

# Perceptions of the Risks and Benefits of Upper Limb Transplantation among Individuals with Upper Limb Amputations

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**Background:** Upper limb transplantation is a life-enhancing rather than life-saving procedure. Little research has investigated how individuals with upper limb amputations perceive the benefits and risks of this complex procedure. To address this knowledge gap, the authors conducted qualitative research with individuals with upper limb amputations to understand their perspectives. **Methods:** Twenty-two individuals with upper limb amputations (age range, 24 to 73 years) participated in a focus group ( $n = 5$ ) or semistructured interview ( $n = 17$ ) about the benefits and risks of upper limb transplantation. Data were analyzed by means of constant comparative methods and a two-phase analysis process.

**Results:** Participants identified enhanced functional performance and improved appearance as the greatest potential benefits. Over half of participants indicated that function was a more important consideration than appearance. Enhanced function performance was a relative concept strongly influenced by individual expectations, which varied widely. Increased sensation, psychological well-being, and social acceptability were also described as potential benefits. Identified risks included health risks and the demands of transplantation and recovery, decreased functional performance, and uncertainty over outcomes from upper limb transplantation as an experimental procedure. Participants also expressed concerns regarding the psychological impact of negative outcomes and adverse events.

**Conclusions:** Participants had a large variation in their perceived importance of the many risks and benefits of upper limb transplantation. These findings elucidate how potential upper limb transplantation candidates evaluate the benefits and risks of the procedure. The findings can also inform important issues to address and outcomes to assess in the pretransplant and posttransplant settings. (*Plast. Reconstr. Surg.* 134: 00, 2014.)

Individuals with upper limb amputations may experience numerous changes in their functional, social, and emotional quality of life.<sup>1,2</sup> Historically, prosthetic restoration served as the

primary approach to improve outcomes; however, a minority of (up to 30 percent) individuals with upper limb amputations reject prosthetic use because of lack of functional benefit, discomfort, and/or lack of sensory feedback.<sup>3,4</sup> With advances in microsurgery and immunosuppression, upper limb transplantation has emerged as a potential alternative to prosthetic restoration. To date, over 90 upper limb transplantations have been performed worldwide.<sup>5,6</sup> The majority of upper limb transplantation recipients recover the functional and sensory ability to perform daily activities following transplantation.<sup>5</sup> Although upper limb

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transplantation may confer benefits for appearance, function, sensation, and quality of life, there are significant risks. Chronic immunosuppression, risk of rejection with limb loss, prolonged intensive rehabilitation regimen, and potential psychological difficulties are possible challenges following transplantation. Although future advances in tolerance induction may diminish the risks associated with chronic immunosuppression, patients and clinicians must carefully weigh the risk-to-benefit ratio.

Multidimensional quality of life could serve as an important consideration in the pretransplantation setting and as an index of the effectiveness of the procedure following transplantation. However, quality-of-life issues have not been adequately addressed in upper limb transplantation research.<sup>7,8</sup> As the first step in developing methodologically rigorous, patient-reported, pretransplantation and posttransplantation quality-of-life assessment tools, we examined the risks and benefits perceived by individuals with upper limb amputations when considering the effectiveness of upper limb transplantation.

## PATIENTS AND METHODS

### Design

This study used a focus group and individual semistructured interviews to examine perceptions of upper limb transplantation risks and benefits among individuals with upper limb amputations. We used an iterative data collection process to develop and refine our questioning route. First, we conducted a focus group with a convenience sample of individuals with upper limb amputations from the local community to identify the most salient issues to include in subsequent individual interviews. This study then guided the format for subsequent data collection. We conducted individual interviews by telephone to enable participation of individuals located remotely from the research institution and to enable participation of individuals with diverse clinical experiences and community living experiences.

We used a theoretically grounded maximum variability sampling strategy to ensure that we captured a range of clinical and demographic variables posited to influence long-term outcomes following transplantation, including sex, level of amputation, time since amputation, age, and prosthetic use status. Unlike quantitative research, a priori determination of the adequacy of the sample size is not possible. Data adequacy

is evaluated for theoretical saturation, a point of redundancy in data collection when no new concepts are elicited in three subsequent interviews. We constructed a data saturation grid to track emergent themes from the interviews.<sup>9</sup> Specifically, verbatim transcripts of interviews were analyzed using constant comparative methods and a two-phase analytic strategy proceeding from descriptive to conceptual coding.<sup>10,11</sup> Emergent themes were entered into the saturation grid. After 17 individual interviews, we determined that we had achieved saturation.

### Participants

Participants were recruited from the following sources: (1) the amputee programs at the Rehabilitation Institute of Chicago; (2) the plastic and reconstructive surgery clinics at Northwestern University Feinberg School of Medicine; (3) the Northwestern University Prosthetics-Orthotics Center; (4) study flyers provided to community-level prosthetists; and (5) an e-mail Listserv (L-Soft International, Inc., Bethesda, Md.) for individuals with upper limb amputations. Eligible participants were aged 18 years or older, fluent in English, and had a unilateral or bilateral upper limb amputation anywhere from the level of the wrist to the upper limb above the elbow. Participants were excluded from the study if they were unable to provide informed consent. Individuals were eligible regardless of prosthesis use.

Participants recruited from clinics were screened for eligibility by a member of the clinic staff and offered the opportunity to participate in either a focus group or an individual interview. Participants recruited from community-level prosthetic clinics and by means of amputee e-mail Listserv were screened verbally for eligibility. A trained researcher explained the study to all interested patients. Participants provided written informed consent before participation in the interview or focus group. Although similar procedures were used to identify patients for the focus group and the individual interviews, participants could not participate in both. The study was approved by the Northwestern University Institutional Review Board.

### Focus Group Procedures

Participants participated in a 90-minute focus group held at the Rehabilitation Institute of Chicago. After participants completed a brief sociodemographic questionnaire, two trained focus group moderators led participants through a discussion

AQ1

about their quality of life as amputees and their perceptions of upper limb restoration options, including upper limb transplantation. Moderators used a semistructured focus group guide to guide the discussion. The discussion followed an open-ended “concept elicitation” structure. The focus group was audio recorded and transcribed verbatim, with identifiers removed.

**Individual Interview Procedures**

Individual participants participated in a 30- to 60-minute semistructured interview led by a trained researcher. Interviews took place either face-to-face or by means of telephone. Similar to the procedure for the focus groups, the trained interviewer used a semistructured interview guide that followed an open-ended concept elicitation structure. All interviews were audio recorded and transcribed verbatim with identifiers removed. After the interview, participants were asked to complete a series of self-report questionnaires administered by means of a secure online platform as a part of a different phase of the study (data not reported here).

**Data Analysis**

Transcripts were reviewed for accuracy and analyzed using constant comparative methods and a two-phase analytic strategy proceeding from descriptive to conceptual coding.<sup>10,11</sup> The first author (S.E.J.) reviewed each transcript to identify themes related to amputees’ discussion of their quality of life since amputation and their perceptions of restorative options. Based on this initial review, the first author developed a coding scheme to classify participants’ comments relative to the themes identified. The study team reviewed the themes in the coding scheme and discussed areas of ambiguity with co-investigators with clinical and research expertise in upper limb amputation. Following development of the coding scheme, each transcript was coded independently by both the first author and the study coordinator. They compared coded transcripts for consistency and resolved discrepancies with discussion. The frequency of themes related to upper limb transplantation perceived risks and benefits were tabulated and the content was summarized to characterize the outcomes participants identified as most important when considering the patient’s perceptions of risks and benefits of upper limb transplantation.

**RESULTS**

Twenty-two participants took part in either a focus group (*n* = 5) or an individual interview

(*n* = 17). Participant sociodemographic characteristics are listed in Table 1 and clinical characteristics are listed in Table 2.

T1  
T2

**Benefits of Upper Limb Transplantation**

Participants identified six key areas of perceived benefit (Table 3). The demographic and clinical characteristics of participants who endorsed each benefit theme are listed in Tables 4 and 5.

T3  
T4,T5

**Functional Improvement**

The possibility of functional improvement following upper limb transplantation emerged as one of the most prominent benefit themes in participants’ discussions. However, many participants stated that they would only consider functional improvement a benefit if the level of posttransplantation functioning met their expectations. Participants described varying criteria for the level of functional improvement that would be required to constitute a benefit. A subset of participants (*n* = 6) who spontaneously used percentages to describe the level of improvement necessary to constitute a benefit reported a median of 90 percent (range, 40 to 90 percent) return of functionality as their criterion. Participants described their desired level of posttransplantation functional

**Table 1. Patient Sociodemographic Characteristics**

Characteristic	No. (%)
Total sample	22*
Focus group	5
Interviews	17
Sex	
Male	14 (70)
Female	6 (30)
Age, yr	
Median	56.5
Range	24–73
Race	
White	13 (65)
African American	3 (15)
American Indian/Alaskan Native	1 (5)
Native Hawaiian/Pacific Islander	1 (5)
Asian	2 (10)
Ethnicity	
Non-Hispanic/Latino	17 (89.5)
Hispanic/Latino	2 (10.5)
Marital status	
Married/partnered	10 (50)
Never married	5 (25)
Divorced	4 (20)
Widowed	1 (5)
Highest education	
Did not finish high school	3 (15)
High school/GED	3 (15)
Some college	3 (15)
College	4 (20)
Advanced degree	7 (35)

GED, General Educational Development.  
\*Two participants who completed interviews did not complete self-report questionnaires.

**Table 2. Patient Clinical Characteristics**

Characteristic	No. (%)
Total sample	22*
Focus group	5
Interviews	17
Amputation type	
Unilateral	17 (85)
Bilateral	3 (15)
Amputation level	
Below the elbow	10 (50)
At the elbow	2 (10)
Above the elbow	8 (40)
Dominant status of amputated arm	
Dominant	11 (55)
Nondominant	9 (45)
Reason for amputation	
Injury/accident	10 (50)
Disease/illness	8 (40)
Congenital	2 (10)
Years since amputation, yr	11
Median	11
Range	0.5–55

\*Two participants who completed interviews did not complete self-report questionnaires.

improvement in comparison with their original limb, their remaining intact limb, a prosthetic, or their general current level of functioning. They also described expectations for specific functional improvement, such as elbow range of motion and dexterity. Participants discussed functional improvement in terms of improved engagement in activities of daily living (e.g., showering, tying shoes), occupational activities (e.g., driving a bus), and leisure/recreational activities (e.g., swimming). The quotations listed in Table 3 illustrate participants' discussion of functional improvement as a perceived benefit.

### Appearance

The appearance of upper limb transplantation was another commonly perceived benefit. However, nearly half of participants who identified appearance as a potential benefit stated that it was less important than functioning. Many participants described appearance as a general benefit but not one that was personally important to them.

### Psychological Functioning

Participants also identified improved psychological functioning as a possible benefit. Several participants spoke about attaining a sense of normalcy as a benefit. Others described the potential psychological benefit that upper limb transplantation might offer individuals before amputation.

### Sensory Improvement

Improved sensory functioning emerged as another key benefit. However, 18.2 percent of participants ( $n = 4$ ) reported that they would not

consider sensory improvement a benefit, primarily because they had acceptable sensory functioning in their intact limb. Participants described sensory improvement as more beneficial in the context of bilateral amputation. For example, participants with bilateral amputations placed greater importance on sensory functioning, and a number of individuals with unilateral amputations stated that although they did not consider this an important benefit for themselves, they would expect it to be more important for individuals with bilateral amputations.

### Social Perception

Participants also identified social perception as a possible benefit. Participants discussed benefits of eliminating stigma, drawing less attention in public, and improved interpersonal relationships.

### Risks of Upper Limb Transplantation

Participants identified nine key areas of perceived risk (Table 6). The demographic and clinical characteristics of participants who endorsed each risk theme are presented in Tables 7 and 8. t6  
t7,t8

#### Negative Impact on Health

The impact of an upper limb transplant on health was the most discussed risk. Participants described a number of *known* risks related to the procedure, including medication requirements (31.8 percent), recovery time (22.7 percent), rehabilitation requirements (9.1 percent), and hospitalization need (4.5 percent). They also described *possible* risks and adverse events, including graft rejection (50.0 percent), infection/immunosuppression (36.4 percent), reamputation (31.8 percent), mortality (13.6 percent), pain (13.6 percent), surgical risks (13.6 percent), side effects (9.1 percent), organ failure (4.5 percent), and graft fragility (4.5 percent). The quotations in Table 4 illustrate the perceived health risks.

#### Psychological Functioning

Possible adverse impact on psychological functioning was cited by a number of participants as a perceived risk. Although some participants described psychological risk in terms of coping with a limb from a dead donor, others described psychological risk associated with potential health outcomes, such as reamputation. The quotations in Table 4 reflect this concern about psychological functioning as a risk following transplantation.

#### Uncertainty

Several areas of uncertainty were also cited as possible risks. When discussing uncertainty, participants expressed not being confident about

**Table 3. Upper Limb Transplant Benefits Identified by Participants**

Benefit Themes	No. (%) of Participants Identifying the Theme as a Benefit	Exemplar Quotations
Functional improvement	15 (68.2)	<p>“Oh, I think it could be extremely beneficial. That I think would actually probably, if it were functioning, that would be the closest you could get to truly having your arm back.”</p> <p>“If I wanted to go to that extent, I want it to be just as good as my right arm. If I’m not going to get to that, if it has some limitations and it’s a debilitating kind of a heavy, stumpy thing that I just kind of have to move around with my right arm because, ‘Oh, I’ve got a hand, but it doesn’t work,’ I’m not interested in that.”</p> <p>“Fine motor skills, you know, like I’d go back to sewing once more and craft work, like, you know, intricate use of your hands.”</p> <p>“I mean if I was with therapy able to comb my hair and tie my shoes and things like that I mean of course that would be a great outcome. ... I mean yeah that is basically a great outcome for me just being able to do everything, driving and showering and all that stuff. Even at work as a nurse starting an IV and doing that kind of thing because I don’t picture that obviously I don’t picture doing that ever again.”</p>
Appearance	11 (50.0)	<p>“Well, I mean definitely if I thought the hands were very compatible to me how I was before or just feminine.”</p>
Psychological functioning	7 (31.8)	<p>“You know those that wouldn’t want, you know, to even consider an amputation it may be something that would help them ease into the transition of a life without your own limb, maybe the idea that the possibility that they could have this and would make their life a little better.”</p>
Sensory improvement	6 (27.3)	<p>“Well, it depends on like if they could wire you up to where you really feel, you know like if you have feeling in it, that would be huge right there.”</p> <p>“Only that if it is a double amputee to be able to have tactile sensation. I think I mentioned that before but if you’re a single amputee, you have one working one, but just to be able to touch your child or pet an animal. I think that’s a very important part of being human. I think that even if you’re missing both of your hands, you can figure out how to do that with your feet or with other parts of your body, but I think it is a very essential part of being human to be able to touch somebody with your hand.”</p>
Social perception	6 (27.3)	<p>“One benefit is the old thing of okay I’m a right-arm amputee and everybody in this society shakes hands right-handed. So, I’m keenly aware, whenever I’m meeting new people and going on job interviews that that’s something I have to deal with. If somebody is maybe missing their right hand, a transplantation would be better because then they wouldn’t have that awkwardness. I’ve talked to other right-arm amputees, and they’ve experienced the same thing that I have with the handshaking. When you meet somebody, everybody extends their right hand, and then, they go, “Whoa.” For purely social purposes, slap a flesh and blood on the right side, if you need it, but on the left side, not so much. But, simply for social acceptance...”</p> <p>“Right and it might make it easier on my family if I didn’t stand out in the crowd. That’s the problem. People don’t forget you, you forget them but, oh yeah, you’re the one-armed person and you know they’ll think that in there head but they won’t say it.”</p>

what they could expect as outcomes. For example, several participants noted that the “experimental” status of the upper limb transplantation procedure was cited as a possible risk. They commented on the small number of transplantations performed thus far and the resulting lack of information to guide expectations. Another subset of participants identified uncertainty about the appearance of the transplanted limb as a possible risk. Uncertainty regarding the extent and timing of functional decline following transplantation was identified by a number of participants as a potential risk. Participants often described this risk as a decline from their current postamputation, pretransplantation

level of functioning. Several participants identified uncertainty about sensory impairment as a possible risk following transplantation.

**Financial Burden**

Concerns about the financial impact of the upper limb transplantation also emerged as a risk. Several participants expressed concern that the procedure would not be covered by insurance and would require out-of-pocket payment. Others expressed concern about their long-term ability to afford immunosuppression medication. Several participants acknowledged that the financial risks may diminish over time if research demonstrates that the outcomes justify the expense, such that

**Table 4. Sociodemographic Characteristics of Participants Who Identified Specific Benefit Themes\***

	Functional Improvement (%)	Appearance (%)	Psychological Functioning (%)	Sensory Improvement (%)	Social Perception (%)
Sex					
Male	76.9	70	71.4	40	40
Female	23.1	30	28.6	60	60
Ethnicity					
Not Hispanic/Latino	84.6	90	100	80	100
Hispanic/Latino	15.4	10	0	20	0
Race					
American Indian/Alaskan Native	7.7	10	0	20	0
Asian	15.4	10	28.6	0	0
Black/African American	7.7	0	0	0	0
Native Hawaiian/Pacific Islander	7.7	0	0	20	20
White	61.5	80	71.4	60	80
Education					
Did not finish high school	15.4	0	0	0	0
High school diploma	15.4	20	0	20	0
Some college	7.7	10	28.6	0	20
Bachelor's degree	23.1	20	14.3	20	20
Graduate/professional degree	38.5	50	57.1	60	60
Marital status					
Never married	23.1	20	28.6	40	40
Married/partnered	61.5	60	57.1	40	20
Divorced	15.4	20	14.3	20	40
Family income					
<\$20,000	15.4	20	0	20	0
\$20,000–\$40,000	23.1	0	14.3	0	0
\$40,000–\$60,000	0	10	0	0	0
\$60,000–\$80,000	15.4	10	28.6	20	40
>\$80,000	46.2	60	57.1	60	60

\*Two participants did not provide sociodemographic data.

**Table 5. Clinical Characteristics of Participants Who Identified Specific Benefit Themes\***

	Functional Improvement	Appearance	Psychological Functioning	Sensory Improvement	Social Perception
Mean years $\pm$ SD since amputation	16.2 $\pm$ 18.6	12.4 $\pm$ 17.7	26.3 $\pm$ 16.4	21.8 $\pm$ 17.7	14.9 $\pm$ 18.4
Loss of dominant limb, %					
Yes	53.8	50.0	42.9	60.0	60.0
No	46.2	50.0	57.1	40.0	40.0
Level of amputation, %					
Below elbow	53.8	40.0	57.1	60.0	40.0
At elbow	7.7	0.0	0.0	20.0	0.0
Above elbow	38.5	60.0	42.9	20.0	60.0

\*Two participants did not provide sociodemographic data.

upper limb transplantation becomes a standard practice covered by insurance.

## DISCUSSION

Upper limb transplantation is a potentially life-enhancing procedure with significant physical and psychological risks. Patients and clinicians must weigh the risks and benefits. Multidimensional quality-of-life outcomes could help evaluate patients' perspectives on the effectiveness of upper limb transplantation. We have limited data on quality-of-life outcomes in upper limb transplantation. As an initial step in developing a

quality-of-life outcomes tool for upper limb transplantation, we examined the benefits and risks perceived by individuals with upper limb amputations when considering the effectiveness of upper limb transplantation.

Participants identified upper limb transplantation benefits and risks, which varied in perceived importance. Functional improvement was the most frequently identified benefit. Other outcomes frequently emphasized in the upper limb transplantation literature, such as appearance and sensory improvement, were considerably less important than function to participants in this study. Participants described specific yet highly individualized

**Table 6. Upper Limb Transplant Risks Identified by Participants**

Risk Themes	No. (%) Endorsed	Exemplar Quotations
Negative impact on health and function	18 (81.8)	“The whole rehab aspect could take months and months so a big chunk out of your time I mean your life. Again, the medication problems associated with it. I think if it didn’t work that is a lot to go through and then your body rejects it or it is not functional. If you wanted it removed, again that is another whole procedure and rehab and everything else; getting back to just where I am at right now. There is a lot of risk to it.”
Uncertainty	13 (59.1)	“Yes, I mean you’d actually have two hands. That would be good but what if you can’t use it for a year in your recovery? It’s going to be like, oh. I mean did you break your hand or something? They’re still going to know. It would have to be useful too. I mean, it looks good but if it completely has like complete muscle atrophy that does no good because it’s still going to look different. So, I mean it would have to work for I think ... it would have to work. It would have to be able to get better and improve. If your hand never improves, then there is no reason to get it. Why would you get it?”
Psychological functioning	8 (36.4)	“The surgery would be bad enough but if it didn’t work, I don’t think my brain could handle that, you know what I mean? I’d be so disappointed they’d probably throw me under the dark side of the world, you know what I mean? So that would definitely be an issue.”
Financial	3 (13.6)	“I don’t think the insurance company would cover a lot of it.”

**Table 7. Sociodemographic Characteristics of Participants Who Identified Specific Risk Themes\***

	Negative Impact on Health (%)	Psychological Functioning (%)	Uncertainty (%)	Financial Burden (%)
Mean age ± SD, yr	54.5 ± 11.3	51.3 ± 14.4	50.5 ± 12.5	52.3 ± 25.2
Sex				
Male	62.5	57.1	66.7	100.0
Female	37.5	42.9	33.3	0.0
Ethnicity				
Not Hispanic/Latino	83.7	100.0	91.7	100.0
Hispanic/Latino	13.3	0.0	8.3	0.0
Race				
American Indian/Alaskan Native	6.3	0.0	8.3	0.0
Asian	6.3	14.3	16.7	0.0
Black/African American	12.5	28.6	8.3	33.3
Native Hawaiian/Pacific Islander	6.3	14.3	0.0	0.0
White	68.8	42.9	66.7	66.7
Education				
Did not finish high school	12.5	14.3	8.3	0.0
High school diploma/GED	18.8	14.3	25.0	0.0
Some college	18.8	28.6	8.3	33.3
Bachelor’s degree	12.5	28.6	16.7	66.7
Graduate/professional degree	37.5	14.3	41.7	0.0
Marital status				
Never married	18.8	14.3	25.0	33.3
Married/partnered	56.3	71.4	50.0	33.3
Divorced	25.0	14.3	25.0	33.3
Family income				
<\$20,000	25.0	28.6	25.0	33.3
\$20,000–\$40,000	12.5	14.3	16.7	0.0
\$40,000–\$60,000	0.0	0.0	8.3	33.3
\$60,000–\$80,000	18.8	14.3	25.0	0.0
>\$80,000	43.8	42.9	25.0	33.3

GED, General Educational Development.  
 \*Two participants did not provide sociodemographic data.

criteria for what would constitute satisfactory functional improvement following transplantation. This variation highlights the importance of evaluating functional outcomes over time, and the need to address functional expectations during the pretransplantation evaluation and the informed consent process. Transplantation candidates who

describe the success of the procedure as contingent on achievement of a specific level of functional improvement may benefit from pretransplantation education or counseling to readjust expectations for function and to determine whether upper limb transplantation is the right option for them. Otherwise, a transplanted arm with 80 percent of

**Table 8. Clinical Characteristics of Participants Who Identified Specific Risk Themes\***

	Negative Impact on Health	Psychological Functioning	Uncertainty	Financial Burden
Mean years $\pm$ SD since amputation	15.9 $\pm$ 17.8	18.2 $\pm$ 18.7	17.7 $\pm$ 18.6	13.4 $\pm$ 21.3
Loss of dominant limb, %				
Yes	56.3	57.1	58.3	66.7
No	43.8	42.9	41.7	33.3
Level of amputation, %				
Below elbow	37.5	71.4	41.7	100.0
At elbow	11.1	14.3	16.7	0.0
Above elbow	44.4	14.3	41.7	0.0

\*Two participants did not provide sociodemographic data.

the functionality of the opposite hand could be regarded as a failure by a patient expecting 90 percent functionality.

Participants also differed in the importance they placed on sensory improvement as a posttransplant benefit. Sensory functioning is important for activities of daily living. It can also play an important role in expressing and receiving physical affection in relationships. However, participants with unilateral amputations placed less importance on restoration of sensory functioning, describing satisfaction with the sensory functioning in their intact limb. Both individuals with unilateral and individuals with bilateral amputations indicated that sensory improvement would represent a much more important outcome in the case of bilateral limb loss.

When discussing upper limb transplantation risks, the majority of participants identified health risks as a concern. Although many participants described risks related to chronic immunosuppression, they also discussed the risk of reamputation. These findings highlight the importance of discussing potential health risks during the informed decision-making process, and the role of the transplant team in managing the health consequences of transplantation and the potential psychological sequelae associated with posttransplantation health. Of note, although increased risk for cancer constitutes one known risk associated with immunosuppression,<sup>12</sup> because this sample of participants was naive regarding this specific side effect, it did not emerge as a prominent risk theme. These findings help elucidate how individuals with upper limb amputations evaluate the benefits and risks of upper limb transplantation. In addition to informing decision-making and the informed consent process for upper limb transplantation, the findings also help identify multidimensional quality-of-life outcomes that might be important to assess from the patient's perspective. This is particularly important given that outcomes perceived as important by patients may differ from the more clinical outcomes of graft

survival, hospitalization time, episodes of rejection, movement, and return of sensibility that have historically been assessed when evaluating the effectiveness of upper limb transplantation.

### Limitations

Although it is possible that certain participant characteristics are associated with specific perceptions of transplantation benefits and risks, the qualitative design does not provide a sufficient sample to quantitatively examine differences in perceived risks and benefits between participant subgroups. Future research should examine how characteristics such as age, time since amputation, and sex are associated with perceptions of transplantation outcomes. Second, participants' prior knowledge of upper limb transplantation ranged widely, from none to extensive. Participants were not provided with information about upper limb transplantation outcomes during the course of the interviews. As the study was not designed to examine whether transplantation knowledge was associated with perception of benefits and risk, future research should examine whether the importance placed on certain outcomes varies by when participants are provided with information about published upper limb transplantation outcomes. Third, this study used focus group and individual interviews. It is possible that the differences in format resulted in differences in the types of responses participants provided to questions. Fourth, although the sample was geographically diverse and included participants from outside of the United States ( $n = 2$ ) because of the multiple recruitment sources, it is possible that cultural influences affect risk and benefit perceptions; thus, readers should generalize the findings cautiously to samples outside of the United States.

### FUTURE DIRECTIONS

We plan several steps to refine quality-of-life assessment in upper limb transplantation clinical

practice and research. To assess outcomes in a standardized way across centers, reliable and valid measures capturing these outcome domains are needed. Future work will focus on developing a battery of patient-reported outcome measures assessing the outcomes identified as important by upper limb amputees. Longitudinal administration of this upper limb patient-reported outcome battery will enable examination of reliability over time and sensitivity to change in upper limb amputees undergoing various restorative interventions, including transplantation. In addition, although this study included amputees with diverse sociodemographic and clinical characteristics, future research would benefit from larger and more diverse samples to ensure greater generalizability of findings.

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