

# Therapeutic Influences on the Upper-Limb Amputee

■ Ruth M. Morris, LMSW

## Abstract

Upper-limb amputees have a unique set of needs and issues they will encounter over a lifetime. Some of the unique issues upper-limb amputees encounter are self-esteem and body-image concerns, the impact on appearance and to social abilities, secondary post-traumatic adjustments for the majority of traumatic injury patients, and feelings of isolation from other amputees, among other concerns. A thorough understanding of the issues facing upper-limb amputees will assist prosthetists, technicians, and other professionals involved in rehabilitative care in providing comprehensive services and ultimately impacting prosthetic success. This exploratory study addresses both quantitative and qualitative data demonstrating psychological implications that impact the overall prosthetic treatment process and, ultimately, patient success. A review of literature of therapeutic influence on many conditions will be adapted to address the needs and issues of the upper-limb amputee population. A proposal for the development of a preliminary assessment instrument and resources will be gathered with an overview of evidence-based practices that will provide practitioners with the tools needed to attend to the exclusive needs of this population. An overview of the psychological impact of amputation and the various ways issues may manifest in the rehabilitative process will enlighten all care professionals involved to provide appropriate treatment and collaboration among disciplines.

## Introduction

Given that there are approximately 1,908 upper-limb amputations a year versus 56,912 lower-limb amputations, there is a much smaller group of upper-limb amputees. Since the causes of amputation also vary greatly between lower and upper extremities, services and resources must appropriately reflect the diverse needs of the amputee population. There are many psychosocial and adjustment issues that may affect all amputees regardless of their amputation level. However, though there is some overlap, how the issues impact upper- versus lower-limb

*Some of the unique issues upper-limb amputees encounter are self-esteem and body-image concerns, the impact of appearance and social abilities, secondary post-traumatic adjustments for the majority of traumatic injury patients, and feeling isolated from other upper amputees....*

amputees may vary as well since there are some particular issues that primarily impact upper-limb amputees. Just as socket design and physical or occupational therapy is guided by the amputation level, so are many of the other support services that enable patients to adjust to limb loss and become successful prosthetic users if they choose to use a prosthesis. Some of the unique issues upper-limb amputees encounter are self-esteem and body-image concerns, the impact on appearance and to social abilities, secondary post-traumatic adjustments for the majority of traumatic injury patients, and feeling isolated from other upper-limb amputees, among other concerns.

## Demographics of Upper-Limb Amputees

The biggest etiology of upper-limb amputations is traumatic injury (Adams et al., 1999). In comparison to lower-limb amputations, only a small percentage are from the effect of tumors or disease.<sup>1</sup> As with any progressive disease, the patient often has some time to prepare for the possibility of amputation. Traumatic injury presents several unique issues that often add a layer to the presenting issues. Additionally, more congenital limb loss occurs within the upper-limb population.<sup>1,2</sup>

## Unique Issues Experienced by Upper-Limb Amputees

Due to the small size of the upper-limb population, it is often noted that upper-limb amputees feel isolated from their peers. Many may attend local support groups in hopes of meeting another upper-limb amputee and fail to do so, or they may request a peer visit and not have the opportunity to speak with someone of the same amputation level. Due to the vast gap



in size between the two groups, most of the literature and resources available for amputees are unintentionally focused on lower-limb concerns. Since upper-limb amputees are looking for resources and information specific to their questions, it can become disheartening to reach out and find no answers.

All amputees experience the restructuring of how they view themselves post-amputation. Compounded by the inability to completely conceal a hand prosthesis or a missing limb, upper-limb amputees have the unique situation of constantly having their physical difference exposed. Body-image issues impact upper-limb amputees in a different way since hands are quite visible in day-to-day life and hold cultural significance as well. It is standard practice in Western culture to extend the right hand to shake hands and to display wedding rings on the left hand. Having to alter how they participate in these cultural practices may be a reminder of the loss they have experienced and may open them up to discrimination and feeling stigmatized by society. Bilateral arm amputees are even more impacted by this since people are not sure how to shake their hands or prostheses. Although individuals with disabilities—regardless of the type of disability—are confronted daily with the positive and negative impact of their abilities, there are certain ramifications when individuals

*Unlike lower-limb patients, when upper-limb amputees lose their dominant side, they essentially have to relearn how to do even the simplest tasks.*

can never choose to feel invisible or take a break from their difference. Even positive attention focused on how they are able to operate within their disability can be emotionally taxing over time.

Functionality of tasks is impacted by the loss of an upper limb. The varying grasping patterns and dexterity abilities of the human hand can be difficult to replace. Many daily activities are eased by having two hands to perform the task. Depending upon the level of amputation, other sustaining injuries, and prosthetic options available, learning to perform certain tasks can be a long process requiring intense occupational therapy. Unlike lower-limb patients, when upper-limb amputees lose their dominant side, they essentially have to relearn how to do even the simplest tasks. The loss of the dominant hand can have a profound impact since it alters ways in which upper-limb amputees may have identified themselves, such as their

handwriting, playing an instrument, drawing, painting, or cooking. During the relearning phase, upper-limb functional activities may have a bigger learning curve than lower-limb mobility activities. Furthermore, there are an unlimited number of tasks in which hand movement is used, adding to the complexity of the limb loss.

Along with traumatic injuries come particular issues that impact many affected by upper-limb amputation. Often persons may experience symptoms of post-traumatic stress disorder (PTSD). This may manifest in the individual through recurring nightmares or flashbacks of the accident, avoidance of the topic, emotional numbing, or the development of hyperarousal. Forgoing treatment of PTSD can impact whether amputees choose to wear a prosthesis and their ability to be successful prosthetic users. Additionally, phantom limb pain can also impact individuals to the point of impeding their ability to cope with their limb loss and progress in

*The reputation of upper-limb amputees for rejecting prosthetic devices at a high rate provokes the question of what resources are needed to enable them to cope with their limb loss and ultimately cope with their prosthesis.*

rehabilitation.

## Review of the Existing Literature

At this time the author was unable to identify any existing research solely focusing on the psychosocial issues impacting upper-limb amputees. Out of 11 studies addressing upper- and lower-limb amputees together, the sample size of upper-limb amputees used is much smaller. Although there are proportionately fewer upper-limb amputees, the sample sizes used do not reflect the entire population. The studies ranged from interviewing four upper-limb versus 90 lower-limb participants<sup>3</sup> to interviewing 97.4 percent lower-limb patients versus 2.6 percent upper-limb patients.<sup>4</sup> Additionally, most studies included below-elbow participants and occasionally an above-elbow participant. Many of the studies encompassed the various levels of lower-limb amputation as well as lower bilateral patients.

Previous studies support that emotional adjustment takes longer for upper-limb amputees and those who have had a traumatic accident, many of whom are upper-limb amputees. Likewise, a study by Price and Fisher<sup>5</sup> supports both upper-limb and traumatic amputees as being the most emotionally affected.<sup>6, 7</sup> The literature reviewed did not expound upon causes or specific concerns leading to this deduction.

It was noted that in more than one article, issues specific to lower-limb amputees such as mobility and gait analysis were addressed. In the Nicholas et al.<sup>3</sup> study reviewed, there were

no paralleling functionality issues addressed with the upper-limb sample. Several questions referred to lower limb-specific activities such as buying shoes, buying pants, going out despite the weather, rehabilitation training of climbing stairs, walking on an inclined plane, and vehicle transfers. Several studies solely evaluating leg amputees examined in detail everyday functioning skills such as walking, biking, and driving.

An interesting conclusion in the study of coping strategies by Gallagher and MacLachlan<sup>8</sup> supports that “patients who express dissatisfaction with their prostheses may be doing so as a form of denial or as an excuse for an inability to cope with the prosthesis.” The reputation of upper-limb amputees for rejecting prosthetic devices at a high rate provokes the question of what resources are needed to enable them to cope with their limb loss and ultimately cope with their prosthesis.

Several studies support existing theories that body image perception and mourning the loss of a limb impact adjustment.<sup>9, 10</sup>

Included in the literature concentrating on lower-limb presentation, many studies support the loss of independence in mobility and inability to perform enjoyed activities as factors in adjustment.<sup>11</sup> Body image, perceived social stigma, and social support were issues that repeatedly surfaced in various studies as well. In a study by Rybarczyk et al.,<sup>12</sup> several scales were developed to measure the psychosocial adjustment to leg amputation. The findings led to the conclusion that mental health professionals need to be involved in the care of this population in addition to a screening tool being available to routinely address psychological adjustment.

## Comparison with Other Disciplines

A cursory review of literature of related disciplines demonstrates the methods in which similar fields have identified issues and developed resources in response to those issues. Fields such as vision loss, physical disabilities, diabetes, and muscular dystrophy, which have some overlapping psychosocial issues, were reviewed. Several studies utilized focus groups to identify common issues among the population as was done in the Owsley et al. study of age-related macular degeneration.<sup>16</sup> Based upon several studies, the diabetes field has begun to develop programs and educational models to promote healthy coping.<sup>17</sup> Among the resources in place are patient psychoeducational classes, support groups, and family therapy. Many articles also promote training and support programs for families to address their own adjustment and that of the patient.<sup>18</sup> Furthermore, several studies in each of these fields also support the conclusion that an interdisciplinary team is necessary to meet all of the patient’s needs.

## Need for Further Research

At this time, the needs of upper-limb amputees have not thoroughly been studied to address the specific nuances of the reha-

bilitative process. A longitudinal study with a large sample size in proportion to the overall number of upper-limb amputees is proposed to further identify the specific issues. Specific questions need to address functionality and day-to-day issues impacted by the loss of an arm and how this interplays with other issues such as body image, perceived stigma, and acceptance. Particular attention also needs to be directed to evaluating bilateral upper-limb amputees in regard to any variations in how these issues impact them. Also needed is a thorough study of the many levels of upper-limb amputation from the loss of fingers to the shoulder disarticulation level. Centered upon the results of the survey, a screening evaluation tool to determine the coping and acceptance of upper-limb amputees would be helpful. Based upon the development and administration of this tool, upper-limb amputees can be referred to appropriate services as needed. Additional service models can be developed to address the identified needs where they are not currently met. Opportunities to study the effect of addressing the psychosocial issues on prosthetic success would also be possible in future studies, in addition to the role and specific coping issues of family members. This tool will be helpful for those professionals who may not work exclusively with upper-limb amputees and who may otherwise overlook the many ways in which an upper-limb loss impacts the individual. Though several studies have found that upper-limb patients have a higher rate of emotional disturbance, no evidence points to what specific issues would address the emotional disturbance. In conclusion, there are many opportunities to evaluate the specific needs of upper-limb amputees in order to best develop tools and resources for ultimate patient success. As new technologies and advancements in upper-limb prosthetic options emerge, so must the support systems to enable and empower patients for success.

## References

1. Dillingham, T.R.; Pezzin, L.E.; MacKenzie; E J. "Limb Amputation and Limb Deficiency: Epidemiology and Recent Trends in the United States." *Southern Medical Journal*, 2002; 95: 875-83.
2. Adams, P.F., et al. "Current Estimates from the National Health Interview Survey," 1996. *Vital and Health Statistics* 1999; 10:200.
3. Nicholas, J.J.; Robinson, L.R.; Schulz, R.; et al. "Problems Experienced and Perceived by Prosthetic Patients." *Journal of Prosthetics and Orthotics* 1993, 5:16.
4. Phelps, L.F.; Williams, R.M.; Raichle, K.A.; et al. "The Importance of Cognitive Processing Adjustment in the 1<sup>st</sup> Year Following Amputation." *Rehabilitation Psychology* 2008, 53:28-38.
5. Price, E.M.; Fisher, K. "How Does Counseling Help People with Amputation?" *Journal of Prosthetics and Orthotics* 2002, 14:102.

6. Price, E.M.; Fisher, K. "Additional Studies of the Emotional Needs of Amputees." *Journal of Prosthetics and Orthotics* 2005, 17:52.
7. Price, E.M.; Fisher, K. "Further Study of the Emotional Needs of Amputees." *Journal of Prosthetics and Orthotics* 2007, 19:106.
8. Gallagher, P.; MacLachlan, M. "Psychological Adjustment and Coping in Adults with Prosthetic Limbs." *Behavioral Medicine* 1999, 25:117.
9. Maguire, P.; Parkes, C.M. "Surgery and Loss of Body Parts." *BMJ* 1998, 316:1086-1088.
10. Andersson, M.; Deighan, F. *Coping Strategies in Conjunction with Amputation*. Division for Health and Caring Sciences, Karlstads University, 2006.
11. Walters, J. "Coping with Leg Amputation." *American Journal of Nursing* 1981, 81:1349-1352.
12. Rybarczyk, B.; Nyenhuis, D.L.; Nicholas, J.J.; et al. "Body Image, Perceived Social Stigma, and the Prediction of Psychosocial Adjustment to Leg Amputation." *Rehabilitation Psychology* 1995, 40:95-110.
13. Bosmans, J.C.; Suurmeijer, T.P.B.M.; Hulsink, M.; et al. "Amputation, Phantom Pain and Subjective Well-being: A Qualitative Study." *International Journal of Rehabilitation* 2007, 30:1-8.
14. Isken, T.; Ege, O.; Gucer, K.; et al. "A Preliminary Report: Evaluation of the Psychiatric Status of Patients Who Had Undergone Major Amputation because of High-voltage Electrical Burns." *Journal of Burn Care & Research* 2007, 28:930.
15. Manson, M.P.; Devins, G.V. "Some Psychological Findings in the Rehabilitation of Amputees." *Journal of Clinical Psychology* 2006, 9:65-66.
16. Owsley, C.; McGwin, G.; Scilley, K.; et al. "Focus Groups with Persons Who Have Age-related Macular Degeneration: Emotional Issues." *Psychological Aspects of Disability*, 2006, 51:23-29.
17. Fisher, E.B.; Thorpe, C.T.; DeVellis, B.M.; DeVellis, R.F. "Healthy Coping, Negative Emotions, and Diabetes Management: A Systematic Review and Appraisal." *The Diabetes Educator* 2007, 33:1080.
18. Wilson, S.; Engel, J.M.; Ciol, M.A.; Jensen, M.P. "Perceived Social Support, Psychological Adjustment, and Functional Ability in Youths with Physical Disabilities." *Rehabilitation Psychology* 2006, 51:322-330.

Ruth M. Morris, LMSW, is affiliated with Advanced Arm Dynamics Southwest Center of Excellence, Irving, Texas. Send correspondence to Ruth M. Morris, LMSW; 3501 North Macarthur Boulevard, Suite 650; Irving, TX 75062; e-mail: rmorris@armdynamics.com

