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Amputation, or the loss of a limb or portion of a limb, is estimated to affect two million people in the United States (Ziegler-Graham, MacKenzie, Ephraim, Travison, & Brookmeyer, 2008). It is widely known that upper limb loss is less prevalent than lower limb loss. Lower limb loss has been estimated to be 15 to 40 times more common. While over half of lower limb cases are the result of dysvascular disease, 70% or more of upper limb amputations are due to trauma-related causes (Dillingham, Pezzin, & MacKenzie, 2002; Ziegler-Graham et al., 2008). A small percentage of people who seek upper limb prosthetic rehabilitation were born with a congenital limb difference, such as a shortened arm or the absence of a hand or fingers (Makhoul, Goldstein, Smolkin, & Magnus, 2003).

Levels of upper limb amputation range from the tips of the fingers to above the shoulder, and presentations of the residual limb are diverse and often unique. This niche patient population is best served by a team of clinicians specializing in upper limb prosthetic rehabilitation. Key considerations for optimal care include recognizing the significance of the hand in daily life, providing an array of prosthetic options and components, integrating occupational/physical therapy interventions into each phase of prosthetic rehabilitation, and providing resources and support for lifelong prosthetic care. The content of this article informs and supports life care planners in developing more effective plans for people with upper limb amputation or congenital limb difference.

Challenges with Upper Limb Loss and Prosthetics

Beyond the relative infrequency of upper limb loss, this level of amputation presents unique challenges to the individual, their family and the care team. Its traumatic nature is often unpredictable and can necessitate the involvement of multiple disciplines to

address concomitant injuries, posttraumatic stress symptoms, and other complications. Additionally, in the cortical homunculus; or the brain's physical representation of the human body; a disproportionately large area of the cortex is dedicated to the hands (Cunningham & Arends, 2016; Penfield & Boldrey, 1937). This is due in part to the importance of fine motor skills and the extensive innervation in the upper limb. The hands and arms are muscle-rich, and their loss means a loss of the complex and primary means of interaction with the environment and the ability to care for oneself.

If a person with upper limb loss or congenital limb difference elects to pursue prosthetic care, considerations are different from someone with a lower limb loss (Cordella et al., 2016). An upper limb prosthesis can be more difficult to hide under clothing, especially when the wearer is interacting with others or gesturing during communication. As an individual engages in activities throughout the day, the person may be responsible for lifting, carrying, pulling, and pushing objects. These actions require the prosthesis to be securely suspended on the residual limb, without the benefits of the weight-bearing nature of walking or running.

Additional considerations include the variety of upper limb prosthetic options and componentry, the unique capabilities of each option, and the need for device-specific training to enable the user to be successful. Lastly, due to the high ratio of lower to upper limb loss cases, prosthetic providers often focus on lower limb care and rarely provide upper limb care. These factors make collaboration with upper limb prosthetic specialists valuable when working with this limited patient population.

Upper Extremity Amputation Rehabilitation

In 2014, the Department of Veterans Affairs and the Department of Defense formulated the Clinical Practice Guideline (CPG) for the Management of Upper Extremity Amputation Rehabilitation (The Management of Upper Extremity Amputation Rehabilitation Working Group, 2014). In this comprehensive resource, publications in the field of upper limb amputation rehabilitation were reviewed and recommendations for care were developed. The framework for rehabilitation and management of patients with upper limb amputation is categorized into four phases that may overlap to accommodate a patient's recovery process. The four phases are perioperative, pre-prosthetic, prosthetic training, and lifelong care. Throughout each phase of rehabilitation, the importance of an interdisciplinary care team cannot be understated. The team is led by a physician with specialized knowledge in upper limb amputation care, and made up of individuals from multiple disciplines including medical, surgical, case management, psychological, rehabilitation, and prosthetic. Each team member lends their expertise, while focusing on the

patient to provide the highest quality holistic care and maximize outcomes following upper limb amputation.

The Perioperative Phase

The perioperative phase of rehabilitation begins when the patient has undergone an upper extremity amputation, or the decision has been made to proceed with an amputation. Due to the traumatic nature of upper limb loss, many cases require urgent care. However, all surgical decisions should be based on standards of care that would result in the highest level of postsurgical functional outcome.

When possible, consulting and collaborating with other members of the care team; for example, the prosthetist; can contribute to the discussion of an amputation that could optimize the residual limb for function with or without a prosthesis. These conversations may also involve emerging and advanced surgical techniques. These include targeted muscle reinnervation (TMR) for potential improved neuroma pain or prosthetic control, or bone procedures, such as angulation osteotomy to assist with prosthetic suspension and rotational stability (Cheesborough, Smith, Kuiken, & Dumanian, 2015).

The perioperative phase also encompasses post-operative recovery, including assessment of the individual's functional level, and informing the person about the role of care team members, overuse syndromes, wound healing, and safety. This education should be reinforced at each phase of rehabilitation. Pain management is also crucial, as most people with limb loss experience one or more types of amputation-related pain, such as phantom pain, residual limb pain, or back pain (Ephraim, Wegener, MacKenzie, Dillingham, & Pezzin, 2005).

For people with upper limb loss, starting rehabilitation may enhance their range of motion, strength, and endurance; and address functional independence. An occupational therapist can provide support and training for maximizing independence

Nursing Diagnoses To Consider

1) Impaired physical mobility (Domain 4, Activity/Rest, Class 2, Activity/Exercise)

- 2) Dressing self-care deficit (Domain 4, Activity/Rest, Class 5, Self-Care)
- 3) Risk for situational low selfesteem (Domain 6, Self-Perception, Class 2, Self-Esteem)
- 4) Disturbed body image (Domain 6, Self-Perception, Class 3, Body Image)

5) Ineffective sexuality pattern (Domain 8, Sexuality, Class 2, Sexual Function)

in activities of daily living (ADLs). The first treatment sessions should focus on basic ADLs, such as self-feeding, oral hygiene, and toilet hygiene, to help the individual reduce feelings of helplessness by improving selfsufficiency (Smurr et al., 2009). This can involve assessment for appropriate durable medical equipment (DME), hand dominance training, and learning one-handed techniques. Throughout all activity, the patient should be encouraged to use good body mechanics and sound posture, and educated on the increased risk of cumulative trauma and overuse injuries that persons with an amputation face (Biddiss & Chau, 2007a).

Individuals with various etiologies of limb loss have been reported to experience symptoms of depression and anxiety at higher rates than the general population (Darnal et al., 2005). Because these challenges can negatively affect the rehabilitation process in chronic conditions, it is crucial to provide psychosocial support to patients. This can include referral to a psychologist, and connection to amputee support groups and other individuals who have gone through similar situations. Additional resources pertaining to upper limb loss and prosthetic rehabilitation can be found

Figure 1. Care Team Prosthetic Options



Figure 1. A comprehensive assessment for prosthetic care involves communication between the person with limb loss and members of the care team. (*Photo courtesy of Advanced Arm Dynamics.*)

at the Amputee Coalition website, <u>http://www.amputee-coalition.org</u> and the Advanced Arm Dynamics website, <u>http://armdynamics.com.</u>

The care team also begins to provide education on prosthetic options, which helps transition the person into the next phase of rehabilitation (see Figure 1).

The Pre-Prosthetic Phase

In the pre-prosthetic phase, interventions started perioperatively are continued as needed and the patient begins to explore prosthetic fitting. This commences with a comprehensive assessment with the care team to determine the most appropriate prosthetic option(s) to prescribe. Factors determining the options that are appropriate for an individual include: patient presentation, goals, motivation, cognitive ability, priorities, social support, and functional and vocational requirements.

Although it is not possible to replace all the functions of a missing upper limb, a prosthesis can be a tool the person uses to help achieve various goals, including function, comfort, protection, suspension, cosmesis, and ease of use. Each person's goals and priorities are different so it is important to gather information about their objectives during the evaluation, and set accurate expectations for the capabilities of the prosthesis. This helps reduce the risk of prosthesis rejection (Biddiss & Chau, 2007b).

Prosthetic Options

There are a range of prosthetic options, and the individual should be made aware of each so they understand what is available, and why they may or may not be a candidate (Bowers, 2014). Following education and evaluation, the person may decide not to proceed with prosthetic care at that time, or may decide that multiple prosthetic options would be most beneficial.

The first option is one all people with limb loss are familiar with, *no prosthesis*. While this means the person has the potential to retain sensation and does not have the added burden of device maintenance, this option can result in limited grasp and function in bimanual activities, which can also increase the potential for overuse injuries. For individuals with a sensitive or an insensate residual limb, not wearing a prosthesis can expose the person to environmental hazards.

Passive prostheses have no active moving parts and are usually designed to be lightweight, with a finish that restores the appearance, the useful length, and surface area of the limb or finger. Passive prostheses are relatively low maintenance when used appropriately and can contribute to a positive body image. While passive devices can be used to assist in stabilizing objects during tasks, they tend to have limited grasp and function.

Body-powered prostheses are durable devices that can be used in a variety of environments. However, they require a restrictive harness for control, and the grip force exerted by the terminal device is dependent on rubber bands whose tension must be overcome by movement of the remaining joints and musculature. This design has a limited functional envelope due to the harness and cables, and can also be difficult to control for people with high level amputations. The mechanical appearance of these devices may not appeal to someone who considers cosmesis (natural/lifelike appearance) to be an important goal.

Electrically powered prostheses are devices that are powered by battery sources and use components that can move actively through muscle signals or other inputs. There are multiple factors that will influence the clinical team to recommend an electrically powered prosthesis. These factors are diverse, and include therapeutic screening, psychological screening, physiological screening, precise measurements to determine what types of control inputs are ideal, and what types of components fit best with the person's unique presentation. An electrically powered prosthesis may eliminate the need for a harness or enable the use of a reduced harness. This creates a wider functional envelope for using the prosthesis and more stable grasp than other options. Advanced electric hands can imitate multiple grasp patterns to more closely approximate

human prehension, and allow for better efficiency and body mechanics during functional activities. The prosthesis can be covered with a cosmetic glove or custom silicone for people who prefer cosmesis. Clear gloves and black gloves are popular options for those who like the high-tech appearance of advanced electric hands.

Hybrid prostheses combine two or more prosthetic designs and can be helpful for individuals with high level amputations requiring multiple components (Billock, 1985). For example, a transhumeral prosthesis may combine a body-powered elbow with an electrically powered wrist rotator and terminal devices.

Lastly, activity-specific prostheses are designed for specific tasks that are important to the person, but hard to achieve with other options. These devices are often designed for use in sports, recreation, and hobbies; but may also include work-related tasks such as using hand tools (Edge, 2015) (see Figure 2).

Determining Prosthetic Costs

The best method for determining accurate costs related to upper limb prosthetic rehabilitation is for the nurse case manager or life care planner to partner with an experienced team of upper limb prosthetic specialists. This team will analyze the unique goals, needs and functional requirements of each client, and determine which of the previously described prosthetic options are most applicable. They will work with the client to select appropriate prosthetic components, such as fingers, terminal devices, wrist units and elbow units.

This careful analysis of the person's needs will ultimately lead to the development of clear and accurate pricing. In the United States, coding and pricing are currently based on a somewhat archaic Medicare Heathcare **Common Procedure Coding System** (HCPCS) that has not made frequent or timely updates in coding and pricing options to reflect the level of treatments, technologies, and material science that is available to the modern upper limb prosthetic patient (Fairley, 2008; Phillips Otto, 2008). For this reason, coding and pricing vary widely depending on the provider. As it relates to establishing accurate cost estimates, it is most advantageous for the nurse case manager or life care planner to create a meaningful working partnership with a trusted and experienced specialist in

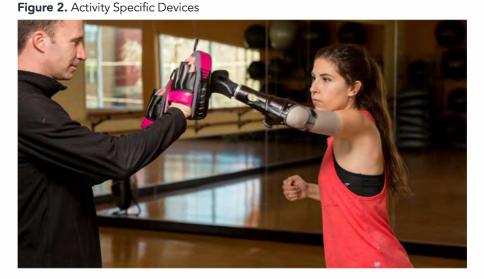


Figure 2. An activity-specific prosthesis enables a person with limb loss to achieve certain goals that a daily prosthesis may not be able to accomplish. (*Photo courtesy of Advanced Arm Dynamics.*)

comprehensive upper limb prosthetic rehabilitation.

The Prosthetic Training Phase

The prosthetic training phase begins when the patient is fitted with a prosthesis and is ready to learn how to wear and use it. In many cases, the first device that a person receives is a preparatory prosthesis. The use of a preparatory prosthesis has been standard practice for decades to prepare, evaluate, and train new users (Brenner & Brenner, 2008). It is made of materials that allow the prosthetist to make modifications in response to issues that may arise as a person progresses through prosthetic training. These can include changes in limb volume, or irritation or discomfort with increased wear time, or participation in dynamic activities.

In an ideal situation, the prosthesis user works with an occupational or physical therapist who is trained in upper limb prosthetics. Training begins immediately after fitting of the prosthesis regardless of whether it is a preparatory or definitive device. The initial stage of training involves familiarizing the person with the components and operation of the new device, and independence with putting on and taking off the prosthesis. With a new device, a wear schedule is encouraged to promote a gradual increase in limb tolerance, and to reduce the risk of skin irritation or breakdown.

Prior to engaging in functional, multistepped tasks, the person will first learn how to operate the individual components of the prosthesis in space before progressing to training tasks to improve consistency in control. The prospective user is also trained in optimal use of the prosthesis to complete tasks efficiently, avoid frustration, and minimize compensatory body movements. This is especially important for new users, as these individuals have often adapted to one-handed living and must now create new motor patterns to complete

Figure 3. Training



Figure 3. Training begins with familiarization of components and progresses to prosthetic usage in functional tasks. (Photo courtesy of Advanced Arm Dynamics.)

ADLs bimanually with a prosthesis. Additionally, the person must learn to rely on visual feedback while using the prosthesis due to the device's lack of sensory feedback (see Figure 3). As controls training progresses, the therapist introduces functional tasks that are meaningful to the individual (see Figure 4).

Figure 4. Training Progression

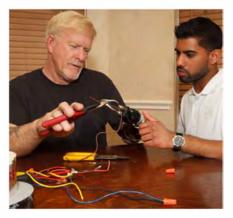


Figure 4. Training progresses to prosthetic usage in functional tasks. (Photo courtesy of Advanced Arm Dynamics.)

Throughout the prosthetic training phase, adjustments are made to optimize the function and fit of the prosthesis. Ongoing communication between the new prosthesis user, therapist, and prosthetist is crucial. It is ideal to make all significant adjustments prior to fabrication and delivery of the definitive prosthesis.

Lifelong Care

Lifelong care is the last phase of prosthetic rehabilitation. It begins when the initial prosthetic fitting and functional prosthetic training are completed. For those individuals with amputations who choose to not pursue prosthetic care, this phase commences after the completion of acute rehabilitation. In all cases, the individual has reached a desired level of function and stability. The care team should follow up at least once every 12 months regardless of the person's chosen prosthetic status. Case managers are especially vital to successful lifelong care with their involvement in planning, implementing and monitoring resources, services, and follow-up care.

Life Care Planning Considerations

Maintaining Independence

Maintaining independence during aging requires special consideration for those with limb loss. It is appropriate to conduct an annual assessment of functional performance, the need for adaptive equipment, modifications to home or vehicle, and prosthetic care requirements to maximize independence.

Vocational Services

For people with upper limb loss, the mean age at amputation is between 20 and 36 (Østlie, Skjeldal, Garfelt, & Magnus, 2011). Vocational assessment, training, and case management will likely be required over the lifetime of an individual whose goals include returning to work following amputation (see Figure 5).

Medical Care

Medical complications may arise over the lifetime of a person with an amputation. Overuse injuries, cumulative trauma disorders, residual limb breakdown and the formation of neuromas are some examples. While these issues can be difficult to predict or project, it is important to assess medical status and address comorbidities at follow-up contact.

Prosthetic Care

Prosthetic devices have limited lifespans and need to be evaluated regularly for repairs or replacement. Changes in a person's lifestyle may lead to the discovery of additional prosthetic needs. Working with upper limb prosthetic specialists can ensure that patients and their care teams get accurate information on what is available, and stay up-to-date on the most modern technologies and fitting methods. Extended warranties may help with prolonging the lifespan of a device.

Continued Psychosocial Support

Planning for psychological services by professionals with experience in trauma care is imperative for people who have experienced amputation. Peer support resources such as the Amputee Coalition annual conference can also be valuable opportunities for people to network, volunteer, learn new skills, and find and offer support. Emotional support for family or caregivers is also important to consider.

Figure 5. Return to Work



Figure 5. A person who wants to return to work may require worksite assessment and training to determine effective ways to incorporate the prosthesis into job duties. (Photo courtesy of Advanced Arm Dynamics.)

New technologies and surgical procedures

The field of upper limb prosthetics is ever-changing, and care team members should keep current with advances in technologies, treatment options, surgical techniques, and even research studies that patients may want to participate in. Technologies and surgical interventions undergoing continuous research and improvement include targeted muscle reinnervation (TMR), pattern recognition, osseointegration, and sensory feedback (Butkus, Dennison, Orr, & St. Laurent, 2014). Ensuring that people with upper limb loss have access to clinicians who are knowledgeable about new advancements, can significantly

improve long-term outcomes. Most importantly, listening to the needs and desires of prosthesis users can increase the ability of future prosthetic designs to "bridge the gap between research lab and clinic, clinic and home" (Biddiss & Chau, 2007b, p. 254).

Conclusion

Comprehensive upper limb prosthetic rehabilitation serves a small, specialized patient population with acquired amputation or congenital limb difference. Optimal outcomes are achieved with a multidisciplinary care team comprised of the patient, his or her physician, a prosthetist, an upper limb clinical therapy specialist, a mental health professional, and a nurse case manager or social work professional. Prosthetic options include a range of body-powered and electrically powered prosthetic components, each with different functional advantages. Ideally prosthetic training begins immediately after fitting of the preparatory prosthesis. Ongoing adjustments are made to improve both fit and function. Successful upper limb prosthesis users will need lifelong prosthetic care from a team that keeps them apprised of new technologies and other key resources. By understanding the specific challenges faced by this patient population, life care planners can be an extension of this team, developing more effective plans for people with upper limb loss or congenital limb difference.

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