

Adjustment to an Artificial Limb: A Qualitative Perspective

PAMELA GALLAGHER & MALCOLM
MACLACHLAN
Trinity College, Dublin, Ireland

PAMELA GALLAGHER is a research associate in the Department of Psychology, Trinity College Dublin. Her major research interests relate to disability and physical rehabilitation in general and amputee rehabilitation in particular.

MALCOLM MACLACHLAN is a senior lecturer in psychology and fellow of Trinity College Dublin. His major research interests concern the interplay between culture and health, embodiment and international aid.

ACKNOWLEDGEMENTS. We are very grateful to the Amputee Support Association which facilitated this research, and to the two anonymous reviewers for their helpful comments. We would also like to acknowledge the National Rehabilitation Board, Ireland, for their assistance in funding this research.

COMPETING INTERESTS: None declared.

ADDRESS. Correspondence should be directed to:
DR MALCOLM MACLACHLAN, Department of Psychology, Aras an Phiarsaigh, Trinity College, Dublin 2, Ireland.
[Tel. 353-1-6081453; Fax 353-1-6712006; email: mlachlan@tcd.ie]

Journal of Health Psychology
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London, Thousand Oaks and New Delhi,
[1359-1053(200101)6:1]
Vol 6(1) 85-100; 015314

Abstract

The purpose of this study was to identify factors considered to be important in the adjustment to amputation and the wearing of a prosthetic limb from the perspective of the person who has had a lower limb amputation. Hence, focus group methodology was employed as a means of acquiring perspectives within a population of young adults who had a lower limb amputation. Preliminary thematic analysis revealed that factors such as self-image, social, physical and practical concerns, the meaning attributed to and the acceptance of the amputation and support among others were important in the adjustment process. These findings have substantial implications for directing future research.

Keywords

adjustment, amputation, focus groups, prostheses

AMPUTATION of a limb refers to the loss of a portion of, or an entire limb. The amputation of a lower limb can occur at different levels (e.g. below knee or above knee), be precipitated by a variety of factors (e.g. accidents, cancer, vascular diseases), be distributed across gender and age groups and result in a large range of disabilities, both physical and psychosocial. However, although the literature describing adjustment to physical illness and disability has grown dramatically in the last two decades, relatively little of this attention has been directed towards individuals who have had an amputation.

Many challenges arise from losing a limb, most notably the process of being fitted for and learning to use a prosthetic limb. Reviews of prosthetic use for those with a lower limb amputation following discharge show that the percentages of 'successful prosthetic users' vary considerably from 46 to 96 percent (Burger, Marincek, and Isakov, 1997; Grise, Gauthier-Gagnon and Martineau, 1993; Moore et al., 1989). Other issues involved in physical adjustment include levels of functional ability (e.g. Pohjolainen, Alaranta, and Karkkainen, 1990; Uiterwijk et al., 1997), stump pain (i.e. pain in the remaining part of the limb; e.g. Davis, 1993), and phantom limb pain (i.e. pain in the part of the limb that has been amputated; e.g. Sherman, 1997). These physical aspects of amputation have received the most attention from researchers to date. This is probably because they embody the most prevalent issues that need to be immediately dealt with, that is, functional restoration and prosthetic use. However, individuals have also to make social and psychological adjustments so as to deal with the multiple issues that arise as a result of amputation and acquiring an artificial limb. Rates of clinical depression found in outpatient settings have been found to range from 21 to 35 percent (Kashani, Frank, Kashani, Wonderlich, & Reid 1983; Rybarczyk et al., 1992; Schulz, 1992; Williamson, Schulz, Bridges, & Behan, 1994). Reactions of anxiety and grief among people with amputations have also been reported (Frierson & Lippmann, 1987; Marshall, Helmes, & Deathe, 1992; Schubert, Burns, Para, & Sioson, 1992). In addition, anger, guilt and other-blame have also been found (Bhojak & Nathawat, 1988; Butler, Turkal, & Seidl, 1992; Frierson & Lippmann, 1987; Monforton,

Helmes, & Deathe, 1993). Burger and Marincek (1997) concluded that lower limb amputation severely changed the social life and free time activities of those who have had an amputation. Recent research has also shown that coping strategies, social support, social discomfort, perceived social stigma and public self-consciousness can influence the adjustment to an artificial limb (Gallagher & MacLachlan, 1999; Hill, Niven, & Knussen, 1995; Livneh, Antonak, & Gerhardt, 1999; Rybarczyk et al., 1992; Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995; Williamson, 1995; Williamson et al., 1994).

As there is a wide spectrum of physical and psychosocial responses to lower limb amputation, the emphasis of this article is on individuals who have experienced the loss of a lower limb. Furthermore, younger age has been related to more emotional distress among people with an amputation as it is difficult to adjust for those who have not yet reached an age where some degree of functional limitation may be expected (Williamson et al., 1994). It would be beneficial to document and develop a clearer picture of the adjustment process experienced by these people. Furthermore, it is important to understand the process from the person's perspective. Despite anecdotal evidence, to date there are no studies that reflect or document adjustment from the perspective of the person who has undergone the amputation. Dunn (1994), Peters (1995), and Rybarczyk, Nicholas, and Nyenhuis (1997) have called for research incorporating an 'insider perspective' on adjusting to a disability. This 'insider perspective' would include the subjective, inner world experience of the individual and lead to a richer understanding of the adjustment process. Peters (1995) argued that this could be captured by conducting qualitative research rather than relying solely on factual information and questionnaire studies.

One potential technique for exploring adjustment from the person's perspective is the use of focus group methodology. A focus group has been described by Krueger (1994) as a carefully planned discussion designed to obtain information of a qualitative nature on a defined area of interest from a predetermined and limited number of people in a permissive, non-threatening environment. It serves primarily as a means of raising issues and considerations not

included before and for generating testable hypotheses, which can be investigated by using the insights gained from the observational work. Basche's (1987) definition of focus groups is a qualitative research technique used to obtain data about feelings and opinions of small groups of participants about a given problem, experience, service, or other phenomenon. In addition, Merton (1987) describes the technique as a set of procedures for the collection and analysis of qualitative data that may help us gain an enlarged sociological and psychological understanding in any sphere of human experience. The method is particularly useful for allowing participants to generate their own questions, frames and concepts and to pursue their own priorities on their own terms, in their own vocabulary (Barbour & Kitzinger, 1999). These definitions indicate that focus groups are particularly appropriate to use when the goal is to explain how people regard the experience of amputation and wearing an artificial limb, and to determine and elicit their perceptions, feelings, thoughts, attitudes, ideas and experiences. As Morgan (1997) suggests, it is a method to acquire understanding of the participants' perspectives on the topic of interest. The intent is not to generalize findings to the whole population, but to gain a more complete understanding of a particular topic (Krueger, 1997). Indeed, Wilkinson (1998a) concludes that focus groups are an ideal method for gaining access to participants' own meanings. Focus groups possess the capacity to become more than the sum of their participants, to exhibit a synergy that individuals alone cannot achieve. As participants answer questions, the responses spark new ideas or connections from other participants. This group interaction allows for greater insight into why certain opinions are held. Furthermore, inhibitions are often relaxed in group situations. The discussion that ensues is comfortable and often enjoyable as ideas and perceptions are shared. Morgan (1997) asserts that 'the hallmark of focus groups is the explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group' (p. 12).

Focus groups have been utilized in both clinical and research settings. The impetus for using focus groups in the clinical setting has been on improving practice and quality care through

consumer input (e.g. Ivanoff, Sjostrand, Klepp, & Axelsson, 1996; Makrides, Veinot, Richard, & Allen, 1997; Meisenhemer, 1991; Peters, 1993). Focus groups have also become an important tool for applied social scientists (Stewart & Shamdasani, 1990). The approach has been used in a variety of research and evaluation settings, including developing appropriate language and questionnaires for new populations as a means of gaining patient input into the research process (e.g. Hyland, Finnis, & Irvine, 1991; McKinley, Manku-Scott, Hastings, French, & Baker, 1997; Skevington, MacArthur, & Somerset, 1997), and to help develop training programmes and needs assessment (e.g. Borkan, Reis, Hermoni, & Biderman, 1995; Carey, 1994; Carey & Smith, 1992; Halloran & Grimes, 1995; Hungin, Rubin, Russell, & Convery, 1997; Johnston & Lockyer, 1994; Mitra, 1994; Schapira, Meade, & Nattinger, 1997). Focus group methodology has also been employed to describe quality of life in different patient populations, for example, disabled elderly (Quine & Cameron, 1995), multiple sclerosis (Lyons & Meade, 1993), diabetics (Anderson et al., 1996) and breast cancer patients (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997).

Thus, the aim of this article was to describe adjustment to a lower limb prosthesis from the perspective of the prosthesis-wearer using focus groups. To date, there have been no studies where focus group methodology has been employed with individuals who have had an amputation. It is hypothesized that this research will contribute to the understanding of the dynamic and unfolding adjustment process involved in the adjustment to amputation and wearing an artificial limb.

Method

Interview guide

In order to elicit information on the person's perspective of the adjustment to amputation and an artificial limb, predetermined, open-ended questions were arranged into an interviewing guide. This was achieved by first identifying potential questions. A number of brainstorming sessions with psychologists, occupational therapists, physiotherapists, consultant in rehabilitation, prosthetists and people who have had an amputation themselves were helpful in obtaining

a range of possible questions. When the list was complete and no further suggestions could be made, the questions were carefully selected and phrased in advance to elicit the maximum amount of information. An interview guide was developed to cover the following questions.

Could you describe how you came to lose a limb?

What was your reaction on being told that you have lost a limb or that you had to have a limb amputated?

What were your expectations about having an artificial limb?

Were the expectations met? If so, in what way? If not, in what way?

Are people satisfied with their artificial limbs?

What are the most common problems that arise because of an artificial limb?

What do you find most difficult to deal with having an artificial limb?

What kind of things do you need to adjust to?

What makes adjustment easier?

What do you think could be done to help amputees adjust?

Has your limb loss affected the way you feel about yourself?

Has anything important been missed that should be included?

The same set of questions was posed for each group although not always in strictly the same order. Furthermore, there was the flexibility to explore unanticipated issues, as there is the opportunity to ask serendipitous questions, which become apparent throughout the focus group interview.

As a means of pilot-testing the focus group interview, experts who were familiar with the purpose of the study and with the participants involved in the study reviewed the questioning route. In addition, a representative of the target audience, that is a person who had had a lower limb amputation, commented on the questions. The first focus group interview also acted as a pilot. As suggested by Krueger (1994) the wording and sequencing of the questions was reexamined and as there were no major changes, the first pilot discussion was included in later analysis. Finally, comments were sought from participants at the conclusion of each focus group. They were also asked if any important issue had been omitted.

Procedure

Potential participants were contacted by a letter, which outlined the study and requested participation. Three to four days later they were contacted by telephone and were asked if they would be willing to attend. Those who agreed to participate were sent information regarding their scheduled session. Finally, each person was phoned the day before the focus group to remind them of the session, and to inquire about their intent to attend.

The group discussions took place in a room in Trinity College, Dublin.¹ Participants were seated around a table to facilitate interaction. Each group was given the same introduction where they were told how members were selected, the purpose of the study, how the data would be handled and how study results were to be used. It was also clearly stated that all comments were important and that negative comments were as important as positive ones. Permission was requested to tape record the session and to take notes. Participants were assured of anonymity. The groups lasted between one and one-and-a-half hours, by which time all participants had had adequate time to contribute their experiences to the discussion.

Sample

Focus groups were conducted until saturation point was reached, that is until no new information emerged. As required, groups of participants for each focus group were selected randomly from a mailing list compiled by the Amputee Support Association. In total, 16 people were invited to attend and 14 people actually attended (participation rate 87.5 percent). Six males and eight females participated. Five participants had an above-knee prosthesis, seven a below-knee prosthesis and two had bilateral amputations. All participants had had their prosthesis for more than five years and their ages ranged between 20 and 50 years. In total, three focus groups were conducted with four to five participants in each.

The focus groups had four to five participants in each group as it was important that they were small enough to enable everyone to share insights and have the opportunity to talk, yet large enough to provide diversity of perceptions. Furthermore, as the intent was to get more in-depth insights from a specialized audience, it

was considered that this would be best accomplished by smaller groups (Krueger, 1994). Also, smaller groups were preferable because these participants had many experiences to share about the topic of discussion.

The three focus groups conducted in this study were deemed sufficient to detect trends and patterns across the groups. As similar themes emerged in each group and since by the third group there were no new themes emerging, it was considered redundant to continue beyond this point. This was consistent with the guideline laid down by Krueger (1994), who only recommended conducting more than three groups if new themes continued to emerge at that stage. In addition, as the topic of the focus group interview related to a narrow category of people with similar backgrounds, fewer focus groups were necessary. Morse (1995) has also argued that detailed descriptions are more important than the amount of data as excess groups do not enrich the results, they simply prolong the collection and analysis of the data.

Analysis

The tapes of the discussions were transcribed verbatim. As the transcript does not reflect non-verbal communication, gestures and behavioural responses, the transcript was supplemented with some additional observational data that were obtained during the session. The goal of the analysis was to identify themes as described by the participants and to describe the range of issues and experiences within each theme.

Two analysts coded the focus group transcripts independently for recurrent themes. These themes were identified both through the analysis of individuals' narratives and through the analysis of the dynamic construction of social meaning that occurs in focus group interactions (see Wilkinson, 1998a, 1998b). Themes were identified by reviewing the transcripts and classifying the material into relevant themes by asking which were meaningful in terms of the data at hand, the related theoretical area and the research questions being asked. Subsequently, as the analysts came across a part of the transcript that was related to a theme, a label indicative of that theme was attached. This coded material may have been phrases, sentences or long exchanges between individual respondents.

The essential requirement was that the material be relevant to the particular theme with which it had been identified. This exercise required several reviews of the transcript as themes evolved. Subsequently, a 'cut-and-paste technique' was employed so that all the material relevant to a particular theme was placed together.

A 90 percent agreement between analysts was found with respect to emerging themes, suggesting reliable thematic analysis. Furthermore, focus group data were tested for reliability by comparing the responses of each focus group. As all groups mentioned similar issues, there was greater confidence in the reliability of the themes reported.

Themes

Several themes emerged from the focus group discussions ranging from the 'Initial reaction to amputation and the artificial limb' to the 'Long-term effects' of having a prosthesis. Themes referring to 'Self-image', 'Social interaction' and 'Effects on family and friends' transpired as important elements in the adjustment process. Furthermore, the importance of the aspects of 'Acceptance' and 'Support' became apparent. Finally, 'Problems with the prosthesis', the 'Physical implications' of having had an amputation and having an artificial limb and the 'Practical considerations' that someone with a prosthesis has to take into consideration on a daily basis materialized as pervasive themes. Each of these themes is described in detail below.²

Initial reaction to amputation and the artificial limb

Participants agreed that the reaction to amputation was one of devastation and distress.

You are devastated and you don't know what to think really . . . My feeling was that I wanted that night to be over. Let them do it and allow me to put the pieces of my life back together. Face it the next day kind of thing. It is very traumatic you are just devastated. It is like a dream that you go through.

One minute I was an able-bodied person and a couple of hours later I was an amputee. I didn't have much time to dwell on it.

A related issue was the discussion in each of the focus groups of the initial reaction on seeing the artificial limb for the first time.

I don't think I realized, but I thought I was getting my leg back and when I saw the prosthesis for the first time, I cried and cried. And I look back on that day and not on the day of the accident but that day as the worst day of my life and I cried and cried and cried . . .

I remember the first day he put the limb on and I remember the emotion was to start crying. It just wasn't the same. That was your immediate reaction to it you know. Subconsciously you are thinking that you are going to be put back together again.

When I saw this contraption, this big monstrosity, this metal rod. I thought I am not wearing that . . . It was terrible. There was this foot sticking out of a metal bar and this bloody big strap.

Thus, a common response to seeing the prosthesis for the first time was of extreme shock and disappointment. Furthermore, it was also generally agreed that it was an emotionally charged experience and that living with an amputation did not simply involve getting a prosthesis made and returning to a relatively unchanged life.

Self-image

Concomitant with the expressed need to deal with the physical aspect of limb loss was the awareness of the emotional adjustment involved in having an artificial limb. The loss of a limb calls into question the way in which the person perceives him- herself and the way in which the body influences self-image.

I often wondered what they did with the legs they took off. Where is one part of me gone? There is part of me gone and where is it . . . Makes you wonder what is the essence of you.

At times it used to depress me, I have to say . . . You haven't changed as a person, but physically you have changed. You have lost a part of your body.

It was also apparent from responses that the adjustment to a changed self-image evolves with time. For example, one participant described it as follows:

After it happened to me and I had got the leg, this monstrosity of a thing with hinges and everything . . . You think oh my God look at that thing. But then you start to move and you realize that you are up and moving again. Then you might have to leave it off . . . I didn't give a damn who was looking at me, I just wanted to get out and about. But now six or seven years on if I had to leave my leg off I would have a problem with it. I feel now as if I am reasonably back to normal with it. I would definitely have a problem with that alright. . . . this is how everyone knows me. Your man limps along you know but he is all there.

Some participants expressed concern about the impression they made on others. One woman described how it was impossible for her to relax, even in her own home, without her artificial limb on, in case visitors arrived unexpectedly. The wish to appear and be 'normal' was reiterated over and over. Participants placed an emphasis on the different aesthetic characteristics of the limb that were important for different people. The importance of the appearance of the limb in establishing a positive self-image was also highlighted.

I don't know whether you had limb toes. Well, this one had toes, which I use to paint. I loved it. It did look normal. Did you ever wear an elastic bandage from your limb to the knee, which makes it a little bit more normal? When it is the flesh colour it continues up and there is no big gap.

Social interaction

Many of the participants reported how they had encountered awkward situations when they told people about having an artificial limb. Reactions varied from patronization to complete shock as the following exchange among focus group participants reveals.

P1 I remember they used to be the worst moments when somebody would say something. Now, if it happens I am torn between wanting to tell them the truth and them having a heart attack when I tell them.

P2 Yeah, but I am always more comfortable if people know. I have been in so many situations for example in pubs where

people might slap my leg and say Jesus what is that. So I would be more comfortable if people knew. At the same time I don't go broadcasting it.

This exchange conveys the various reactions of people when finding out about the artificial limb and how the person who has had the amputation deals with these situations. As a result of these encounters, one individual expressed that he found meeting people awkward.

If you are in different companies you feel at a disadvantage straight away. Everyone else is normal and you are wearing the limb. That is why when I am going to places I am uneasy.

The frequent comments and jokes that people make were also alluded to (e.g. references made to Long John Silver). Some participants reported being asked what they considered to be demeaning questions regarding their capabilities (e.g. in interviews for employment). While people are sometimes joking, there are also those occasions when it is out of ignorance. Sometimes, people's reactions are hard to deal with as evident in the following interchange.

- P1 Even the very word amputation would freak them out. I used to say anything to get away from that kind of thing. That is traumatic in its own sense.
- P2 Some people didn't want to talk to you about it and others were horrified. Maybe they did not know what happened and asked you what was wrong with you. They were absolutely 'oh my God'.
- P3 I am just browned off when I am walking by people and they look down at my leg first before my face.
- P1 Yeah . . . You think you are the only one at times, there are people who are pig ignorant. They will think you are the only one as well.

This awkwardness can also extend into relationships that an individual may have.

- P1 Yeah . . . you are constantly explaining, because you do not want people to die of fright. However, you don't want to presume too much. You might never get

that far. My husband knew, and most of the guys that I went out with knew.

- P2 It does help if they kind of know the story.
- P3 It effects when you have to tell them. There is a big barrier there. You don't want to meet strange people at all. Once they get over the fact of the limb and they take it, you either accept or reject them depending on that.
- P4 I suppose it is the kind of thing you would rather wait to be asked. It is not the first thing you are going to say to someone. Then you might let it run on too long as well . . . It depends on the person as well.

Thus, having an artificial limb is an issue that can occur in the initial stages of a relationship. Participants agreed that it is difficult to explain to another person that they have an artificial limb and the situation can be facilitated if others already know about the prosthesis.

Effect on family and friends

The prevalent feeling expressed was that the effects of losing a limb were definitely worse on friends and relatives than on the person himself who had had the limb amputated. One woman described how her parents had to make the decision regarding her leg and how they have had to live with this decision, constantly wondering whether they made the right choice. Furthermore, some participants described how their family members still harboured resentment towards those who were responsible for the limb loss, while others described how family relationships also suffered.

It is tough on the people around you. Worse I thought . . . It was tough on her [girlfriend] alright and on my parents to the point that they almost fell out with each other arguing over what was best for me. I was in the bed trying to referee it. That has never really settled down you know. So it definitely has an effect.

Acceptance

Several participants equated adjustment to a bereavement process.

Psychologically, it is like a bereavement because you have lost something that is very

important to you and is precious, but once you accept it you get over it. It is a little bit like that. It is like when somebody you know dies, it takes a while to get over it. But gradually you do.

There was also the general belief that there is always somebody who is worse off than oneself. Alternatively, there are always people who are unable to perform certain activities.

There is also something which adds to more of an acceptance of it. By the time you hit the 30s or 40s, everybody has their area of weakness. You get it somewhere along the line. Everybody has something. Be it high blood pressure or if you can't have kids . . . Nobody ever escapes completely. There is always something.

The loss of their limb(s) was not considered to be the end of the world and it did not stop anybody from doing something they wanted to do.

It depends on your attitude as well. I have never let it hold me back. I have done everything that I ever wanted. My last thing is to drive. I have never let it keep me back.

In some ways I think it has given me a confidence I think I wouldn't have had. I know that if people think about me at all, which I know they probably don't, but if they do, they probably think she is great really because she got on with her life. So that gives you a bit of a confidence. You know you say to yourself, I did have this trauma in my life and I did deal with it. Maybe I am a bit of a better person for it. And I feel that I can certainly go out and hold my head up to the world and I don't feel . . . inadequate in any way.

What you do is, you adapt your life to suit it. You do it. It might look weird but it works. You get to a point where you can't not accept it.

Support

An important theme that arose in all focus groups was the need and importance of support. Those who received support described its benefits and those who did not explained why it would have been necessary.

I think initially, there should be some kind of

counselling . . . from day one. As I say, it was in, out, it was like getting a tooth out. The only counselling I got was the pilot showing me the limb. That was the only thing that helped me get my head sorted out. If I hadn't seen him, I wouldn't have known what to expect.

There was general agreement among the participants that counselling should be obligatory pre- and post-amputation. They discussed the importance of explaining the nature of the operation, the various events attendant to it, potential problems and complications to be encountered, care and treatment of the stump, what rehabilitation would involve and information about the prosthesis itself. For example, as discussed earlier, being introduced to the prosthesis for the first time could be traumatic.

Your stump is very big after the operation, so your first limb is ugly. You think is this it and people don't go to the effort of explaining to you. It is awful.

The importance of meeting and talking with other people who had undergone an amputation was also strongly advocated. It was considered very useful to have talked with somebody who had already gone through the process.

Another thing that helped was that I asked the Rehab to put me in touch with somebody my own age. When I met this girl she was very attractive. She walked in and she actually had a short skirt on and a pair of red boots on and she really looked great. The limb I had on at the time, was bulky and had a hole in the front. It was awful looking . . . So when I saw her, that helped me an awful lot.

Before I was in contact with amputees I used to say that this was really driving me nuts. It can't be like this for everyone you know. Especially if you were having bad days. But then you realize everybody goes through it.

I would have loved to have seen somebody walk into the ward and say there was life after amputation. I thought my life was over. I thought that I would never do anything again.

Talking with another person who had had an amputation offered the proof that rehabilitation was possible. It was considered more beneficial than talking exclusively to doctors who were

often unable to answer the questions that they wanted to ask. In some cases, the participants felt that the doctors were not telling them anything and were 'speaking over their heads'.

Problems with the prosthesis

One of the most prevalent issues regarding the limb itself was the expense incurred.

Once you settle down and get used to wearing it, paying for these things is the greatest hassle. We are always plugging that we should get the limbs for free that it is a basic living right. It is like a diabetic needing insulin. You can't live your life without it.

Other problems specific to the prosthesis referred to the noise it could make and the subsequent awkward situations that could arise as a result.

The noise is a good one. Occasionally, you may be walking with somebody and they will say what is that noise and if it is somebody that you don't know you are thinking: Is this the right time to tell them?

Furthermore, the reliability of the limb was considered to be of extreme importance. Most participants revealed how on occasion their respective limb broke or fell off. For example, being at a disco and the leg flying off, jumping into a swimming pool and leaving the leg behind or the limb simply breaking while walking. These incidents rendered them immobile and dependent on others around them.

It happened to me in work one day when the knee went on it. I just couldn't move. Two fellas had to carry me out into another fella's car to give me a lift home. The thing broke and you couldn't move. Recently in the house the foot went altogether.

You get more confidence if it is more secure. You don't have to worry about it. But if you think it is going to keep falling off . . .

You can't help those mechanical problems. They can throw your confidence to bits. You are relying on the strength of the limb all the time.

There is also a general difficulty in getting a limb that one is completely comfortable and satisfied with. One man described how he preferred what

would nowadays be classed as a 'wooden leg' over a more modern one, for the simple reason that he could walk on it.

No matter what you have, there is always part of yourself that wants to perfect it.

It is very frustrating. Sometimes you can get them and you can walk for miles and they will be grand. The next day you could put on the limb and it will start cutting you . . . It is the most annoying part. If you let it get in on you.

Physical implications

Pain in the amputation stump (the site of an amputation extremity) was frequently mentioned as the resulting discomfort impeded the use of the prosthesis and subsequent mobility. The most commonly reported cause of stump pain was improper prosthetic fit. Other factors elicited as affecting the stump include changes in climate (particularly hot weather) and increased activity.

My stump is very short so I can't control it very well when I am walking and that never went away . . . It wastes away so it might get to the stage where I can't control it at all. It also breaks down as well, as there is only a small area to carry all the weight.

I used to find that up until last year if I got a blister or anything I had to get crutches and stuff, but now it is grand. It is a discomfort but it is not major anymore.

The above exchange of information highlights the pervasive nature of stump pain, its varying causes and the limitation that occurs as a result.

Phantom limb pain was described as 'sharp shooting pain', 'darting pain' and 'squeezing pain'. Participants agreed that it got worse when they were tired, anxious or getting a cold or flu. However, there was variation in the frequency and duration of the pain. One man described his experience of pain as 'not so much now but at the start I used to be banging my head off the wall. The pain . . . and you could literally say it was that toe'.

Furthermore the importance of considering the other effects of illness or injury that gave rise to the amputation or which have developed independently of the cause of amputation were emphasized. For example, one woman described

how arthritis had impeded her prosthesis wearing. Another explained how her limb came off in an accident and that it was not a very clean cut. This resulted in revisions of the stump, which were particularly painful.

The importance of the good leg and how the person cannot afford to have anything happen to the good leg as the inevitable outcome would involve a wheelchair was also emphasized in the following exchange among the focus group participants.

- P1 That is one thing that struck me . . . when we get older how will it work?
- P2 Even now, if I wake up in the middle of the night, I have to think which is the least hassle hopping or putting on the leg. I have never thought of it before. Hopping was always the least hassle.
- P3 When you get older, it will probably be more of a social problem.
- P2 Yeah, if you get arthritis or something.
- P1 Yeah, oh God, yeah.
- P2 Your good leg is really your good leg. It is so important.
- P1 You just couldn't afford anything to happen to your good leg.
- P3 God forbid if any of us broke it . . . it would definitely be a wheelchair for a while.

Concern is clearly expressed for the future when the person is older and weaker and for the welfare of the remaining intact limb.

The importance of the knee joint was made evident in the following conversation. It is apparent that walking is made easier and the functional efficiency of a below-knee artificial limb is greater than that of an above-knee prosthesis.

- P1 The knees are very important in amputees. They make all the difference. Once you lose that knee, you are gone. Originally they put the knee down as a simple knee joint. It is far, far from it.
- P2 I wish I had my knee . . .
- P3 You have more control with below knee . . .

P1 It is terrific to have it . . .

Consequently, one of the most traumatic periods was the possibility of losing the knee and this fear remains constant.

The traumatic part for me was when they started talking about having to go a bit more. There was talk throughout the 12 months that at any stage that it didn't work they may have to go higher.

Practical considerations

One of the overwhelming themes to be elicited was how everyday restrictions and practical considerations were so important. This is exemplified in the following conversation.

- P1 I can't stand the snow. It is very dangerous with the leg. The ice is the problem as you could slip very easily.
- P2 You are always very nervous.
- P1 I have to be very wary of wet floors.
- P2 Yeah, you have to watch them.
- P3 Another thing is buying clothes and communal changing rooms . . .
- P2 Yes, that's an awkward thing . . . the communal changing rooms that they have in some shops.
- P4 What about wet leaves on a footpath or crossing at lights . . .

As described, participants discussed many mutual issues related to practical concerns. For example, not being able to run for a bus or wear dresses or skirts, communal changing rooms in shops, the heat, snow/ice and wet floors that make slipping easier, crossing the road and wet leaves on a footpath. This emphasizes the actual restrictions encountered by people who have had a lower limb amputation. They are simple, routine daily activities that are restricted and heighten the awareness of people who have had an amputation to their environment.

A very common problem was the difficulty in finding shoes to fit and having to have a new limb made if one wanted to wear high heels, for example.

I bought a pair of shoes in Marks and Spencers. Now they had only a tiny heel. I put

it on the right foot and thought that they were grand. I went home and I had the limb and I was beating it against the bath to try and get the shoe on and then when I put it on I was totally off balance. If I wanted to wear stiletos I would have to get a special limb made. Then I wouldn't be able to wear runners.

Other common problems encountered included taking a shower (i.e. the issue of getting in and out of the shower) and being able to get reasonable insurance to drive. Participants also discussed the weight of the leg, the perspiration caused by the socks on the stump on a warm day, and the general incapacity caused when the artificial limb was taken off for whatever reason. Another prevalent issue referred to the fear of falling. Most participants recounted stories of falls and the consequences, such as immobility, increased disability due to the use of crutches and loss of confidence.

I fell on a slippery floor and it tore a cartilage in the knee joint. I was out of action for about two months. I was back on crutches and I couldn't wear the limb. I had to go back in for surgery and that. I am fairly nervous now . . . I learnt a lesson from it as well. I take my time now and take things a bit slower. You get carried away with yourself and you forget.

The effects of these constant practical considerations are elucidated in the following comment.

No matter where I am going I plan ahead . . . You have to think of everything. I don't go anywhere without really thinking about it.

Long-term effects

Throughout the groups the fact that adjustment is a long-term process was clearly illustrated.

You have the benchmarks where you get to a stage. You go through a stage and then you are over it and you have to go through the next stage.

The hardest thing I found is that it is gone. It is not going to be back . . . That is it, just every-day before you get up, that it is gone . . . it never leaves you.

Discussion

Research involving people who have had an amputation has relied almost exclusively on

quantitative methodology, thereby largely ignoring the perspective of the person who has had the amputation. This research sought to remedy this situation by providing an opportunity for people who have had an amputation to voice their opinions. The liveliness and animation expressed by participants confirmed that the focus group discussions were socially enjoyable and an appropriate means for data collection. Participants generally enjoyed the opportunity to contribute their views, as evidenced by laughter and smiles. Participants spoke freely, joked, teased each other and continued the discussion beyond the allotted time. After the initial introductory period, participants relaxed and began asking questions of each other. These questions facilitated the sharing of experiences. In addition, participants did not appear to be fearful or deferential in voicing their objections, which implies that there was no apparent social desirability biasing in their responses. All the participants were willing to talk. As they had all worn their prostheses for at least five years, the way in which they related their accidents and subsequent adjustment was very matter of fact. Furthermore, the fact that they had had their prostheses for so long meant that they could discuss retrospectively the issues involved in adjustment, their reactions, the difficulties and problems and their methods of dealing with them.

The discussion on the importance of the knee joint reinforced the belief that it is a major determinant of a person's ability to walk. This is because using a prosthesis involves expenditure of energy that increases with more proximal level amputation (Thornhill, Jones, Brodzka, & VanBockstaele, 1986). According to Walters (1992), walking with a prosthesis requires 40 percent more energy for a below-knee prosthesis and 60 percent more energy for an above-knee amputation. The emergence of this issue is consistent with previous research (e.g. Hagberg, Berline, & Renstrom, 1992; Pohjolainen et al., 1990; Williamson, 1995), where it was clearly illustrated that a more proximal level of amputation was associated with greater activity restriction and lower levels of functional ability. This also relates to participants' concerns about their abilities when they grow older, in particular for people with above-knee amputations, as walking for the elderly with their lower

physiological reserves can be very tiring. When this is compounded by the greater energy levels required for walking with an above-knee prosthesis, there is a fear that they may not have the energy or the ability to use a prosthesis. Furthermore, the finding that concomitant diseases (e.g. arthritis was highlighted in the focus groups) may exacerbate the problem, substantiated previous research (e.g. Nissen & Newman, 1992).

The common presence of stump pain and phantom limb pain in the lives of people who have an amputation also emerged from the discussion. No matter how well fitting the prosthesis may be, their residual limb does not stay the same. It swells, shrinks, gets pimples, muscle cramps, calluses, blisters and all other afflictions of human skin. This is often compounded by abnormal skin (e.g. scar tissue). Thus the experiences varied from innocuous occurrences to occasions when the pain would inhibit prosthetic usage, highlighting the pervasive nature of this issue. The causes of stump pain were consistent with those reported in the literature (e.g. Davis, 1993). With regard to phantom limb pain, the experiences were more transient and it did not appear to interfere to a great extent in daily lifestyle.

A related theme emphasizing the importance of a reliable prosthetic limb emerged. Few studies have investigated the role of satisfaction with the prosthesis and how this may relate to adjustment. Rybarczyk et al. (1992) reported no correlation between satisfaction with the prosthesis and social discomfort. However, the frustration and uncertainty described here would seem to suggest that further investigation of the role of satisfaction with the prosthesis is warranted. In addition, satisfaction with the prosthesis was dependent on the extent to which the capabilities of the limb coincided with the person's expectations of what could be achieved (e.g. shoes/swimming). This emphasizes the importance of establishing the person's expectations when assessing prosthetic outcome.

While it is expected that the loss of a limb is physically challenging, it was interesting how the discussions emphasized the impact on everyday activities and the restrictions imposed on mundane activities (e.g. crossing the road, shopping for clothes and shoes and taking a shower). Most probably, this focus on more

mundane activities as opposed to walking, running, etc. arises from the fact that most participants had had their prosthesis for a long period of time. Consequently, they had overcome the initial challenge of learning to re-walk with a prosthesis. However, learning to deal with these practical aspects may help patients adapt to their loss, as they master the activities of daily living on which the amputation has had an adverse impact. Furthermore, it is evident that there are short- and long-term limitations in physical mobility that need to be accommodated into their lifestyle. This discussion on the practical considerations of having an artificial limb also facilitates our general understanding of everyday life for a person with an artificial limb.

It also appears from the information elicited that it may be beneficial to attend to the issue of social discomfort. Indeed, this corroborates with Rybarczyk et al.'s (1992, 1995) assertion that a potential mediator of adjustment of an artificial limb is in fact social discomfort. The attitudes of others may be disabling, affecting self-image and causing discomfort and self-consciousness. Individuals also differed in the extent to which they were concerned about the impression they made on others. Limb amputation may be more distressing for those high in public self-consciousness as suggested by Williamson (1995). They may feel that their amputation causes them to be perceived negatively by others, perhaps fearing that such negative perceptions will result in rejection. Thus, these emerging themes from the focus groups stress the importance of attending to the social discomfort experienced by people who have had an amputation since an inability to function socially often results in the prosthesis not being used to its full potential and could result in self-imposed restriction of activities.

It is a widely held belief that rehabilitation is more successful when individuals are accepting of their disability and are willing to adapt to the many changes that disability entails (Marinelli & Dell Orto, 1984). If perceived as a misfortune, disability can lead to an underestimation of existing abilities and even devaluation of the whole person. However, as delineated by the focus group discussions, it is important and beneficial to adjust one's value system such that the actual or perceived losses from the disability do not negatively affect the value of existing abilities. For example, the manner in which

participants compared themselves with others, not simply in terms of physical capabilities but more generally, and the realization that everybody is flawed in some way, may have facilitated the acceptance of disability.

As can be seen from the focus groups, in the initial stage the patient is very insecure and apprehensive so it is important to provide support, reassurance and encouragement. This may help to allay fears relating to treatment and the future. Participants seemed to benefit from contact with other people who had had an amputation, as they appeared to provide a form of positive modelling and help to promote adaptive change for the person who had experienced the limb loss. For example, being able to see and talk with someone who had a limb amputated and discover what their abilities were was important in establishing a belief that they too could achieve this. This finding is consistent with the study of MacBride, Rogers, Whyllie, and Freeman (1990) where the exchange of information was also reported as the most helpful and important part of recovery after the amputation of a limb. As evident from the focus group discussions, people with recent amputations have questions about mobility, the length of time necessary for rehabilitation, the appearance and function of the prosthesis and the possibility of participating in sports and social activities. These are real and pragmatic concerns. Consequently, every person about to have an amputation should be educated as thoroughly as possible about the upcoming process and rehabilitation. Sherman (1997) suggests that this reduces the enormous stress associated with the situation and permits the individual to use for the recovery process the great amount of energy that would otherwise be expended on responding to the stress. The therapeutic effect of reducing anxiety by giving preoperative information has been documented by Swindale (1989). Furthermore, Donohue (1997) reports that patients feel better able to cope with surgery if they understand what to expect rather than fearing the unknown. Overall, the information elicited through focus group discussions emphasized the benefits to be reaped from having the opportunity to talk with someone else who has had a lower limb amputated. Thus, people who have had an amputation may benefit from a support network where early and continued

contact with other people who have had an amputation could be established. Furthermore, the importance of involving the family and caregivers in the rehabilitation process also became apparent, as amputation has consequences not just for the individual but also for his or her family. Thus, alleviating the extra stresses that they may be experiencing will enable them to provide better care for the person who has had a limb amputated. Similarly, emerging from the focus group discussions was the need for the provision of counselling. This should extend beyond the immediate hospital stay, as there are several benchmarks to be overcome as the person becomes accustomed to living with an artificial limb. The present findings demonstrate that the adjustment process following amputation is complex and long term. Thus, it is important not simply to focus amputee care on the initial adjustment to a prosthesis, but to provide holistic care that extends beyond the immediate postoperative period. After all, prosthetic users have a lifelong need for their artificial limb and the associated issues encountered will change with the progression of years.

The information from the focus groups emphasizes that in addition to financial and practical concerns, the emotional and psychological ramifications of amputation are of vital concern. It can be seen that they mourn the loss of a visible body part and the loss of function, and the effects of the amputation on lifestyle and body image. Even when the prosthesis has been a constant and useful feature, it never truly replaces the limb. Furthermore, it is important to take into consideration that throughout the lifespan the adjustment process is constant. This is supported by Hill, Niven, Knussen, and McCreath (1995) and Pierce, Kernek, and Ambrose (1993) who found that social problems, psychological distress, pain and disability were long-term issues for people with lower limb amputations.

Finally, future larger scale qualitative studies that will allow for a greater analysis of themes and the relationships between them are recommended. In addition, the qualitative findings from this article may be applied to larger samples using quantitative methods. These focus groups could provide the information necessary to prepare for a large-scale study as quantitative procedures could be developed based on these insights as opposed to solely

testing or confirming a preconceived hypothesis or theory. They could be used to develop question wordings that correspond to the respondent's own approach to a topic and to ensure that the respondent's own thoughts and theories about a topic receive fair weight in comparison to hypotheses derived from prior theory and research. O'Brien (1993) notes that focus groups enable the researcher to identify concepts and practices central to the respondents, and to construct more appropriate items using the respondents' own words or phrases, thereby enhancing their understanding of the questions. The insights from this research could enable the development of a suitable evaluation instrument to be used to better understand the adjustment to a prosthesis by people who have had a lower limb amputation, to identify the factors related to prosthetic use and to explore relationships between the themes (see Gallagher and MacLachlan, 2000). Based on the information elicited in this study, factors such as self-image, social, medical and practical concerns, activity restriction, satisfaction with the prosthesis, the meaning attributed to and the acceptance of the amputation, and support could be investigated in greater detail using a questionnaire. The first step involved in developing a questionnaire (i.e. determining its content) has been achieved through the use of focus group methodology.

Overall, this research has contributed to a better understanding of the adjustment process faced by people who have had an amputation and are wearing a prosthetic limb. An accurate and detailed understanding of life with an artificial limb is always helpful in managing problems that arise after the loss of a lower limb and in developing successful strategies to ensure that all people who have had an amputation benefit from the use of a prosthesis. This research demonstrates the usefulness of conducting qualitative research and further research in this field to expand on the information already obtained is to be encouraged. A stronger emphasis on person-centred care should be helpful in managing problems that arise after the loss of a limb and the present data help to develop this perspective.

Notes

1. Focus groups were facilitated by the first author.
2. Unless otherwise stated, the quotes throughout the

thematic analysis are illustrative of the particular theme being discussed. Examples of actual interchanges between focus group participants are explicitly stated.

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