

# Measuring Outcome in Upper-Extremity Transplantation

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**Abstract** Measuring the outcome in upper-extremity transplantation is important to understand the potential of the procedure and to assist the patient and surgeon in decision making. The outcome of replantation varies with the anatomic level and mechanism of amputation; factors which inform the indications for replantation. We review the outcome measures used in upper-extremity transplantation and advocate for a combination of patient-answered outcomes, physical measurements, preference-based measurement, and cost analysis. Since this procedure is not common, and there is significant risk associated with immunosuppression, a catalogue of measurements should be accumulated for each patient to further inform surgeons and patients of the merit of these procedures.

**Keywords** Hand transplantation · Outcome · Measurement · Utility · Upper extremity transplantation

## Introduction

Upper-extremity transplantation is performed to improve quality of life, which must be balanced against the morbidity of immunosuppression. To ensure this procedure is providing more benefit than harm, accurate measurement of the outcome has critical importance. The benefits of upper-extremity

transplantation take the form of improved quality of life that can be achieved by increased function, improved self image, and a reduction of suffering. The potential for harm lies in the need for a prolonged surgical procedure and currently the need for life-long immunosuppression with its varied risks. It is obvious that the requirement for measurement to consider these multiple and varied outcomes is complex.

At this point in time the indications for major replantation of the upper extremity guide our indications for upper-extremity transplantation. For major replantation, the probability of achieving a reasonable result is one of the most important considerations. These indications have been based primarily on the anatomic level of the amputation, developed from the observed results from replantation. For example, from early replantation experience we know that replantation of an amputation at the wrist or distal forearm has the highest probability of yielding the best functional result. This has been measured as a Chen level 1 or 2 in more than 80 % of cases [1]. For replantation at the level of the upper arm, this probability drops significantly to 40 % of patients achieving Chen level 1 or 2 function in the 20 cases reviewed [1]. An accurate measure of the results of upper-extremity transplantation with respect to both probability and quality of outcome will inform the surgeon and patient of the potential result. The value of the outcome, weighted by the probability, is called the expected value. It is this expected value from transplantation that will inform our indications and contraindications for transplantation in the future.

In this paper we review the methods currently used to measure the outcomes of upper-extremity surgery and specifically upper-extremity transplantation. We will advocate for the increased use of utility, also known as preference-based measurement, which we believe to be well suited to measure this multidimensional construct, especially to clarify our decision making about the indications and contraindications of these procedures.

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## Principles of Measurement

In the act of measurement we are trying to determine if the object of the measurement has more or less of a given characteristic. This can be a characteristic like the height of a table or a characteristic that does not have a physical presence, like the measurement of happiness. The measurement tool must be able to discriminate differences in the characteristic being measured to provide useful information. Some of the traditionally important qualities of a measurement are:

- 1) reliability (if repeated, the measure yields the same answer);
- 2) validity (if the measure is measuring the characteristic it is purported to);
- 3) sensitivity to change (the ability of the measure to detect small but important changes in the underlying characteristic).

Interesting concepts in measurement such as item response theory are developing a presence in upper-extremity surgery and offer the advantage of accurate measurement with reduced burden on the respondent. We anticipate this approach will be used to measure the results of transplantation in the future.

We will discuss the measurement of the results of surgery using health status instruments, preference-based measurement, and the use of physical measurements. With further clinical experience and research, we believe they will be best used in combination as each provides information that is useful.

## Outcome Measures in Upper-Extremity Transplantation

### DASH

The Disabilities of the Arm, Shoulder, and Hand (DASH) is a patient-answered questionnaire that has been widely used to measure the results of upper-extremity care and is reported for a sample of transplantation patients on the International Composite Allograft Registry [2]. Higher scores on the DASH represent higher levels of disability. For patients having upper-extremity transplantation, the DASH scores show improvement for the first couple of years and plateau at a level of about 20 for bilateral transplants. Interestingly, this score suggests that the disability resulting after transplantation of both upper extremities is lower to that reported in the literature for carpal tunnel syndrome. In a carpal tunnel study, Follmar et al. included a control group of patients with carpal tunnel syndrome and no chronic pain. The preoperative DASH scores for this control group were 37 [3]. For unilateral transplants, the DASH score is less than 10.

In a review of outcomes of upper-extremity transplantation, Landin et al. summarized the results of 28 patients discussed in 56 clinical manuscripts [4••].

They specifically reported DASH scores, Hand Transplant Severity Scores, and scores using Chen's functional grade. The post-transplant mean DASH score was 36 for bilateral transplant recipients, once again similar to published scores for carpal tunnel syndrome as noted above.

The DASH scores seem useful in understanding the time course of events after transplantation and may be useful to compare the results within populations having upper-extremity transplantation. The seemingly inexplicable results when comparing across conditions, however, make it difficult to interpret DASH scores when taken on their own, in isolation. Therefore, we believe that although the DASH may have value when comparing upper-extremity transplants, and following them over time, DASH scores are likely not useful in their current state to compare across conditions or to be used as a stand-alone outcome measure.

### Hand Transplant Scoring System

Lanzetta and Petruzzo have detailed a specific scoring system for upper-extremity transplants [5].

They state "*The main purpose of this score is to allow evaluation of cosmetic and functional results as well as to take into account 'what really happened to the patient' following hand transplantation, assessing his or her psychological outcome, social behavior, work status, satisfaction, body image, and well being.*" ... "*The score is based on the concept that the word 'hand function' must be expanded to embrace aesthetic, psychological, and socioeconomic factors.*"

This scale has six domains, 'appearance', 'sensitivity', 'movement', 'psychological and social acceptance', 'daily activities and work status', and 'patient satisfaction and general well being'. Each domain has multiple items with a total of 27 items forming the scale.

Scores of this measurement are reported on the International VCA (vascularized composite allotransplantation) Registry. Of note on the registry is that patients with long-term follow up are close to the upper end of the measurement scale. This ceiling effect will limit the discriminating ability of this score and therefore limit its usefulness. The score does show change over time and like the DASH may be useful when comparing within populations of upper-extremity transplantation.

### Chen's Functional Grade

In 1981, in a review of the results of replantation, Chen presented a grading scheme with four levels of functional recovery [1].

- 1) Able to resume original work  
Range of motion (ROM) exceeds 60 % of normal  
Complete or nearly complete recovery of sensation  
Muscle power of grades 4 and 5

- 2) Able to resume some suitable work  
ROM exceeds 40 % of normal  
Nearly complete recovery of sensation  
Muscle power of grades 3 and 4
- 3) Able to carry on normal life  
ROM exceeds 30 % of normal  
Partial recovery of sensation  
Muscle power of grade 3
- 4) Almost no function of survived limb

In the review paper noted above, Landin et al. [4••] found that nine of seventeen patients had recovery of Chen level 1 or 2, with seven having a recovery to Chen level 3, and one with no recovery of function at level 4. In our opinion, from a functional standpoint at least, a Chen level 3 or 4 would be considered an inadequate result when weighed against the morbidity of immunosuppression.

In future decision analysis evaluating the decision to transplant we recommend considering the Chen level of 1 or 2 as successful and 3 or 4 as a failure of transplant. Although Chen's method is simple compared with the International Registry Hand Transplant Score System, it has served as the basis for decision making in major limb replantation, clearly showing the probability of a good result is linked to level of amputation and replantation. As a quick method to score the results of transplantation we think Chen's functional score has a lot of merit.

## Utility

Since upper-extremity transplantation is used to improve quality of life and utility measurement is a widely used method to measure health-related quality of life, utility seems well suited to measure the results of upper extremity transplantation. Utility is a term that refers to the strength of preference for a health state, a procedure, or complication. The utility score can vary between zero, which is assigned to death, to one, which is the score assigned to perfect health and happiness.

In advocating for the use of utility in quality-of-life measurement, Torrance et al. noted

“The underlying reasoning here is that, in attempting to measure the concept of health related quality of life, the appropriate construct is one of preference.

That is, a health state considered by an individual to represent a greater health related quality of life will be preferred by that individual. Indeed it is hard to see what else quality of life could mean” [6].

Utility is well suited to measure the multi-dimensional outcome seen in transplantation and when weighted by probability in a formal decision analysis, can be a useful aid for

decision making. By measuring patient preference, constructs that are difficult to measure, such as sense of wholeness, will be included. Utility measurement is the only method described that can include and represent the potential for the negative effects of immunosuppression. In two published decision analyses evaluating upper-extremity transplantation, utility was used as the measure of health-related quality of life [7, 8].

Decision analysis aims to make the best decision in the face of uncertainty and can be used when a randomized trial is not possible. Since upper-extremity transplantation is an uncommon procedure, it is unlikely that randomized trials will be used to guide our management. Decision analysis, therefore, can have a role in decision making for transplantation.

Not only can decision analysis guide our indications and contraindications, the process requires clarity of thought and can focus our attention to the most important aspects of a decision. Initially it became obvious that distal transplants had the highest expected value and that bilateral transplants offered significantly more benefit than unilateral. The use of utility and decision analysis helps to clarify the value of unilateral transplantation, offering a method to understand the patient's preference for a transplant, even when function is poor.

## Physical Measurements

Herzberg et al. developed a ‘one page’ evaluation chart for upper-extremity transplantation that documents four domains: ‘the general condition of the transplanted hand’, ‘the range of motion and muscle strength’, ‘sensation’, and ‘function’ [9]. This captures the typical physical measures commonly performed and reported by hand surgeons. He also measures the Chen score and DASH.

Jablecki et al. reported the final results of a unilateral hand transplant at the wrist level at 41 months post-transplant [10•]. The authors measured sensibility using Semmes–Weinstein monofilaments, grip strength of 5.4 kg, as well as Chen grade 1, a DASH score of 65, and a Hand Transplant Score of 93.5.

The traditional physical measures continue to have an important role in understanding the results of transplantation. Surgeons will find these physical measurements important because measurement of nerve recovery, joint motion, and strength, among other aspects of the clinical course of the patient, are most proximate to the technical details of the surgery and will be the most sensitive indicators.

Since upper-extremity transplantation is not a common procedure, clinician researchers must document and measure a wide range of attributes. Some aspects of the results of this

surgery will be most interesting and useful to the patient, whereas other features of the recovery may be primarily of interest to the surgeon, the therapist, or others. None of the upper-extremity measures include the distant effects of immunosuppression and therefore can only be considered partial outcome measures at best. We believe preference-based measurement, the utility, has an important role to play in this regard. When this is used in formal decision analysis, possibly on an individual basis with prospective patients, we have a powerful tool to help in this complex decision making.

## Conclusion

Currently we recommend that upper-extremity transplant patients have a catalogue of measures to follow the outcome. This will include the physical measures advocated by Herzberg, the DASH and Hand Transplant Scoring System, the Chen functional score, utility, an itemized list of complications, and a running summation of cost. Only through further experience and long-term follow up will the value of these items reveal their importance. To record only limited outcome information at this point in time will be to create a lost opportunity for the future.

## Compliance with Ethics Guidelines

**Conflict of Interest** Steven McCabe and Brett McClelland declare that they have no conflicts of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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