyway. Still, there was a statistical relationship between sense of misfortune and reported level of functional impairment.

Our second technique called for a ranking of six disabilities in order of severity: going blind, losing a leg, losing the preferred arm, becoming deaf, severe facial disfigurement, and paralysis (eg, polio). Again there was a major discrepancy between those with experience of amputation and those without it. Amputees and their spouses agreed in ranking it as the least severe handicap, whereas only blindness was rated as more severe by the naive group. Here the element of denial—or at least understatement—seems even more pronounced. But although some kinds of personal disaster may be almost too awful to contemplate, when actually faced with them many of us find that we can summon up the necessary coping strategies even without knowing how, and we may perceive others as even worse off than ourselves.

#### Self-consciousness

We tried to measure self-consciousness from a series of responses to questions on body image, anxiety about the partner's reaction, willingness to declare that one is an amputee where the fact might otherwise remain hidden, or to expose the stump in situations of varying intimacy. Where facial disfigurement was ranked first or second in severity of handicap another point was added to the score, which ranged from 0-8.

Not unexpectedly we found that heightened self-consciousness went with less belief in one's own good fortune. There was also a sex difference which carries conviction despite the small numbers. Six out of eight women but only three out of eleven men considered the change in body image as a more intrusive handicap than the impairment of function. Intuitively this makes good sense, and runs counter to the Limb Fitting Service's order of priorities—comfort, function, cosmesis. It also helps to explain the lingering dissatisfaction felt by Dr. Beattie (1979) and his wife.

That amputees may well expect to feel uneasy in their social relationships is suggested by a mismatching of attitudes expressed by amputees and naive informants. None of the latter would admit to feeling embarrassed if told by someone that he had an artificial leg, whereas a third of the amputees stated that they had met with such a reaction. In contrast, no amputee mentioned curiosity as a reaction they had ever met except from children, whereas over 80% of the naive informants said they would feel curious. Clearly there had been all too little communication between disabled and non-disabled people in this highly-charged area, and we wonder where the initiative should lie. Ought amputees to be more open about their private feelings, or should those who interact with them be more ready to overcome their own inhibitions?

The artificial limb was experienced as part of the body image by most amputees—as a friend affectionately given a pet name by at least two, but as something of a cross to bear all the same by the majority. Self-consciousness was again a major factor in certain contexts. A woman might refrain from wearing a skirt because she could not get an artificial leg to match her natural one. A student was constantly afraid that his leg would be noisy when walking through the college library or, worse still, that the foot might suddenly drop off in public. Fears of exposure and looking ridiculous had led in several instances to a restricted life style, geared to the avoidance of risk.

#### **Mourning of the absent limb**

It has been suggested that loss of a limb has something in common with loss of a loved one, and that the mourning process may follow a similar course. Anyone who has taken great care of his legs, only to have one of them removed without warning, is liable to feel cheated. Yet there was no hint of lasting depression as a response to amputation except where it happened to follow other disturbing events. The overall pattern was of initial sadness as an in-patient, giving way to optimism with physical improvement and increased confidence, though some experienced a temporary setback after discharge. Only two patients needed treatment for their depression, and both were divorced women living alone. In the same way relatively few bereaved people require anti-depressive medication, and prolonged grief reactions are

more common in those with personality problems or other major stresses.

Sometimes a short delay between accident and amputation can help the individual and partner to adapt to the loss, possibly through a process of anticipatory mourning. This was shown in the contrast between two men who were involved in road traffic accidents during late middle age. In each case there was a month's delay before a leg was amputated; but whereas the first man had already accepted his loss in advance ("I didn't feel the leg belonged to me any more"), the second despite great pain had to wait longer than he wished because his wife pleaded with him and the doctors to persist in their efforts to save the leg. When the operation was finally performed she was so distressed that she cried for a week, a fact which three years later she found hard to understand. Here it may have been the partner whose grief was more troublesome, although she claimed that her sole concern was to protect her husband in case he might be unable to cope with the loss. Doctors needed to be aware of the dynamics of human relationships in their work with prospective amputees.

#### **Factors promoting rehabilitation**

There appears to be a genuine divergence between how members of the public visualize the consequences of amputation and how amputees themselves experience the reality of it. Our interviews convey a strong impression that persistent suffering or psychological disability was rare in this series, although individuality in coping styles was marked. We can still ask, therefore, what it is that enables one person to cope better than another? Whereas the amputees themselves were inclined to think that family support had been the crucial factor in coming to terms with their new situation, their partners were more likely to lay stress on the amputee's own personality. The extent to which loss of a leg could change the victim's whole life was apt to be underestimated by partners as well as by naive informants, yet the possibility of positive change (the familiar triumph over adversity) was more easily recognised by partners and perhaps others in daily contact.

Granted that the worst effects of disablement will be overcome by a robust personality almost regardless of rehabilitation facilities, a final question is what could be done to improve existing services at limb fitting centres. At this

centre a consultant psychiatrist is available to see patients on request, eg, in the event of gross depression or other unmistakable psychopathology. We believe that a psychologist (not currently available) would also have much to contribute. Reactions to stress vary in intensity even when within the normal range; and the fact that most patients seem to get by without specialized psychological help is no argument against deploying it in selected cases.

The tendency of naive informants to overestimate the functional impairment of amputation is echoed in the finding that most of our amputees felt they had made better physical progress than they had expected. Experienced amputees may have a role in counselling recent patients and helping to promote realistic expectations, but care in their selection will need to be exercised. Thus a young woman in our series related how, two days after she had lost her leg from an accident, an unknown man "bounced" into her room and, without introducing himself, told her of all the things she would be able to do once fitted with an artificial limb. She was feeling low at the time and enquired irritably "How do you know?", to which he triumphantly retorted "Oh, I forgot to tell you, I'm an amputee too!" Any therapeutic effect had already been ruined by the total ineptitude of his unheralded approach. But,

subject to certain safeguards, volunteer counsellors might be particularly welcome in hospitals where amputees are rare and nursing staff correspondingly ill-informed. A young man whose life revolves around cars does not like to be told that he will never drive again when there is no basis for such an assertion. Amputees who have achieved a good adjustment are well placed to offer sensible guidance in straightforward cases, always provided that the patient is receptive.

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