

Long-Term Follow-Up Evaluation of Bilateral Total Hand Loss

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Purpose: Bilateral total hand loss is rare, and the challenges faced by the patient immediately after the loss are quite different from the long-term responses to the physical loss of both hands. This study evaluates the problems of these patients years after their injuries. The goal is to evaluate long-term adaptation to the loss and the degree of successful coping achieved by the patients.

Methods: Seven subjects in this descriptive study participated in an interview and physical exam. They were asked about their physical, psychological, and social problems. Functional Independence Measure (FIM) and Functional Assessment Measure (FAM) were used to assess the levels of the major functional areas.

Results: All of the subjects considered their handicap a serious disfigurement but not an impediment to finding a marriage partner or pursuing educational goals. All of the subjects, however, were dependent economically although they wanted to be employed based on their capabilities. Although 2 subjects used prostheses for activities of daily living, they all needed assistance for self-care. Three of the subjects had diagnosed psychological problems of anxiety and depression.

Conclusions: Bilateral total hand loss does not simply represent double the problems of unilateral hand loss. The problems resulting from the loss of both hands are physical, social, psychological, and economic and unique to these patients. The strength of the subjects came from having good family relations, stable environments, and family emotional support to help solve the numerous problems encountered on a daily basis. The subjects are able to maintain stable personal lives because they experience respect and comprehension of their problems by family members. (J Hand Surg 2007;32A:1148–1153. Copyright © 2007 by the American Society for Surgery of the Hand.)

Key words: Bilateral total hand loss, land-mine injuries, prosthesis usage, upper-limb amputation.

Bilateral total hand loss, which is rare, is a totally different problem in terms of physical impairment than unilateral loss or bilateral partial hand losses or even bilateral congenital amputation. The bilateral total hand amputee has a severe physical impairment, probably exceeded only by direct brain or high spinal cord injury.^{1–3}

The actual extent of physical loss has little relation to the patient's response to it.³ Research has shown that there is little relationship between the patient's immediate and long-term responses to the physical loss and damage.¹ As with all severe losses, there is a grieving process that occurs and defines the changes over time in response to the loss.

With traumatic amputation, patients pass through 3 rather well-defined phases of emotional response. The first is disbelief and denial that the loss has occurred and what permanent changes this will bring to the patient's life. The second phase is realization of what has happened and confrontation of the limitations, as well as dealing with the loss emotionally (ie, anger, guilt, sadness, despair). The third phase is characterized by acceptance of the loss, attributing appropriate importance to it, and achieving progressive adjustment with use of all remaining assets (adaptation).^{1,4}

There are limited studies that deal with the long-term results of bilateral upper-limb amputations.³

Table 1. Physical Characteristics of the Subjects

Case	Age at the Time of Amputation (Years)	Age at the Time of Evaluation (Years)	Time From Injury to Follow-Up Evaluation (Years)	Level of Amputation		Use of Prostheses		Phantom Pain		Phantom Sensation		Marital Status		Children
				R	L	R	L	R	L	R	L	R	L	
1	6	9	3	BE (mid. third)	BE (mid. third)	-	-	-	-	+	+	-	-	-
2	13	16	3	BE (prox. third)	BE (prox. third)	-	-	+	+	+	+	-	-	-
3	13	18	5	WD	WD	-	-	-	-	+	+	-	-	-
4	20	33	13	WD	WD	+	+	+	+	+	+	+	+	+
5	20	34	14	WD	BE (mid. third)	+	+	+	+	+	+	+	+	+
6	26	36	10	WD	WD	-	-	+	+	+	+	+	+	+
7	20	40	20	BE (mid. third)	BE (mid. third)	-	-	-	-	+	+	+	+	+

BE, below elbow; WD, wrist disarticulation; mid. third, middle third; prox. third, proximal third; -, no; +, yes.

This study assesses the problems of patients with bilateral total hand loss years after their injuries. The goal is to evaluate long-term adaptation to the loss and the degree of successful coping achieved by the subjects.

Materials and Methods

The Foundation of Martyrs and Veterans Affairs in West Azerbaijan Province, northwestern Iran, provides services for 80 upper-limb amputees, and this is where we found our sample population. The single criterion for inclusion in the study was total bilateral hand amputations. The age at the time of injury was not a factor nor other injuries sustained during the incident. Nineteen of the amputees had bilateral upper-limb amputations and were invited for an interview and physical examination. Twelve of these subjects had partial hand loss. The remaining 7 subjects had bilateral total hand loss, ranging from disarticulation at the wrist to the proximal third of the forearm (Table 1).

Seven male bilateral total hand amputees participated in the interview, and their characteristics are summarized in Table 1. Three individuals were 13 years of age or younger at the time of injury. In all of the men, the cause of the injury was land-mine manipulation and blast, although none of the men were injured directly in the battlefield. Three of the subjects were involved in de-mining activity. All of the subjects suffered from injuries such as hearing and visual problems, burns and shrapnel injuries to the trunk, face, and extremities, but none of the subjects had a notable head injury, spinal cord injury, brachial plexus injury, or complete blindness. Four subjects had sight in both eyes. Two subjects had 1 eye blinded, and 1 subject had 1 eye blinded plus blurred vision in the other eye. One of the men required an above-knee amputation.

The average age at the time of evaluation was 27 years (range, 9 to 40 years). The average age at the time of the injury was 17 years (range, 6 to 26 years), and the average time between injury and follow-up evaluation was 10 years (range, 3 to 20 years). All of the subjects were right-handed before the injury and remained right-side dominant after the injury.

With oral consent, these 7 people were asked about their physical, psychological, and social problems. A questionnaire about stump quality, stump pain, phantom sensation, phantom limb pain, independence in activities of daily living, prosthesis usage in activities of daily living, aesthetics of the limbs, psychological problems, and socioeconomic

status was completed. They were asked whether they have married and whether they have children.

A physical exam of the stump was performed by the investigators to determine stump quality (bulbous stump, soft tissue defects at the stump, skin graft, adherence of skin or eschar to bone stump, neuroma formation). Stump pain was defined as pain in the remaining part of the limb. Phantom sensation was defined as feelings, other than pain, in the missing part of the limb. Phantom pain was defined as pain in the missing limb.⁵

Functional Independence Measure (FIM) and Functional Assessment Measure (FAM) were used to assess the levels of the major functional areas.⁶ The items of the FIM and the FAM have 7-level ordinal scales: a rating of "1" means total assistance, and a rating of "7" means total independence.

In our observation, some of the items were irrelevant to our subjects (eg, swallowing; bladder and bowel management). The physical and psychological aspects of the subjects' lives had stabilized years before the current study. We did not add the levels of the items to produce a score; instead, we described the functional areas of the subjects by the identified levels of the FIM or the FAM items.

Self-Care

Self-care problems (feeding, grooming, bathing, dressing upper body, dressing lower body, and toileting) were evaluated using the 7-level ordinal scale of the FIM.

Prosthesis Usage

For prosthesis usage, subjects were asked the following: Do they use prostheses in activities of daily living? What kinds of prostheses were provided for them? What kinds of prostheses do they prefer to use? How many hours do they use prostheses in a typical day?

Aesthetic Considerations

Aesthetics of the limbs were assessed by subjective evaluation. Subjects were asked how they rank their disfigurement and how they assess that their injuries affect interpersonal contacts? Their responses were ranked as mild, moderate, or severe.

Psychological Problems

Psychological problems (emotional status, community access, reading and comprehension, speech, attention, safety judgment, social interaction, and memory) were evaluated using the 7-level ordinal scale of the FAM.

Socioeconomic Status

For socioeconomic status, the subjects were asked about their income, occupation, and education. Economic independence was assessed by the balance of their incomes and expenses. They were asked how they earn money. They were asked about their occupations at the time of the injury and at the time of evaluation. Their employability was evaluated using the 7-level ordinal scale of the FAM. They were asked about their education at the time of injury and whether they have continued or not.

Results

The quality of the subjects' amputation stumps was good and did not need further surgical corrections. All 14 limbs had phantom sensation, but 9 limbs had phantom pain sensation. Only in case 6 was the phantom pain constant and disturbing; in the other subjects, the phantom pain did not interfere with the activities of daily living. In all of the subjects, the remaining joints in the other limbs had normal range of motion.

Self-Care

None of the subjects have complete independence in performing activities of daily living, particularly self-care activities. The most needed assistance was in eating, grooming, bathing, dressing (upper and lower body), and toileting. Functional Independence Measure ratings of the 3 youngest subjects for self-care each were 2. They performed 25% to 49% of tasks and needed maximum assistance. The oldest subject needed minimum assistance. He performed 75% or more of tasks, and his FIM rating for self-care was 4. Functional Independence Measure ratings of the remaining 3 subjects each were 3. They performed 50% to 74% of tasks and needed moderate assistance.

Prosthesis Usage

The 3 youngest subjects had never been fitted with prostheses for their limbs. Four subjects were fitted with a variety of prostheses including myoelectric, mechanical (body-powered), and cosmetic. The first prosthesis that was fitted in these 4 subjects was myoelectric. At the time of follow-up evaluation, 2 subjects used bilateral mechanical prostheses (body-powered, voluntary-closing terminal device) for most activities of daily living and for more than 8 hours a day. The 2 oldest subjects gave up use of any prosthesis after being fitted because of limited usefulness and the difficulty of donning and doffing the bilateral

prostheses. They prefer a sensate stump to manipulate objects instead of an insensate, extended gadget. None of the subjects used cosmetic prostheses for their limbs.

Aesthetic Considerations

The subjects considered their limbs a serious disfigurement. The remaining part of the amputated limb is conspicuous enough to be disturbing to others and can adversely affect interpersonal contacts, especially at the time of the first meeting.

Psychological Problems

Three subjects (cases 1 and 4, depression; case 5, anxiety) had co-occurring psychological problems as a result of posttraumatic stress, and their behaviors interfere with general life functioning only occasionally, so their FAM ratings for emotional status each were 4.

The emotional status of the other 4 subjects was normal (FAM rating of 7). All of the subjects had normal (FAM rating of 7) general appearance, speech, attention, reading and comprehension, memory, and safety judgment. The subjects successfully adjusted to the limitations that interfere with general life functioning and have reached the third stage of completion of grieving and adaptation to their losses described earlier.

Three subjects who were 18 years old or younger were single. The remaining 4 subjects are married and have children. Only 1 subject had been married before his injury; however, none of the subjects believed that the injury was an obstacle to finding a marriage partner. All of the subjects reported that they liked to spend most of their time with their families but could not contribute much to the domestic work. They did report preferring shopping for what was needed at home as this was something they could do more easily.

Socioeconomic Status

All of the subjects above 18 years of age were economically dependent upon someone. The subjects were dependent on welfare systems that provided a vast spectrum of medical and social support such as insurance help for employment, compromise of and exemption from various governmental fees and taxes, facilities for participating in cultural and recreational activities, and different kinds of consultations. Medical support included but was not limited to consultations and referral to specialists when needed, dentistry, provision of prostheses, and insurance for their families. One subject was in the mili-

tary at the time of the injury and retired when injured. His employability FAM rating was 6, and he was able to complete due to his limitations an adjusted work. One subject was a farmer before the injury and never worked again because psychological problems developed after the loss of his hands. His employability FAM rating was 3, and he was not able to function without someone assisting him at all times. One subject was 6 years old at the time of the injury and was studying in primary school at the follow-up evaluation. He had total independence in completing his school assignments.

The remaining 4 subjects were studying in undergraduate schools (primary or intermediate schools) at the time of injury. At the follow-up evaluation, 2 were in high school and 2 were employed, one in a customs house and the other in a trading business. Their FAM ratings for employability each were 7. They had total independence in performing their tasks. The subjects emphasized that they wanted to be employed based on their capabilities rather than on their particular condition and limitations. Five of the subjects had continued their education, and 2 of these each received a master's degree. Two are in high school and 1 is in primary school. They used the stumps of their limbs as tongs for picking up and holding a pen for writing. They did not use a computer or keyboard. One subject was in military service but did not continue his education after his injury, and another abandoned all education completely.

Discussion

Bilateral total hand loss is a totally different impairment than unilateral upper-limb amputation, bilateral partial hand loss, or bilateral congenital amputation (agenesis). In agenesis, there is no handicap in the child's mind until he or she learns it from others, because these children automatically use their feet to substitute for their hands.¹ A child with acquired bilateral amputation never is able to acquire such a skill.³ With 1 normal hand, a patient can readily do about 90% of activities of daily living and with some gadget or effort can perform the remaining activities to be fully independent.² Bilateral partial hand amputees with intact wrist joint do not necessarily need functional prostheses. There might be an occasional need for an aesthetic hand replacement.³

The goal of this study was to evaluate how well 7 subjects adapted to bilateral total hand loss and the degree of successful coping achieved over the long-term. In this study, we see that the age and the

follow-up period are important factors in functional levels of the subjects. With increasing age and longer follow-up time, the functional levels of the subjects do progress. The oldest subject's self-care and independence in activities of daily living and social interaction are better than those of the youngest subject. It seems that there has been more adaptation to the loss. For all of the subjects, disfigurement is a heavy burden; however, the subjects are able to maintain stable personal lives and social roles in spite of the disfigurement and changed body image. All of the subjects reported that good family relations, family emotional support, family respect and comprehension helped solve many problems.

Bilateral upper-limb amputation is rare, occurring at an estimated rate 20 to 50 times less than that of unilateral amputation. Apart from congenital limb amputation, it is usually caused by trauma and rarely by Buerger's disease or leprosy.³ In the current study, bilateral upper-limb amputation is more frequent, 19 of 80 subjects, with 7 of the 19 experiencing bilateral total hand loss. This occurred because of the particular type of injury that the subjects had received.

There are national variations in causative factors of traumatic upper-limb amputation. In Western Europe, the 2 common causes of traumatic amputation are work activities and road-traffic accidents.⁴ Violence including gunshot injuries is the main causative factor in the United States and in Israel.⁷ War-related injuries are the major cause of upper-limb amputation in Iran.^{5,8} The cause of bilateral total hand loss of the cases in this study was blast while manipulating an explosive device. Unfortunately, the handicaps of these subjects had been increased by other injuries such as blindness, shrapnel injury to the body and head, burns of the body and face, hearing loss, and lower-limb amputation.

The subjects of this study are less dependent on prostheses: 2 of 4 who had the opportunity to use prostheses compared with the study of Wright et al, where 4 of 4 subjects were dependent on prostheses.⁹

Many parameters are involved in the successful rehabilitation of upper-limb amputees. One should consider the reason for the amputation, the type of the prosthesis, the level of the amputation, hand dominance, time interval between amputation and rehabilitation, stump quality, range of motion of proximal joints, and pain.^{3,10} All of these factors contribute to the successful use of a prosthesis (or failure to use), which can potentially lead to greater adaptation and satisfaction with an individual's life-

style. A high level of functioning seems to be determined by the number of hours a subject uses a prosthesis.^{7,11}

Functional prosthesis wear greater than 8 hours a day is an indication of success, and no prosthesis wear or use of a purely cosmetic prosthesis is considered a prosthesis failure.⁷ Only 2 of the subjects (4 limbs) of this study were wearing their prostheses more than 8 hours a day. Five subjects were not wearing any prostheses. Three subjects of this study who were under 13 years of age at the time of injury were never given the opportunity to use a prosthesis. Roeschlein and Domholt suggest successful users wore their prostheses for most of the day, whereas partially successful users wore their prostheses for specific tasks only.¹¹

Malone et al defined prosthesis success as use of the prosthesis by the patient for the same job or activities done before the amputation and failure as no functional prosthesis use. They also categorized a rejection group who voluntarily gave up use of prostheses after being fitted.¹² Patients with wrist disarticulation may prefer to manipulate objects with the long, sensate stump rather than with an insensate prosthesis.⁹

In the current study, the 2 oldest subjects voluntarily have given up use of prostheses. They prefer a sensate stump to manipulate objects instead of an insensate, extended gadget.

In this study, the subjects did not change their upper limb dominance after the injury. A bilateral amputation is almost never absolutely symmetrical.³ Patients may change their dominance because there is always a better side due to a somewhat longer stump, better joint motion, and natural dominance. This better side is better trained and accomplishes the main work, and the opposite side has an assistive role.³ Lacoux et al, in a short-term study on 40 cases of upper-limb amputees from the Sierra Leone civil war (1990–1994), reported 90% had phantom sensation and 29% had phantom pain.¹³ In a long-term follow-up evaluation by Ebrahimzadeh et al of 25 war-related upper-extremity amputees, 16 reported phantom sensation, 8 reported phantom pain, 6 had psychological support, and 15 were re-employed.⁵ Ebrahimzadeh et al believe a longer follow-up period lowers the rate of phantom sensation and phantom pain. In the current study, however, all of the subjects had phantom sensation, 9 had phantom pain, and 3 needed psychological support. The difference may be explained in that bilateral total hand loss is a complex

and challenging condition to adjust to and with which to continue with normal activities of life.

We were unable to find other long-term studies about bilateral total hand loss with which to compare our results. We used studies that address upper-limb amputation generally, and almost all of the subjects of those studies had unilateral amputations.

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