Rehabilitation After Bilateral Hand Transplantation in the Quadrimembral Patient: Review and Recommendations

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Abstract: The hand transplantation is a unique entity in the fields of medicine and rehabilitation. Hand therapy and rehabilitation programs are consistently reported as essential to a successful functional outcome for the hand transplant patient. In September 2011, our medical center performed their first bilateral hand and forearm transplant on a 28-year-old female 4 years after losing her lower extremities and upper extremities due to multorgan system failure and pressure-induced extremity ischemia. She participated in 4 months of hand therapy, occupational therapy, and physical therapy at our institution, and then returned to her hometown to continue with an intensive therapy program. At 16 months after transplantation, she had sensory return to diminished protective level and motor return to all transplanted muscles except for intrinsics. Our hand therapy team established a treatment program based on literature, collaboration with other transplant centers, and clinical experience. Now, 2 years after our first hand transplant case, we assess our plan and program, offer suggestions for developing a treatment program and encourage therapist to collaborate with their own transplant team and others around the United States and the world.

Key Words: hand transplantation, forearm transplantation, hand therapy, quadrimembral amputee, rehabilitation

In the 2011 report of the International Registry on Hand and Composite Tissue Transplantation, 39 patients received hand transplants corresponding to 57 upper extremity (UE) transplantations at 15 centers around the world.1 Although this is an extensive accumulation of transplant data, it should be noted that not all transplant centers submitted information to the Registry. There has been a steady increase in bilateral hand transplant with at least 3 patients having quadrimembral involvement. Quadrimembral transplant patients participate in hand therapy and these rehabilitation programs are consistently reported as essential to a successful functional outcome.2–7

The hand transplantation team is a unique entity in the fields of medicine and rehabilitation.8 At the Hospital of the University of Pennsylvania, the transplant team consists of 20 different specialties that offer a wide array of expertise and varying perspectives in the care of the transplant patient. Commitment to the hand transplant patient is long-term with a significant amount of time spent together during rehabilitation. The relationship begins before transplantation, and lasts months to years after surgery. Navigating this therapeutic relationship takes extensive planning, frequent adjustments, and a great deal of patience and understanding.

HAND THERAPY PROGRAM DEVELOPMENT

Research and preparation is the key to any successful therapy intervention. In developing a hand transplant therapy program, therapists should do a thorough review of literature and communicate with other transplant programs. To facilitate this process and to help therapists develop their hand transplant program, the therapy team at Pennsylvania organized the first therapy forum at the American Society of Reconstructive Transplantation. The 2012 meeting brought together therapist from existing and developing programs to share their experience in hand transplantation. Therapy programs must consider the financial implications, as hand transplantation is not covered under insurance at this time. Programs should plan for appropriate staffing needs due to extensive time requirements for team meetings/communication, treatment planning, intervention, and documentation that can consume 20 to 30 hours per week. Supplies for orthosis fabrication, treatment, and assessment tools should be inventoried and treatment space assessed for these unique cases. Finally, therapists should familiarize themselves with the International Registry on Hand and Composite Tissue Transplantation and the Hand Transplant Score System.8

Candidate Selection and Education/Pretesting

Hand transplantation is not a life-saving procedure, however it is a life-enhancing procedure aimed to improve the quality of life for individuals dealing with loss of their upper limb(s). The medical and anatomic screening is more easily evaluated while the psychosocial screening is less precise. Focus on the importance of psychological component is gaining momentum in the hand transplant community and transplant literature.3

During the initial patient interview process at Pennsylvania, the hand therapists meet with the patient and their family/caregivers and collect data on the candidate’s range of motion (ROM), strength, and sensation of the residual limbs. Pain is recorded by verbal analog scale, Disability of Arm Shoulder and Hand questionnaire and the Patient Satisfaction Functional Scale are issued for patient-related outcome measures, and history of prosthetic use and prior therapy intervention is noted. A significant amount of time is dedicated to discussing physical and psychosocial factors of the rehabilitation process. This includes the patient’s motivation for transplant surgery and their expectations for recovery, with respect to both timeline of recovery and level of function. The conversation also touches on the patient’s coping skills. Therapists provide education on the postoperative hand therapy program with an emphasis on the high level of commitment and time required. The patient is asked to share information about their previous experience with therapy intervention and their commitment to the long and arduous transplant rehabilitation schedule. The
patient should expect to start hand therapy within a week after surgery while still in the acute care hospital. Hand therapy occurs 5 days a week for an average of 4 hours a day for the 3 months the patient is required to stay in the local area after transplantation. Their commitment is vital to obtaining maximal functional recovery. Treatment hours may vary depending on the level of transplant and other medical and psychosocial factors and should be tailored to the individual. The patient will work with the same certified hand therapists throughout their continuum of care in the local area. The assurance of a consistent team of therapists is a comfort to the patient and caregiver. They may also work with other occupational therapist (OT) and physical therapists (PT) depending on their overall rehabilitation needs.

Patients have many questions regarding the functional outcomes of hand transplantation. From a therapy perspective, the patient is made aware initially after transplantation that the limbs will need to be protected. Functional use will be limited depending on the rate of sensory-motor recovery, ranging from several weeks for distal transplants to several months proximal transplants. Extrinsic muscle function recovers first, followed by intrinsic function returning in 57% of the patients ranging from 9 to 15 months posttransplant.25 Function is highly dependent on sensation and the insensitive limb is at risk of injury. Fortunately, sensory recovery in hand transplant patients has been very good. International Registry on Hand and Composite Tissue Transplantation reports all patients recovering protective sensation, 90% tactile sensation and 84% discriminatory sensation.5 Therapy will include teaching the patient to protect the limb during the early phases of recovery and on sensory training techniques as regeneration occurs.

A consistent and reliable caregiver should be identified for assistance after surgery. Patients, particularly those receiving bilateral hand transplants, are unable to use their hands for activities of daily living function for weeks to months after surgery. This is compounded with the physical fatigue from rehabilitation and the immunosuppressive medications, and the emotional challenges of the overall demanding program. It may be said, the caregiver is the single most important person for the transplant patient during the early phase of recovery. This caregiver will need to perform intimate self-care tasks including bathing, dressing, and personal hygiene. They will give physical assistance for transfers, ambulation, and community mobility as well as assistance with eating and medications. More importantly, they are a vital emotional support system. These are important and difficult facts the patient must learn and accept.

Case

Initial priorities are not dissimilar from replants or other trauma cases, including protective positioning with specially fabricated orthoses, protection of bone fixation, pain and edema management, prevention of joint contractures and soft tissue adhesions, maintaining muscle-tendon integrity, and motor-sensory reeducation. Although the stages of biological healing are fairly universal, each patient has their own unique challenges and variability in nerves regeneration, therefore each patient deserves an individualized program.4,10 The main focus of the therapy program should be the patient’s quality of life, personal goals, and self-esteem.10

Again, it should be emphasized that no hand transplant case is the same. We promote the concept of looking at developing a treatment plan in phases rather than weeks as weekly goals can be arbitrary and misleading in these cases.

In September 2011, surgeons at the Hospital of the University of Pennsylvania performed a bilateral forearm and hand transplants on a 28-year-old female. Four years earlier, the new college graduate with a degree in fashion merchandising, experienced complications during her treatment of Crohn disease. This resulted in a multiorgan system failure and pressure-induced extremity ischemia leading to amputation of her UEs at the proximal forearm level and her lower extremities (LEs) below the knee. She decided to undergo bilateral UE transplant to “improve her quality of life and to have a sense of touch.” She wanted to perform her own self-care, live independently, and don her own LE prosthetics. She had goals to return to school and work as well as an active lifestyle including outdoor activities, pet care, driving, and a sports and fitness routine. As is often reported by users of UE prosthetics, our patient disliked using the prosthetics because they were cumbersome. She only used her UE prosthetics for toileting, eating, and putting on make-up.

Two senior level hand therapists were assigned to this case and cared for the patient throughout her entire postoperative care while she was in Philadelphia. Phase 1 began on postoperative day 6 in the patient’s acute care hospital room with her mother as the primary caregiver present for nearly all session. Initially, the therapists worked together with the patient to manage the extensive UE orthosis fabrication and early treatment plan. But within a few days, treatment changed from a 2:1 to a 1:1 basis with therapist working on alternating days. It should be noted, 4 hours of time was allocated to hand therapy, but not all of the time consisted of direct therapy intervention. Part of this time was used for rest-breaks due to fatigue, pain, stress, meals, medication routine, nursing priorities, and bowel and bladder needs. Time was also needed for documentation and team communication.

The primary goals of phase 1 were protection, proper positioning, and safe AAROM of the transplanted UE all within the parameters clearly detailed by the surgeons. The patient was fit with bilateral long arm volar-based orthoses consisting of 2 sections. The proximal section began at the upper arm and ended at the distal forearm, with the elbow positioned at 30 degrees of flexion and the forearm in neutral. The distal section was forearm-based including the wrist and the hand. The 2 sections overlapped one another at the forearm level. The distal section maintained the wrist at 20 degrees of extension, held the hand in an intrinsic plus position with the metacarpal-phalangeal joints at 50 degrees of flexion, the interphalangeal joints in extension, and the thumb in palmar abduction. The “crane outrigger,” an orthosis developed and used in the Louisville program, is designed to allow early tendon gliding, protecting the delicate extensor tendons with passive digit extension yet allowing active flexion while preventing a claw deformity.11,12 The dynamic orthosis design is beneficial for patients with a more distal level of attachment who have retained their own long flexor and extensor musculature. A static orthosis design was appropriate for our patient because the forearm muscles were part of the transplant and without active motor function during this early phase (Fig. 1). ROM exercises were initiated to both UEs. Exercises consisted of AAROM to the shoulders and elbows; gentle PROM of the forearms, wrists, and digits in a tenodesis pattern (Fig. 2). It is vital for patients to accept the new limbs as their own. We assisted our patient in feeling her new hands against her face and provided verbal cues during ROM exercises to imagine functional use with her new hands. Daily assessment to monitor for rejection included skin checks for rash or abrasion and circumferential measurements for any signs of increased
edema. Patient, family, and nursing education was a priority to ensure proper positioning and protection of the UEs and correct orthoses donning and doffing. The patient was unable to use her newly transplanted UEs for any function; therefore she was completely dependent on nursing staff and family members for all activities of daily living. This was a difficult and frustrating time for both the patient and her family.

The acute care PT and OT were consulted by week 2 postoperative to begin side of bed sitting, LE prosthetic fitting, activity tolerance, functional transfers, and mobility. Because of the long arm orthoses, a platform walker with wheels was initially used for ambulation assistance (Fig. 3). At 3 weeks postoperative, the attending surgeon discharged the long arm orthoses and the patient continued with just the forearm-based orthoses. With discharge of the long arm orthoses, the platform walker was no longer needed to support the weight of the arms. We designed slings to support the arms while allowing safe and balanced ambulation (Fig. 4). The patient was able to walk the hospital hallway with guidance but mobility proved to be more challenging than anticipated due to LE swelling, deconditioning, and managing the weight of her new arms. With recognition of these challenges, our discharge plan of moving the patient to an independent living situation needed to be changed.

Phase 2 began at 4 weeks postoperative when the patient was discharged from the acute care hospital to our inpatient rehabilitation facility. The goals were to increase independence in functional transfers, including getting in and out of the car, and long-distance ambulation so that the patient could reside in an independent living facility and begin a more intensive outpatient hand therapy program. In addition to inpatient rehabilitation OT and PT treatment sessions, 2 hours of hand therapy was scheduled daily. We continued with the ROM program and introduced light functional use of her arms with adaptive equipment such as a universal cuff attached to her orthoses. Feeding herself, socializing with friends back home by computer

**FIGURE 1.** Post operative immobilization orthosis.

**FIGURE 2.** Passive range of motion of digits in tenodysis pattern.

**FIGURE 3.** Gait training with rolling platform walker to support the weight of her new arms.
use, managing a standard call bell and TV remote were some of the activities practiced to increase independence (Fig. 5).

Phase 3 began at week 6 postoperative when the patient was discharged from inpatient rehabilitation to the Pennsylvania Transplant House, a nonmedical facility where she lived with her mother as the primary caregiver. Outpatient hand therapy was scheduled for 4 hours from Monday through Friday and PT 1 hour, 2 days a week. At week 7, the hand therapists designed dorsal-based forearm orthoses allowing for skin contact of the digits with use of the patients touch pad computer (Fig. 6). Core and proximal UE conditioning was a major component of the program to help prepare her for functional use of her new arms. As the nerves began to function, pain and hypersensitivity became an issue. Therapy addressed this with pain management strategies and desensitization techniques. Both motor and sensory return was closely tracked and monitored by Semmes-Weinstein Monofilaments, ROM, and MMT assessments. The patient demonstrated active wrist extension and finger flexion 3 months postoperatively. At this time, hand-based anticlaw orthoses (helmet orthoses) were fabricated to allow use of the wrists and digits while promoting increased strength and function (Fig. 7). The helmet splints maintained the intrinsics in a shortened position to prevent claw deformity. The forearm orthoses were gradually weaned once the patient’s wrists reached the strength of 3 out of 5.

Just before discharge home the patient experienced her first acute rejection episode. She was hospitalized and treated for the rejection. There is no defined protocol for whether to continue or hold therapy during a rejection episode, but our center decided to hold therapy for the first few days of the episode. Discharge home was delayed until the end of her forth postoperative month. This additional time was beneficial for upgrading her therapy program to meet the needs of her new motor and sensory regeneration, make LE prosthetic adjustments, and address any medical and pharmacological modifications. Returning home and working with a new team

FIGURE 4. Modified arm slings to support new arms.

FIGURE 5. Training with adaptive equipment to improve independence with ADLs.

FIGURE 6. Modified orthosis to use of iPad for social networking with family and friends.
provoked both excitement and fear for the patient. Modifying the discharged date helped with the transition.

Phase 4 is the transition to her hometown. The patient returned home to live with her mother. She started hand therapy with the local hand therapist 3 times a week and PT 2 times a week on alternate days. Initially, she was required to return to Philadelphia monthly for medical assessment, tissue biopsy and hand therapy follow-up, which then reduced to bimonthly, and eventually annually. To assist the local therapist, we recommend providing a thorough discharge assessment and instructions, including guidance for goal setting, splint recommendations, and guidelines for regular progress updates. Past medical history, history of therapy care, and intervention strategies should be outlined. Open communication through formal assessments and casual updates and inquiries is strongly encouraged.

At 16 months postoperative, the patient returned to Philadelphia for formal therapy reassessment (Table 1). She reported significant improvements in her functional independence, including moving out of her mother’s house into an apartment with a roommate and organizing a fashion show to benefit organ donation. Although she still required some assistance for morning and evening self-care, she was able to perform all grooming tasks, light meal preparation, feeding/drinking, computer and cell phone use, writing and lifting up to 6 pounds. She was independent with transfers and ambulation. She was still attending therapy on a regular basis including pool therapy. Electrical stimulation was initiated once the patient regained protective sensation to the skin where the electrodes would be placed.13

SPECIAL CONSIDERATIONS

Rejection Episodes
The hand therapist spends a significant amount of time with the hand transplant patient and has visual and physical contact with their new limbs, so it is important for the hand therapist to recognize the signs of an acute rejections (AR) episode. Visual inspection is the primary method for recognizing an AR episode and is characterized initially by a faint pinkish maculopapular rash with or without edema (Fig. 8). AR may also include scaling or blistering.2,4 A suspicion of AR should be reported immediately to the medical team. Continuation of therapy services during an AR episode should be discussed with the team and managed on a case-by-case basis.

Assessment Tools
Any number of standard assessment tools may be used throughout the course of care. Formally assessing recovery is important for treatment planning, validating intervention, and establishing a roadmap for future hand transplant cases. A comprehensive list of tools and methods for assessing recovery after transplantation has been published and are used to record sensation, ROM, edema, coordination, pain and overall function.10,14 The Carroll Upper Extremity Function Test15 is a tool used in some programs to track functional recovery.

TABLE 1. 16-Month Reassessment

<table>
<thead>
<tr>
<th>Muscle strength</th>
<th>Right</th>
<th>Left</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shoulder (all planes)*</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td>Elbow extension*</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td>Elbow flexion*</td>
<td>5/5</td>
<td>5/5</td>
</tr>
<tr>
<td>Wrist extension</td>
<td>4/5</td>
<td>4/5</td>
</tr>
<tr>
<td>Wrist flexion</td>
<td>2/5</td>
<td>2/5</td>
</tr>
<tr>
<td>Digit extension (digit 2-5)</td>
<td>3 +/5</td>
<td>3 +/5</td>
</tr>
<tr>
<td>Digit extension (flexor digitorum superficialis/flexor digitorum profundus) (digit 2-5)</td>
<td>3 +/5</td>
<td>4/5</td>
</tr>
<tr>
<td>Thumb extensor pollicus longus</td>
<td>3 +/5</td>
<td>2/5</td>
</tr>
<tr>
<td>Thumb flexor pollicus longus</td>
<td>3 +/5</td>
<td>4/5</td>
</tr>
<tr>
<td>Hand intrinsics</td>
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<td>0/5</td>
</tr>
<tr>
<td>Sensation (Semmes-Weinstein Monofilament testing)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distal phalanx median</td>
<td>Diminished protective</td>
<td>Diminished protective</td>
</tr>
<tr>
<td>Distal phalanx ulnar</td>
<td>Diminished protective</td>
<td>Diminished protective</td>
</tr>
</tbody>
</table>

| Function testing |       |      |
| Sollerman† | 24 | 27 |
| DASH (disabilities/symptoms section)‡ | 57.5 |  |
| DASH (optional work module)‡ | 12.5 |  |
| DASH (optional sports module)‡ | 75 |  |

*Muscles/joints not transplanted.
†Higher number indicates higher function (80-point scale).
‡Lower number indicates higher function (100-point scale).
DASH indicates Disability of Arm Shoulder and Hand.

FIGURE 7. Hand based orthosis to hold intrinsic muscles in shortened position to prevent claw-deformity.

FIGURE 8. Visual inspection and edema measurements to monitor for signs of rejection.
However, our program uses the Sollerman Hand Function Test. We prefer the Sollerman because it incorporates occupational-based tasks and considers quality of grip and pinch patterns for those tasks (Fig. 9). Neither the Carroll nor the Sollerman are commercially available. We found the Sollerman easier to build and simple to administer.

The IRHTT collects specific data on hand transplant cases worldwide. To do so, IRHTT created the Hand Transplant Score System. The Disability of the Arm, Shoulder, and Hand score and any LE issues. Common assessment procedures and timelines will be beneficial for uniform outcome data and research. Further research and communication among the therapy community will help to formalize rehabilitation guidelines and data collection for the UE transplantation. Doing so will help the candidate selection process, better prepare the patient for what to expect after transplant surgery, institute better and more efficient treatment planning, and establish reimbursement and funding for therapy intervention.

**REFERENCES**