

Adjustment to amputation and interest in upper limb transplantation

SAGE Open Medicine
Vascularized Composite Allotransplantation
Volume 7: 1–6
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DOI: 10.1177/2050312119858248
journals.sagepub.com/home/vca



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Abstract

Objective: Upper limb transplantation provides a new restorative option for individuals with amputations. As true for most operations, patient selection is critical to optimizing transplantation outcomes. To improve on the patient selection process, we used qualitative methods to better understand the issues regarding upper extremity loss as well as upper limb transplantation from the amputee point of view.

Methods: Individuals with upper limb amputations (age range = 24–73 years) discussed their adjustment following amputation and their interest toward transplantation in either a focus group (n = 5) or semi-structured interview (n = 17). Transcripts were coded by theme and summarized.

Results: Participants described a year-long process typified by adjustment to a new role as an amputee, both psychosocially and functionally. We found that the extent of adjustment was inversely related to an interest in transplantation.

Conclusions: These findings could explain the difficulty in identifying “ideal” candidates for upper extremity transplantation and may have implications for patient selection and counseling.

Level of Evidence: Prognostic Study, Level V

Keywords

Upper extremity, vascularized composite allotransplantation, psychosocial

Date received: 4 April 2019; accepted: 4 April 2019

Introduction

The experience of upper limb amputation can result in profound changes that impact amputees’ physical, functional, and psychosocial status.^{1–3} The emergence of innovative surgical restoration options, such as upper limb transplantation, provides an alternative to traditional prosthetic restoration. However, the risks of transplantation due to long-term immunosuppression,^{4,5} the required intensive rehabilitation protocols,^{6,7} and the uncertain functional outcomes temper enthusiasm for this procedure.^{8–10} The upper limb transplantation literature has focused increasingly on the importance of patient selection in optimizing outcomes.^{11–13} Comments are made at meetings by transplantation centers of the large numbers of patients screened for possible surgery, but the difficulty involved in finding the “ideal candidate.”¹⁴ Upper limb transplantation teams comprising hand surgeons, solid organ transplant specialists, and psychologists have generated patient evaluation and selection criteria borrowed from their respective fields. In the abstract, the ideal candidate for upper limb

transplantation would demonstrate a profound motivation for transplantation, a strong psychological profile to endure the ups and downs of potential rejection, self-discipline to perform the necessary rehabilitation protocol, compliance with medical regimens for taking of immunosuppressives, a supportive psychosocial environment, and the appropriate intelligence to understand the potential risks. An additional assumption made by transplant centers may be that patients

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Table 1. Participant recruitment sources.

Recruitment source	N (%)
Amputee Clinic, Rehabilitation Institute of Chicago	7 (31.8)
Division of Plastic and Reconstructive Surgery, Northwestern University Feinberg School of Medicine	4 (18.2)
Northwestern University Prosthetics-Orthotics Center	1 (4.5)
Community-level prosthetics clinics in Illinois	1 (4.5)
Upper limb amputee email listserv	9 (40.9)

who self-select and are screened for possible limb transplantation are desirous of improved extremity function and have poor acceptance of conventional prostheses. However, there are many driving factors to seek transplantation, including social reasons, financial drivers, and media hype. There is also risk of a limited understanding of the implications of surgery and immunosuppression in self-selected patients. In order to replace assumptions with patient-centered data, we designed a study to specifically address the factors that may increase or decrease a patient's interest in limb transplantation. Answering this question may assist extremity surgeons in better understanding and counseling patients who may be candidates for transplantation. In addition, a better understanding of the psychological issues associated with upper extremity amputation may help improve the care of the new amputee.

Materials and methods

Design

This study employed qualitative methods to explore perspectives on the psychosocial issues of upper limb loss and how these patient-centered factors influence interest in transplantation. A qualitative approach allows for an in-depth examination of patient perspectives without imposing investigator bias. The survey methodology was implemented via focus groups (with geographically local participants) and semi-structured individual interviews (with geographically dispersed participants) to collect data on participants' adjustment to amputation and their attitudes toward upper limb transplantation. The study was approved by the Northwestern University Institutional Review Board.

Participants

In an effort to enroll a diverse sample, we recruited participants from multiple sources (see Table 1). Individuals who were 18 years of age or older, fluent in English, and had a single or double upper limb amputation anywhere from the level of the wrist to the shoulder were eligible to participate. Excluded were individuals who were unable to provide informed consent and already transplanted individuals. Use of a prosthesis was neither an inclusion nor exclusion criterion.

At clinical recruitment sites, members of the clinic staff screened individuals for eligibility and offered the

opportunity to participate in the study. For individuals recruited from non-clinical sources, a member of the research team screened for eligibility via telephone. A member of the research team explained the study to all interested individuals. Although similar procedures were used to identify patients for the focus group and the individual interviews, participants could not participate in both. All participants provided informed consent prior to participation in either the focus group or the interview. Sample size was determined using standard qualitative methods. Transcribed interviews were analyzed and saturation of concepts were assessed continuously. Sample sizes of 12–15 subjects are typically required to demonstrate a saturation of concepts with no new concepts emerging after three subsequent interviews.

Data collection procedures

For an initial evaluation of themes, subjects ($n=5$) participated in one 90-min focus group at Northwestern University. Following completion of a brief sociodemographic questionnaire, two moderators guided participants through a discussion about their quality of life following amputation and their perceptions of upper limb restoration options, including upper limb transplantation. They facilitated discussion among the participants on specific topics and encouraged commentary on other members' perspectives. The focus group discussion was audio-recorded and transcribed. Members of the prosthesis and transplantation teams were not involved in the interviews to reduce bias.

Additional subjects ($n=17$) participated in one-on-one interviews with a trained researcher. Interviews took place either face-to-face or via telephone and typically lasted between 30 and 60 min. The interviewer used a semi-structured interview guide about subjects' quality of life post-amputation and their perceptions of upper limb restoration options, including upper limb transplantation. Interviews were audio-recorded and transcribed. Members of the prosthesis and transplantation teams were not involved in the interviews in an attempt to reduce bias.

Data analysis

Descriptive statistics summarize the sociodemographic and clinical variables of interest. We reviewed focus group

Table 2. Participant sociodemographic characteristics.

Characteristics	Total sample (N = 22) ^a (focus group, n = 5; interviews, n = 17)
Gender, n (%)	
Male	14 (70)
Female	6 (30)
Age (years), median (range)	56.5 (24–73)
Race, n (%)	
White	13 (65)
African American	3 (15)
American Indian/Alaskan Native	1 (5)
Native Hawaiian/Pacific Islander	1 (5)
Asian	2 (10)
Ethnicity, n (%)	
Non-Hispanic/Latino	17 (89.5)
Hispanic/Latino	2 (10.5)
Marital status, n (%)	
Married/partnered	10 (50)
Never married	5 (25)
Divorced	4 (20)
Widowed	1 (5)
Highest education, n (%)	
Less than high school	3 (15)
High school/GED	3 (15)
Some college	3 (15)
College	4 (20)
Advanced degree	7 (35)

GED: General Educational Development.

^aTwo participants who completed interviews did not complete self-report questionnaires.

and interview transcripts for accuracy, then analyzed them using constant comparative methods and a two-phase analytic strategy proceeding from descriptive to conceptual coding.^{15,16} The first author reviewed each transcript and identified themes related to limb loss, adjustment, and interest in transplantation. Based on this initial review, the first author developed a coding scheme to classify participants' comments by theme. The study team reviewed the coding scheme and made revisions based on the team's clinical and research expertise in upper limb amputation. Next, each transcript was coded by two individuals separately for consistency. Discrepancies were resolved by discussion. The frequency of themes was tabulated, and the content was summarized to characterize patient-identified issues regarding upper limb loss and interest in transplantation.

Results

A total of 22 upper limb amputees participated in this study. Table 2 displays the sociodemographic characteristics of participants. The majority of participants were white (65%) and male (70%). Participants were a median

of 56.5 years old (range = 24–73 years). Of all the participants, 85% were unilateral amputees, with 50% reporting an amputation below the elbow, 10% reporting an amputation at the elbow, and 40% reporting an amputation above the elbow. A slight majority of participants reported having lost their dominant arm (55%). The reasons for amputation were injury or accident (50%), disease or illness (40%), or congenital conditions (10%). The participants' median time post-amputation was 11 years (range = 0.5–55 years).

Three psychosocial factors emerged during this qualitative analysis of this patient group that related to the individual's interest in upper limb transplantation. As a broad statement, each of these factors reflects on the individual's adjustment to amputation. These factors were adaptation since amputation, functional adjustment to limb loss, and the development of a new self-identity as an amputee. These three adjustment issues are discussed below with quotes taken from the patients found in Table 3.

Adaptation since amputation

Adaptation since amputation was a prominent factor in people's attitudes toward upper limb transplantation. Participants' responses suggested that interest in upper limb transplantation generally diminishes as more time passes since amputation. Conversely, several recent amputees expressed greater interest in upper limb transplantation and several long-term amputees noted that retrospectively, they believe they would have been more interested in upper limb transplantation closer to the time of their amputation. Several participants expressed that time since amputation might constitute an important consideration when determining an individual's eligibility as a transplantation candidate.

Functional adjustment

Participants who expressed less satisfaction with their current level of functional adjustment had greater interest in upper limb transplantation, whereas those who described satisfaction with their functional adjustment reported minimal interest in upper limb transplantation. Dissatisfaction with function may include inability to adapt to a prosthesis as well as exhausting the capabilities of a prosthesis. The former is a limitation of the patient; the latter is a limitation of technology. Many participants who expressed satisfaction with their current level of functioning cited concerns about potential declines in functioning post-transplantation, relative to their current functioning, as a factor diminishing their interest in upper limb transplantation. Anecdotally, we have found that while above-elbow amputees score lower on objective assessments after transplantation, their profound pre-transplant disability makes their change in score much greater than below-elbow or wrist-level amputees. The same is true for bilateral amputees who are significantly more disabled than

Table 3. Adjustment themes identified by participants.

Adjustment theme	Exemplar quotations
Adaptation since amputation	<p>“Well it used to seem more important to me, as I have gone on in years as I currently am I guess I am more settled and comfortable with it. It is not something like I am hoping for; if it happens and they can do it successfully without a lot of negative impact on you then, great. I don’t know that I would look into it at this point simply because I have moved on to sort of like this is what I have and I am comfortable with it now and I am doing other things.”</p> <p>“If they would have gave me that option, a year and a half ago, when I was in the hospital, I’d be a lot more open to it right at the time of the accident, then I would be a year and a half, two years, thirty years later. I mean once you adapt, it’s kind of hard. Well, now you do have to meet these expectations. If they had amputated my one arm and then the next day, we can give you this hand. I’d be a lot more open to it then, then, I would be down the road.”</p> <p>“I was just fresh out of the hospital so of course I was like I want to do it. And I met with him [the doctor] a couple of times and he got to really talk to me about the procedure and the risks and all of that stuff ... he said wear your prosthetics for six months and come back and we will talk. If you feel the same way then let’s do it because I will give your prosthetics a chance because this is a big deal so you don’t want to make this decision just because you want your hands back and it looks better.”</p> <p>“I would make them wait a certain amount of time and I mean years after losing their limb before they would be considered for it. ... I would say first you’ve got to go through a lot of counseling and make sure this is really what is going to be the best thing for you, and if somebody is truly that unhappy, then that moves it way up on the list. Me, I would say, minimum five years after loss of limb, just to get people to settle in and see if they can have a different perspective ... But, if you’ve had a chance to live with it for a while, or with a prosthesis for a while, it may, after you talk about the risks, it may not be worth it, but for some people it will be.”</p>
Functional adjustment	<p>“That would be a horror story in my book. I am comfortable where I am at and I have accepted what I have and learned to function with it and that’s fine so why would I want to interrupt that for something that is so high risk, although it has high benefits if it works but the high risk as well.”</p> <p>“I’ve dealt with it and I’ve accepted it. I just wouldn’t want to get my expectations really high and then end up back depressed and right back where I started from, you know what I mean?”</p>
Identity post-amputation	<p>“I mean so, at some point, if somebody were to say you could do a transplant. That scenario, then, maybe there’s an absolute there but I’ve been so long without it, I’ve gotten where I’ve gotten good at doing what I do, being able to relate that to another generation. Then, unless every amputee in the world had already gone through it, and I’ve got nobody to talk to and help out, then, I would be interested.”</p> <p>“It is a big deal and I am still considering it to this day because I hate my prosthetics. I mean I love how they are going to help me put on my makeup and wash me but I hate the way they look. I look like a robot I hate it. I don’t think I will ever accept it so it is tough so that is why I am still considering it.”</p>

unilateral amputees. We have, therefore, found more risk- and uncertainty-tolerance in bilateral above-elbow amputees.

Self-identification as an amputee

Participants who described acceptance of their *new identity as an amputee* expressed minimal interest in transplantation. Many of these participants reported a lack of perceived need for restoring the lost limb through transplantation. Several described concerns about the possibility of re-amputation as a factor that significantly decreased their interest in upper limb transplantation, as they had adjusted to their role as an amputee and wished to avoid a second adjustment process in case the transplant was non-functional for any reason. Conversely, several amputees who expressed difficulty accepting their self-image and identity post-amputation described greater openness to upper limb transplantation. Several of these participants stated that transplantation may serve as a means to restore their pre-amputation identity.

Discussion

Surgeons who perform elective surgeries designed to improve quality of life need to optimize patient selection and to fully understand patient motivations in order to have the best chance for successful outcomes. However, there is little data on which to base patient selection for an upper limb transplantation. For instance, should appropriate candidates only be those *self-selecting* for evaluation by transplant programs, or should a wider net for potential candidates from the general amputee population be cast? Data from Kiwanuka et al.¹⁴ suggest that patients are generally poor evaluators of appropriateness. In an initial effort to answer these fundamental questions, we performed a patient-centered investigation regarding attitudes toward upper limb loss and transplantation. The findings suggest that when considering patient selection factors, the adjustment to amputation that occurs over time is critical and appears to be inversely associated with an interest in transplantation. Our qualitative research shows that the patients most interested in and suitable for transplantation are those with traits

and characteristics that *limit* their ability to adjust to amputation along the timeline experienced by most new amputees. Conceptually, the patients most interested in transplantation have never truly *become* amputees.

Psychological profiles of patients are neither “good” nor “bad,” but instead should be thought of as “typical” or “atypical.” While there is little in the upper extremity literature regarding adjustment to limb loss, it is appropriate now to generalize from other fields and specialties as to what is a typical response to great life changes as well as disturbances to the human form. Adjustment takes time to occur, as has been shown with vision loss,¹⁷ spinal cord injury,¹⁸ and stroke.¹⁹ Many of these fields describe a 6- to 12- month process. Recent longitudinal research examining adjustment following lower limb amputation found that individuals with stronger goal pursuit (ongoing striving toward attaining a goal) and goal adjustment (revise goal and manage emotional consequences) tendencies at the time of admission to rehabilitation were more likely to experience better adjustment 6 months later.²⁰ The results also parallel conclusions from research examining suitability of functional electrical stimulation for persons with spinal cord injury.²¹ Patients who self-select for suitability for transplantation may predominate with “atypical” reaction patterns to limb loss, namely, a reluctance or inability to adjust over time. Some patients referred for consideration may be identified soon after their limb loss when they have not had the time to adjust. As time is a critical issue, several participants spoke of the potential value of waiting 6–12 months before pursuing upper limb transplantation, especially given the risks associated. This reflects the importance placed on this waiting period by many transplant programs. The general consensus among transplant centers is that amputees with strong coping skills, discipline, and compliance with medical caregivers will be the best candidates to receive a transplant. Our concern is that the patients with “atypical” reaction patterns to limb loss with low adjustment patterns may not have these psychosocial traits in abundance.

We have found anecdotally that patients who adapt and use prostheses well tend to manage well with transplanted hands (and vice versa). A transplant, at least initially, is a denervated limb, and being able to manage an insensate limb with limited motor function is similar to learning to use a prosthesis. Hence, the ongoing catch-22 that the ideal transplant candidate may not necessarily be the one who “fails” with a prosthesis.

The functional adjustment to limb loss also impacts interest in limb transplantation, with those more profoundly affected and unable to perform activities of daily living more interested in the procedure. It is perhaps here that hand surgeons have most focused their interest and debated selection criteria in terms of preoperative analysis of who would best benefit from a transplant. The wisdom of performing a unilateral transplant where the newly placed hand will be a “helper” hand to the intact limb is extremely controversial. Here too, the passage of

time is critical to allow amputees to adjust to their residual limb, to areas of neuroma pain, to phantom discomfort, and to prostheses as they contemplate a potential procedure. Improved functional outcomes with targeted reinnervation, pattern recognition, and osseointegration may further change the calculus for an individual patient considering a transplant. The expected benefit of functional improvement deemed necessary to accept the risks of transplantation was as high as 90% in some of our study patients. Moreover, it is critical to evaluate the change in function after limb restoration rather than isolated functional metrics. The ideal candidate may be the patient who stands to see the greatest improvement in function, and not just the patient with the highest final scores on our evaluative metrics. For example, a bilateral above-elbow amputee will often be turned down by transplant surgeons because the expected outcome is objectively worse than a lower-level transplantation. However, they stand to gain the most from the transplant.

It was unexpected that our amputee subjects described a hesitation to having an upper extremity transplantation because they had already adjusted to their limb loss. They stated that they would avoid a transplant to ensure never needing to go through the adjustment process of limb loss a second time in the case of unsuccessful surgery. This topic is illustrative why patient-centered research is critical to understand the motivations of the potential recipients of care.

Although these findings provide a preliminary perspective on how adjustment following amputation may affect attitudes toward transplantation, several limitations must be noted. The methodology of the study does not allow for conclusions about the statistical significance of the relationship between adjustment and attitudes toward transplantation; rather, as a qualitative study, the intent of this research was to codify factors that influence amputees’ attitudes toward transplantation and to ensure that future research includes these factors in patient selection protocols. Validated survey tools to assess adjustment to loss of the upper extremity as we have described do not exist, but these can be created. This study is limited by its cross-sectional design. While we attempted to include participants across a wide range of time post-amputation and even included two patients with congenital limb loss, future prospective studies will require far greater numbers than possible for these lengthy conversations with rigorous analyses. We maintain that longitudinal research is needed to better understand the post-amputation adjustment patterns with a goal to shorten and improve the process. Those patients with atypical adjustment patterns could be identified early, with a goal either to help their psychosocial reaction become more typical or alternatively to link them with a transplant center. The percentages of patients with “typical” and “atypical” adjustment patterns as a function of time will also need to be determined. We suspect that the findings of this study in part explain the difficulties involved with finding suitable candidates for transplantation despite screenings of large numbers of potential candidates. While there are many exceptions,

patients who self-select for evaluation for transplantation in all likelihood have atypical adjustment patterns who have not accepted their status as an amputee, while surgeons search for amputees with typical adjustment patterns desirous for improved function.

While some may regard these findings as intuitive, these concepts have not entered the consciousness of caregivers to this patient population.¹² The findings of our study have changed how we personally approach the psychological issues of the new amputee, having early discussions regarding adjustment rather than focusing on “loss” or post-traumatic stress. Despite the limitations of the study, these findings highlight the need to focus on the amputee and the process of adjustment when considering possible upper limb transplantation. The findings may also serve as a useful starting point for creating standardized assessments for adjustment and reactions to upper extremity amputation.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was funded by the Julius N. Frankel Foundation and the Northwestern Memorial Foundation.

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