



MONASH University

Medicine, Nursing and Health Sciences

ADAPT

Social aspects of amputation in urban and rural Victoria

In December 2004, Professor Lenore Manderson, Professor Peter Disler and Narelle Warren from Monash University commenced a research project involving rehabilitation consultants at four centres across Victoria, on the immediate and long-term impact of lower limb amputation. They sought to gain an understanding of patients experiences of surgery and rehabilitation, i.e. what it is like to be a patient, decision making about using prosthetics, and the impact of amputation on self-esteem and social relationships, family and where applicable work. Patients perspectives were compared with those of health providers, families and friends.

What was done?

Approximately 80 men and women who were undergoing rehabilitation following the amputation of one or both legs were invited to take part in the study. Whilst they were still inpatients, 61 participants provided informed consent to be interviewed, and then completed a health and well-being questionnaire; with a follow-up interview to be completed 9 to 12 months later. To date all of the participants have completed first interviews and follow-up interviews are ongoing. A snapshot of preliminary findings on social support and adaptation to amputation, including following discharge, is presented here.

What are the findings so far?

The study involved a mostly elderly population-the average age of participants was 68 years (ranging from 21 to 91 years), with 68% aged over 65. 67% were Australian born and 72% were males. 72% had undergone a below knee amputation due to diabetes. Several participants underwent a bilateral amputation (below knee, above knee or both). Other reasons for amputation were vascular disease (18%), trauma (2%) Or cancer (1%). Often it was difficult to determine one single cause of amputation, as many participants had long-term (chronic) health problems which were complicated by other factors, such as obesity or smoking.

Data from the questionnaire showed a somewhat different story to what we learned during interviews. The data below was obtained from open-ended questions which preceded the questionnaire. As expected, whilst in-patients, participants reported that they had low levels of physical functioning; interviews showed that they understood the associated limitations as temporary and most anticipated a return to their former levels of independence in the future:

"I don't expect big things. I just want to be able to go home, walk about my home and be independent. Be able to go to the toilet and do all the little things for myself" (Shirley)

"I hope I'll be able to get out and walk around. I am hoping the main thing is that I can drive again because I really enjoy driving... I hope one day I will be walking around again like the different [amputees] you see here.

Their comments were common and were in line with the goals of the rehabilitation process and the health professionals. In contrast, social and mental function was relatively high according to questionnaires; however, interviews showed participants tended to be socially isolated. Female participants reflected more on the roles of others in their adaptation whilst men spoke more about drawing on their inner characteristics and coping strengths. For many participants, isolation was related to their age and general life circumstances, and not specifically to their amputation. For some the social isolation was because of the participant's psychological response to their amputation:

"I don't want visitors and I didn't have visitors at the hospital... I spoke with girlfriends on the phone but I really don't want them to come because I feel ashamed at the state [my - amputation] is in" (Peggy)

Some participants felt that their friends responses to their amputation contributed to their isolation:

'Friends, you know who your friends are. We probably had 15-20 or so who were good friends. Now it is probably 3 or 4... There are the 4 that you classify as your real friends and the rest are your fly-by-nighters that are great when the good times are there but not so great when the bad times hit." (Dale)

Like others, Dale's quote above was poignant given the emphasis on the importance of family and friends in adaptation.

"The fact is, right now I have got to get on [with life]. It is really hard for me to make a cup of tea, just little things like that. If I want a cup of tea, I have to ask [my wife]. It's been a big drag on her. It's more the drag on other people around me that frustrates me." (Dale)

Other's also reported that they tried to become self-sufficient and reduce the burden on their care givers:

" My husband is also old. He can't do much, but he'll do anything for me. He say's, 'even if I have to crawl to and look after you I'll do it'... I don't like to be a burden to anyone, to my children or my husband." (Doris)

Social supports provided more than just care for many participants, they also provided encouragement and reasons for perusing rehabilitation:

"For the first few days or so, I just didn't want to do [rehab]. I said to my husband I don't want to get a leg or anything, I just want to go home. He said, you have to do this yourself. I can't be there all the time to look after you. I thought well that is true and I can't just be reliant on him as he has got his own life to live." (Doris)

Such quotes pointed to the importance of having social supports for encouragement. The family and friends of many participants gave them reasons to be actively involved in rehabilitation and to obtain the highest level of mobility they could reach. It

was not only family members who provided encouragement for rehabilitation. Several participants were visited by peer-support volunteers, which positively influenced their recovery:

"[This lady] came to the ward... She showed me her leg and took it off and put it on, took it off again and put it on... She walked out and walked back and said "Have you got any question that you would like to ask me?" I said "How old are you?" She said, "I'm 86, nearly 87." I said, "You bloody well amaze me." "You will be like this" she said "if you keep trying hard"...If she hadn't taken her leg off, I would have reckoned she was putting one over me. It's just a matter of being determined and patient." (Eddie)

What does this mean for Limbs 4 Life?

This study emphasised the importance of social support for people who have recently undergone an amputation. This support appears in a number of guises-partner, child, friend, acquaintance, health professional, or peer support volunteer-and serves a range of functions, including: from encouragement and inspiration through to day-to-day business of getting on with life. Several participants had spoken with peer support volunteers around the time of their amputation and described these visits as providing a unique form of support that they were unable to get from any other source.

Those that hadn't experienced a peer support visit sometimes had unanswered questions, and would have liked that contact with another amputee. Peer support alleviated the fears that accompanied the amputation and responded to the worries and concerns of participants.

In this way peer support volunteers have an essential role in adaptation to amputation. Ultimately most people facing, or having recently undergone, an amputation, gain benefits from such visits. The presence and values of peer support organisations and services should be emphasised during rehabilitation and at follow-up appointments. Participation and involvement in advocacy groups such as Limbs 4 Life is a step towards allowing this practice to become more widespread and readily available.

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