

Identifying Health-Related Quality of Life Domains after Upper
Extremity Transplantation

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ABSTRACT

Objective: To identify the most important health-related quality of life (HRQOL) domains and patient-reported outcomes following upper extremity transplantation (UET) in individuals with upper extremity amputation.

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Design: Verbatim audio-recordings of individual interviews and focus groups were analyzed using qualitative, grounded theory-based methods to identify important domains of HRQOL and provide guidance for outcomes measurement following UET.

Setting: Individual interviews were conducted by phone. Focus groups were conducted at five upper extremity vascular composite allotransplantation (VCA) centers in the US and at an international conference of VCA experts.

Participants: Individual phone interviews were conducted with five individuals with lived experience of UET. Thirteen focus groups were conducted with a total of 59 clinical professionals involved in UET.

Interventions: Not applicable.

Main Outcome Measures: Not applicable.

Results: Twenty-eight key HRQOL domains were identified, including physical functioning and medical complications, positive and negative emotional functioning, and social participation, relationships, and independence. We identified key constructs for use in evaluation of the potentially substantial physical, medical, social, and emotional effects of UET.

Conclusions: This study provides an overview of the most important issues affecting HRQOL after UET, including several topics that are unique to individuals with UET. This information will be used to establish systematic, comprehensive, and longitudinal measurement of post-UET HRQOL outcomes.

Keywords: Hand transplant; patient-reported outcomes; quality of life; reconstructive

transplantation; upper extremity; upper-limb amputation; vascularized composite allotransplantation

List of Abbreviations:

BWH/MGH	Brigham and Women's Hospital/Massachusetts General Hospital
CDEs	Common Data Elements
HRQOL	Health-Related Quality of Life
IRB	Institutional Review Board
Neuro-QoL™	Quality of Life in Neurological Disorders
PRO	Patient Reported Outcome(s)
PROMIS®	Patient Reported Outcomes Measurement Information System
QOL	Quality of Life
SCI-FI	Spinal Cord Injury – Functional Index
SCI-QOL	Spinal Cord Injury – Quality of Life
TBI-QOL	Traumatic Brain Injury – Quality of Life
TORCH	Transplant Outcomes Research Collaborative for the Hand
UCLA	University of California – Los Angeles
UE	Upper Extremity
UET	Upper Extremity Transplantation
VCA	Vascularized Composite Allotransplantation

Individuals with upper extremity (UE) amputation face many challenges that even state-of-the-art prosthetics can't solve.¹⁻³ Hand loss – and the resultant loss of sensibility and

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prehension – affects nearly every activity of daily living, resulting in physical disability^{4,5} and, in many cases, significant psychological distress.^{6,7} In the US alone, there are over 500,000 individuals living with upper extremity amputation,⁸ and despite promising technological advances in upper extremity surgical care and prosthetic componentry (e.g., targeted muscle re-innervation, osseointegrated implants, LUKE arm), the rates of upper extremity prosthesis rejection remain high. Residual limb discomfort, prosthesis weight, and limited utility are among the most commonly cited reasons for rejection of upper extremity prosthetics.⁹ Furthermore, current commercially available prostheses cannot reliably replicate the complex prehensile and haptic functions of the native hand and arm.⁹⁻¹¹

Vascularized composite allotransplantation (VCA) of the UE offers unprecedented potential to enhance independence, restore physical functioning, and dramatically improve the quality of life (QOL) of individuals living with UE amputation.¹² However, the lack of standardized and validated outcomes measures, a lack of third-party payer support (due in large part to scarce outcomes data)¹³⁻¹⁵ and waning availability of research funding for clinical trials have limited the application of this procedure. UETs remain rare, with approximately 150 having been performed in fewer than 100 patients worldwide as of 2021,¹⁶⁻¹⁹ each requiring extensive private or research funding.

While some work has been done to collect and disseminate information on immunologic and functional outcomes²⁰ on a majority of UETs from around the world,¹⁷ physiologic viability alone cannot define success.^{13-15,21} Yet, to date, evaluations of UET outcomes have focused primarily on physiologic survival of the allotransplant, and

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secondarily on UE function.^{16,22,23} These efforts have demonstrated the viability of the UET. However, in contrast to the life-saving goal of solid organ transplant, the goal of UET is QOL improvement. Therefore, it is critical to assess HRQOL and other psychosocial outcomes after UET.²⁴ Unfortunately, assessments of HRQOL, including satisfaction with medical, psychological, social, and physical outcomes after UET, are lacking. In 2022, Bound Alberti and colleagues lamented the insufficiency of HRQOL measurement in VCA, and emphasized that it is currently conducted without reference to patient-reported outcomes (PRO).²⁵ There has been a dearth of studies examining HRQOL in individuals with UET. The few measures used have been overly broad (e.g., Medical Outcomes Study SF-36),²⁶ focus primarily on functional abilities (e.g., Disabilities of the Arm, Shoulder, and Hand),²⁷ or are not primarily reported from the patient's perspective (e.g., Hand Transplant Score System).²⁸ Systematically collected PRO data across all relevant HRQOL domains are necessary for widespread acceptance of UET,^{13-15,21} and experts have called for improved measurement of HRQOL after UET.^{14,25,29,30} Using PRO measures will amplify the patient's voice in the decision-making and treatment processes, enable clinicians to monitor changes in health and well-being across a wide variety of domains, and mitigate physical and psychosocial complications.

For individuals with UE amputation, UET has the potential to provide incredible improvement in functioning, sensation, psychosocial well-being, and overall HRQOL. Some of the most advanced UE prosthetics – for example, experimental multi-articulated prosthetics with direct neural interfaces – have also been shown to enhance functioning and increase the verisimilitude of sensation, including haptics and

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proprioception.³¹⁻³³ Recent work has shown that the use of such prosthetics can improve psychosocial well-being for individuals with UE amputation.^{34,35} What is unclear at this time is the type and extent of differences in outcomes between UET, traditional prosthetics, and these newer, more advanced devices.³⁶ A comprehensive assessment battery covering the most relevant and important physical, emotional, and social aspects of HRQOL is needed to compare the effectiveness of UET to other treatments for UE amputation. This paper provides the necessary data for developing a patient-centric assessment system for evaluating HRQOL after UET.

Studies that have administered HRQOL or psychosocial outcomes measures to UET recipients have been largely limited to single-case studies³⁷ or those with small sample sizes for quantitative research.³ There has been a small body of qualitative work to define the QOL topics salient to UET. For instance, Herrington and Parker (2019) conducted a narrative study with 5 UET recipients that identified topics including lifestyle, values, identity, affordability, and risks of immunosuppression, surgical complications, and graft-related illness.³⁸ They also synthesized the narratives into three ethical areas: treatment compliance, evolving goals over time, and the patient and family's conception of possible outcomes. More recently, Kinsley et al. (2021) conducted interviews with 4 UET recipients³⁹ and a group of 13 clinicians⁴⁰ to understand the perceived impact of psychosocial factors on UET outcomes. Results imply that factors such as realistic expectations, social support, and a positive attitude or coping style are associated with better perceived outcomes.^{39,40} This research recognizes important QOL topics for assessment; however, additional work is needed to identify the domains of QOL impacted by UET, with a comprehensive consideration of

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the three major areas of health: physical, emotional, and social. UET researchers have called for additional qualitative research to complement these small studies that will inform HRQOL measurement in UET candidates and recipients.³⁸

To select and/or develop HRQOL scales appropriate for a given population, one must first identify the most important domains and then evaluate extant scales for appropriateness. This paper is focused on the first goal.⁴¹ To identify essential measurement domains for recipients of UET, it is critical to discuss HRQOL issues and outcomes with UET stakeholders,⁴²⁻⁴⁶ including UET recipients and experts from a wide range of specialty areas. The qualitative methods used in this study have been applied to identify important HRQOL domains in other stakeholder populations.^{41,47-56} Specifically, this study included individual, open-ended interviews with people with lived experience of UET as well as focus groups with experts from VCA centers. All interviews and focus groups relied on a parallel set of open-ended questions, and all data were analyzed using the same grounded-theory-based techniques; thus, the interview and focus group data analysis methods and results are reported together.

Methods

Participants

To facilitate cooperative UET research, the principal investigators of the research team (SL, DT, LSL) established the Transplant Outcomes Research Collaborative for the Hand (TORCH) Consortium. TORCH investigators recruited English-speaking adults with a history of UET from the University of Pennsylvania (Penn) and the University of Louisville (Louisville) to participate in individual interviews. The research team also conducted focus groups with experts from the TORCH sites, including Penn and

Louisville, as well as the Johns Hopkins University School of Medicine, the University of California-Los Angeles (UCLA), and Harvard Medical School-affiliated facilities (Brigham and Women's Hospital/Massachusetts General Hospital; BWH/MGH).

Additional expert focus group sessions were conducted at the 2018 meeting of the American Society for Reconstructive Transplantation (ASRT). For all focus groups, experts were recruited if they had a minimum of one year of experience working in a clinical setting with individuals who are candidates for and/or recipients of UET.

Data Collection Procedures

Individual Interviews. Individual phone interviews were conducted by a trained data collector and a PhD-level co-investigator (CT) using a semi-structured discussion guide that started the session with open-ended questions: "*In what ways has your life changed since your hand transplant?*" and "*How has the hand transplant surgery affected your quality of life?*" Participants were encouraged to discuss anything that came to mind, positive or negative. All interviews were audio-recorded and transcribed. All participants provided informed consent and data collection was approved by each site's institutional review board.

Focus Groups. Two clinical psychologists with experience in focus group facilitation (DT, DV, and/or CT) moderated each group. Moderators started each focus group session with an open-ended question (e.g., "*How have your patients' lives been affected by hand transplantation?*") and encouraged participants to discuss freely. Moderators facilitated the discussion and asked follow-up questions when necessary. Participants were encouraged to interact with one another and consider all possible

impacts of UET. Focus group activities were approved by the University of Delaware IRB, and all participants provided written informed consent.

Qualitative Analysis Procedures

A grounded-theory-based approach^{41,50-54,56-60} was used to identify HRQOL impacts of UE transplant. Open coding was used to identify themes.⁵⁸ Next, an emergent coding strategy⁶¹ was employed to iteratively update the list of themes (i.e., the codebook)⁶² in Microsoft Excel based on re-review of all transcripts. Saturation^{63,64} was achieved when no new themes emerged. Throughout the coding process, the researchers harmonized terminology, eliminated redundant content,⁶⁵ and described the relationships among the codes (i.e., axial coding). Finally, using NVivo⁶⁶ software, all codes were applied to all transcripts as applicable (i.e., selective coding) to determine the frequency of mention of each HRQOL theme.

Results

Sample

Individual Interviews. Five UET recipients were interviewed by phone. Sample characteristics may be found in **Table 1**.

[INSERT TABLE 1 ABOUT HERE]

Focus Groups. Thirteen focus groups were held across five TORCH centers and at the 2018 ASRT meeting. Participants were 59 professionals involved in UET. See **Table 2** for detailed participant information.

[INSERT TABLE 2 ABOUT HERE]

Qualitative Results: Major Themes for HRQOL after UET

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The themes identified as important to HRQOL after UET span the areas of emotional, physical, and social health.

Emotional Health. The most salient HRQOL-related themes in the domain of Emotional Health (see **Table 3**) included negative (e.g., anger, anxiety/fear, depression, grief/loss) and positive (e.g., positive affect & well-being, resilience/grit, self-esteem/body image) concepts, as well as aspects of emotional adjustment (e.g., expectations, fitting in with others, integration and assimilation of the transplant). Exemplar quotes for each theme are shown in **Table 3**.

[INSERT TABLE 3 ABOUT HERE]

Among negative emotions, recipients mentioned frustration and anger as a reaction to loss of one's limb(s) as well as in the context of side effects or medical complications. Experts described acute psychological distress, including symptoms of depression, anxiety, and PTSD as common reactions to losing a limb. In the area of positive emotions, recipients reported more positive feelings after the transplant and described gratitude for their new hand(s). Experts also reported that many patients felt happy or satisfied following UET, and further described the trait of resilience as a key predictor of adjustment following UET.

Recipients described increased feelings of self-worth and emphasized a reduction in stigma and a return to normalcy. For individuals whose self-esteem was affected after their limb loss, the experience of integration and assimilation of a new hand that feels like a part of their body can restore dignity and wholeness. Experts described the transplant as providing normalcy for their patients and reducing patients' internal sense of being different from others. Experts did, however, point out that while

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patients report a return to normalcy in appearance, their life and routine must revolve around the transplant in a way that is far from normal.

Expectations contribute to HRQOL,^{67,68} and this was reiterated by study participants. One recipient discussed the challenges inherent in setting realistic expectations for transplant outcomes. Experts described higher concordance between patients' expectations and the reality of their post-transplant life as leading to better post-transplant adjustment.

Physical/Medical Health. In the physical domain (see **Table 4**), the most prominent themes encompassed aspects of the recipients' experiences with their new hand(s), including hand functioning, satisfaction with function, sensation and aesthetics, and medical challenges and complications. Exemplar quotes for each theme are shown in **Table 4**.

[INSERT TABLE 4 ABOUT HERE]

Experts and recipients reported that for some individuals, improved ability to complete self-care activities defined the success of the transplant. Recipients who were quadrimembral amputees focused on the drastic improvement in their ability to conduct activities such as showering or managing lower limb prostheses. Recipients and experts emphasized the importance of restoration of sensation in the hands, focusing not only on the physical sensations of touch, but also the social and reciprocal aspects of touch—for example, being able to touch and feel the touch of a loved one such as a spouse or young child—as a major improvement over a typical prosthesis.

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In the area of hand aesthetics, recipients emphasized the improvement over prostheses. Participants described concerns about appearance, size, and skin tone, which impacted the acceptance of the transplanted hand(s).

Experts and recipients also reported many post-surgical challenges and complications. These include the burden of intensive rehabilitation programs and frequent medical appointments, immunosuppressive medications, and lifestyle changes such as travel restrictions. The consequences of lifelong immunosuppression and rejection risks^{12,69-71} are similar to those affecting individuals with solid organ transplants.²³ Medication side effects, such as weight gain and trouble sleeping, were especially salient for recipients of UET.

Post-transplant medical challenges and risks for complications affected recipient HRQOL. Recipients and experts described hand therapy and medical care as requiring a major commitment of time and energy. Experts focused extensively on long-term effects of immunosuppression—such as kidney failure, infection, or malignant disease—and the difficulty recipients can have adhering to the medication regimen due to side effects.

Social Health. Recipients and experts made numerous comments about how UET affects participation, independence, social roles, and relationships (see **Table 5**).

[INSERT TABLE 5 ABOUT HERE]

Stakeholders reported that many recipients have more social engagement and confidence than before the transplant. However, clinicians pointed out that certain social activities (e.g., gardening) may need to be discontinued due to the risk of opportunistic infection. For recipients who work, the time needed for treatment is a drawback. At the

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same time, the UET gave some recipients a chance to work in a way that they couldn't otherwise. Exemplar quotes for each social theme are shown in **Table 5**.

The primary goal for many recipients was improved independence, particularly in the ability to care for oneself, which can have major HRQOL implications. Stakeholders described that independence worsens immediately after transplant, but increases over time and often exceeds one's pre-transplant level. For instance, some recipients reported requiring live-in personal care before transplant and then living alone after transplant. Independence is also relevant for social relationships, with pre-transplant caregiving burdens straining relationships with family members or partners. One recipient described that prior to her transplant, it felt "wrong" for her partner to also be in the role of "nurse." Recipients described relationships improving as their independence improved. Nevertheless, it was also reported that relationships can be strained by the demands of post-transplant care, particularly for recipients with significant complications or rejection episodes. Furthermore, stakeholders described the potentially profound economic burden of the transplant on recipients and their families. The financial burden of managing lifelong immunosuppression—including appointments, medications, and therapies— affects all recipients concurrently with limitations in employment. However, some recipients indicated that UET improved their economic situation, describing the transplant as a gateway to employment.

Stakeholders discussed positive impacts of UET on specific relationships, including those with intimate partners, children, and grandchildren. In these comments, the connections between improved sensation and bodily confidence with the transplant

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feeling more natural than a prosthetic was seen to have major social HRQOL implications.

Summary Altogether, participants described 28 domains of health and function important to HRQOL after UET (see **Table 6**).

[INSERT TABLE 6 ABOUT HERE]

Eight were unique to UET (**Table 6**, first row), while 20 were common to individuals who have other disabilities or medical conditions (**Table 6**, second row) and have been included in other HRQOL measurement systems [Patient Reported Outcomes Measurement Information System (PROMIS),⁵⁶ Quality of Life in Neurological Disorders (Neuro-QoL),⁷² Spinal Cord Injury Quality of Life (SCI-QOL),^{49,59,73} Spinal Cord Injury Functional Index (SCI-FI),^{74,75} Traumatic Brain Injury Quality of Life (TBI-QOL)^{60,76}].

Discussion

UET offers the potential to transform HRQOL and daily functioning for individuals with UE amputations. However, as recently as 2019, the Department of Defense Congressionally Directed Medical Research Programs reported that "...research regarding QOL and psychosocial factors in the reconstructive transplant field is in its infancy."⁷⁷ To date, measurement of individuals' HRQOL following UET has lagged, and psychosocial, HRQOL, and other PRO measurement tools have not been validated or even created. In 2022, Bound Alberti and colleagues wrote, "More research is required in VCA that explores patient...psychosocial experiences in order to gain a better understanding of how 'life-enhancement' might occur in a VCA transplant patient. It is this neglect of patient...voices that prevents the field from moving more towards standardized practice (pg. 2)."²⁵ Furthermore, to fully understand all the effects of UET

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on HRQOL, we must examine areas of HRQOL that have worsened as well as those that have improved after transplant and collect data from all candidates and recipients. Recent work has begun to examine psychosocial factors in VCA outcomes;^{39,78} however, without a more comprehensive understanding of the domain structure of HRQOL in this population, it is not clear which domains are the most important to assess. This study includes a diverse set of stakeholders to identify the most important domains for HRQOL after UET.

The systematic, comprehensive, and longitudinal assessment of HRQOL is vital to advancing the field of UET and understanding its effects on all aspects of recipients' lives. Given this procedure's life-enhancing (rather than life-saving) attributes and dynamic recovery course, it is critical to create an assessment battery that can be administered shortly before and after transplant, as well as at regular intervals for the life of the allograft. Systematic collection of data from the patient's perspective across a diverse set of variables measuring physical functioning, medical complications and symptoms, emotional well-being, and social outcomes is key to advancing scientific understanding and increasing the acceptance and use of UET. Systematic and comprehensive outcomes will also inform decision-making for potential candidates.

This project engaged UET stakeholders, including individuals who are recipients of UET and a variety of clinical experts, to ensure that the most relevant HRQOL domains were identified. The extremely small worldwide UET population necessitates collaboration and sharing of HRQOL data among the limited group of centers performing UET procedures.⁷⁷ As such, our team established the TORCH Consortium with the overarching goal of fostering and facilitating such collaboration.

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Many areas of functioning relevant to individuals with UET can be assessed by scales developed for the general population, such as measures from PROMIS or from similar measurement systems (e.g., Neuro-QoL, SCI-QOL, SCI-FI, TBI-QOL). These systems provide a variety of existing scales that are consistent with the domains identified through this study. This study has also identified domains that are unique to UET. Developing measures in these new areas will allow for assessment of aspects of HRQOL that are unique to individuals with UET. While the worldwide population of individuals with UET is too small to develop or validate new measures using accepted psychometric techniques, experimental measures in these new areas will still yield valuable descriptive information about subjectively important aspects of HRQOL for individuals with UET. This is particularly important for a procedure such as UET where there are tradeoffs between improvements in some areas (e.g., functioning, appearance) and increased complications in other areas (e.g., side effects of immunosuppressants). The current manuscript identifies the areas which would benefit from new, structured questions on issues that are unique and important to people with UET. We describe these targeted issues and domains in more detail in a parallel manuscript.⁷⁹ Currently, the absence of widespread implementation of HRQOL measures limits the promise and employment of UET to enhance functioning and well-being following UE amputation. It is critical for VCA centers to systematically assess HRQOL to support future decision-making about the value of UET as a treatment option for individuals who have sustained UE amputation.

Study Limitations. The techniques used in this project are in accordance with well-established standards for the identification of PRO domains and development of

PRO measures.⁸⁰⁻⁸³ Given the limited number of individuals who have received UET (i.e., about 40 people in the US and about 100 worldwide), individuals who are recipients of UET were assessed individually via interview, creating a difference in the methodology between experts and individuals with lived experience. The number of UET recipients was lower than the number of professionals who provided input. Finally, healthcare professionals have a unique relationship with their patients with UET, and may thus have reflected on similar HRQOL issues as did the UET recipients.

Conclusions

UET is often described as a procedure that improves HRQOL for persons with UE amputation, yet without data on the overall health, wellness, and psychosocial effects of the procedure on recipients in the short and long term, it is difficult to verify this claim. As the number of individuals who have received a UET is extremely small, this manuscript describes a collaborative endeavor of several UET centers. This study documents the most important issues affecting HRQOL after UET, including 20 domains that are common to other populations (e.g., upper extremity function, body image, independence; see **Table 6**, second row) as well as 8 issues unique to UET (e.g., sensation of the hand, hand aesthetics, fitting in, integration and assimilation of the transplant; see **Table 6**, first row). These results provide an HRQOL measurement framework for UET and represent a critical step toward establishing standardized, prospective assessments that can be utilized to improve outcome measurement following UET.

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Table 1. Demographic Characteristics for UE Transplant Recipients

Age (M, SD)	45 (12.6)
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HRQOL after Upper Extremity Transplant

Time Since Injury in Years (M, SD)	15.3 (5.1)
Time Since Transplant in Years (M, SD)	6.8 (3.5)
Gender (n)	
Male	2
Female	3
Ethnicity (n)	
Non-Hispanic	5
Race (n)	
White	4
Other	1
Education – Highest Grade (n)	
Completed high school (includes GED and vocational HS)	4
Bachelor’s degree	1
Transplant Location (n)	
Left only	1
Right only	1
Bilateral	3

HRQOL after Upper Extremity Transplant

Table 2. Focus Group Participant Characteristics

	Plastic surgeon (n = 12)	PT or OT (n = 10)	Hand surgeon (n = 9)	Transplant surgeon (n = 6)	Nurse or NP (n = 6)	Psychiatrist or psychologist (n = 4)	Social worker (n = 3)	Researcher (n = 3)	Other medical specialty (n = 6)	Total (n = 59)
<i>Time involved in UE transplant screening or surgeries</i>										
Average	8.5	8.1*	9.3	4.3	3.7	9.8	5.3	10.2	8.5*	7.7†
Range	1-13	3-18*	1-21	0-5.5	2-9	8-12	4.5-6*	1.5-20	1-20*	0-21
<i>Involvement in screening</i>										
Involved in candidate screening	75%	90%	55.56%	83.33%	66.67%	100%	100%	100%	83.3%	79.7%
<i>Involvement in Surgery</i>										
Involved in surgery	91.67%	–	100%	16.67%	16.67%	–	–	–	16.67%	38.98%
Number of surgeries*										
1-2	27.27%	–	25%	100%	–	–	–	–	100%	31.82%
3-5	45.45%	–	62.5%	–	100%	–	–	–	–	45.45%
6-10	36.36%	–	12.5%	–	–	–	–	–	–	22.73%

PT=physical therapist, OT=occupational therapist, NP=nurse practitioner

* data missing or incomplete for one participant

† data missing or incomplete for three participants

Table 3. Emotional Health: Participant-reported HRQOL domains with exemplar quotes

HRQOL after Upper Extremity Transplant

Domain	Mentioned in Recipient Interviews (n = 5)	Mentioned in Clinician Focus Groups (n = 13)	Sample Quotes from <i>Recipients of UET</i> and UET Clinicians
Anger	1	9	<i>"...a few months before the transplant I... really felt down and bad and was angry."</i> "So, that particular gentleman ended up losing his limb, and, boy, was he angry. So, even though he had reservations, when it did finally happen, he was really angry to have lost it, you know?"
Anxiety/Fear	2	8	<i>"I've always had a little bit of social anxiety, but it has increased tenfold when I lost my limbs."</i> "[Coming back to the hospital for repeated biopsies] sort of interrupts her normal, quote-unquote "lifestyle," and maybe sort of brings home the reality of what's going on and what we have to worry about in the back of your mind, the possibility of rejection and losing what you have."
Body Image	4	10	<i>"I still felt like I was this foreign object... on the outside and then on the inside, I was still me."</i> "I think that people want to get to a point where they are confident enough they have a limb that's close enough to human appearance to take it out of the sock or the pocket, or from behind their back, or the sleeve of their coat." "And they struggle with a lot of body image issues as well... I saw [one recipient] a day or two after her transplant, probably a day. And she was just in shock about the color of the skin because it didn't match."
Depression	5	8	<i>"I was never fully happy being an amputee, I wanted to have 2 hands, I mean, I am sure, most amputees would feel the same way. I mean there is periods of just being down or depressed about things, it is harder for you to do things or some things you can't do. So there were times like that."</i> <i>"I went into a pretty good depression, because I did feel insecure."</i> "This is going to be a lot of work before this thing functions; it's not going to be easy and it's not going to be perfect, then the depression sets it."
Grief/Loss	5	12	<i>"I was never fully happy being an amputee. I wanted to have 2 hands."</i> "They go through a...grieving process." "It's almost like a second...loss; they've already gone through it the first time and there's always a chance that they can go through it a second time."

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Health-related Self-efficacy	4	13	<p><u>"I just have to prepare [all of my] medication; once in a month I prepare for [the month], so I take the boxes, the boxes are for 4 days and I change the boxes every 4 days."</u></p> <p>"Even when things are going perfectly well, there's still a lot of responsibility for even just taking your meds, prophylaxis. The restrictions you have on your life about what you can eat, what you can't eat; can't go on a subway, can't go on – if you have a very committed patient, they're kind of all over all these things."</p>
Positive Affect & Well-being	5	12	<p><u>"... and the most important is that I feel better, and I'm very optimistic for the future."</u></p> <p><u>"Now I'm very grateful, very happy, and it is incredible. It's a new life for me."</u></p> <p>"But still he's like really, really happy. And he's now four years out and the last time I spoke to him he said I am so happy."</p>
Psychological Trauma/PTSD	0	4	<p>"Some of the patients, the last time they were in the hospital was because of a traumatic event, so they may have some PTSD related to just being hospitalized, let alone what it's from."</p>
Resilience/"Grit"	5	13	<p><u>"I had some very clear objectives and I wanted to go back to my school, I wanted to finish my school, and then I have many goals, that was to have the transplant, so I always had a new goal, and that was, the fact of having a goal helped me to move forward in every step, each step."</u></p> <p>"The people who have that resiliency, who have that grit, they're going to do well no matter what."</p> <p>"And some of the candidates that are really fine with it are probably more resilient folks... they just kind of accept it and are able to cope and handle in those situations, like, "Yeah, I had an accident. I'm okay, though."</p>
Self-esteem	4	9	<p><u>"You are more comfortable in being your own person, you just feel more comfortable in public settings ... nothing really has changed socially, you just feel better about yourself."</u></p> <p>"And it seems like she, in general, is just more self-confident, and she feels like she is able to kind of love herself more and kind of start over."</p> <p>"And because of the cosmesis it gives them that confidence to go forward and try these things... to be more outgoing, to feel more confident in the community..."</p>
Stigma	2	10	<p><u>"You are obviously different, you don't have 2 hands like everyone else. So, everyone just looks at you differently. If you are at a restaurant, you are just looked at differently."</u></p> <p><u>"After getting the hands, I felt like I could blend in more."</u></p> <p>"I think it's for some – we had one, a very young patient really was suffering with...the stigma of not having a hand; people staring at his amputation stump."</p>

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Expectations	2	12	<p><i>"I don't know you really ever completely prepare for [UET] and to feel like that because I have never felt like that and everything, nothing to compare it to."</i></p> <p>"No matter how many times I told them, the actual experience was unexpected."</p> <p>"I think hearing it and living it are two different forms of understanding."</p>
Fitting In (i.e., Semblance of Normality)	4	12	<p><i>"[The transplant] makes me feel like a normal woman."</i></p> <p><i>"You are looked at just like anyone else, a normal person in the world."</i></p> <p><i>"Since the transplant, I've been able to work, I've been able to date, I've been able to have an animal, I've been able to [do] everything that normal people do."</i></p> <p><i>"It's is a 2-handed world. So, when you go from having 2 hands to 1 hand, then back to 2 hands again, I mean it is an adjustment, but lot of times, I don't even remember being an amputee any more, it just is automatic that you are back to 2 hands, so you can do everything in a normal way again."</i></p> <p>"But if you drill down to what the patient really wants it's simpler. I think they just want to be normal and whatever that means to the patient."</p>
Integration and Assimilation of the Transplant (i.e., Sense of Wholeness)	3	12	<p><i>"I feel more like a whole human being. I only miss [my feet] now, but before I was really missing 4 important parts of my body, now it is only the legs that are missing, the feet, but, at least like the high part of my body is not, something is not missing. [This] is really important for the way I had seen myself, so I feel more complete."</i></p> <p>"But I think without that feeling of wholeness, there's a sense of embarrassment and shame."</p> <p>"I think that it not only increases the completeness, the wholeness, and the functionality, but it enhances a lot of these folks' social presence."</p>

Note: **Bold** text indicates domains that are novel to UE transplant as compared to other traumatic injury/amputation populations.

Table 4. Physical Function and Symptoms: Participant-reported HRQOL domains with exemplar quotes

Domain	Subdomain	Mentioned in Recipient Interviews (n = 5)	Mentioned in Clinician Focus Groups (n = 13)	Sample Quotes from <i>Recipients of UET</i> and UET Clinicians
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Hand Function	5	13	<p><u>"Without my prosthetic arms in my home I was able to do some things, but when I went outside with my prosthetic arms, I wasn't able to do anything."</u></p> <p><u>"I want to have a child, my own child, and I consider that I couldn't have one before because I couldn't hold him in my arms with my prosthetic hands."</u></p> <p><u>"I can just put my finger on my face...or just put cream on my hands and then put it directly to my face. Those are the things that I couldn't do for years... Then also washing my hands, something that I really missed before."</u></p> <p>"And I think it might be because they have completely lost that function without having hands and then when they get that back even something as simple as just lifting a cup of water brings them joy and they get excited over that."</p>
Fine Motor Function	4	9	<p><u>"I can't cut my meat, I can't cook. I can't open my button, small button..."</u></p> <p>"And then as motor starts to come back, it's very gross motor motion and then fine-tuning that to more fine motor coordination."</p> <p>"You want functioning to improve, but the return of very intricate fine motor tasks or lifting heavy things, they're too extreme."</p>
Self-Care	5	13	<p><u>"So, the big change is that I can take my shower by myself."</u></p> <p>"The most important parts [of being independent] are feeding, transportation, and that means literally getting around the house, or anywhere else. Like can I drive, can I push my own wheelchair, can I get myself up on my own prosthetics, and then hygiene."</p>
Sensation	4	10	<p><u>"Sensation is so important."</u></p> <p><u>"I can feel what I touch, I can feel if it is hot or if it is cold, if it is soft, or if it is itchy or anything, and that is the way that is very or so, that is something that is very important for me."</u></p> <p>"Particularly [for] eating and hygiene issues, the ability to have some sort of tactile sensation, and the quality and texture, and tactile capabilities of human skin would be significantly better."</p>

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Satisfaction with Hand	4	13	<p><i>"I am very, very satisfied about my hand transplant... before my hand transplant it was very, very difficult."</i></p> <p><i>"But she's happy with the function that she has and the ability to go out in society, she sees them as acceptable."</i></p>
Satisfaction with Hand Function	3	13	<p><i>"My hand functions wonderfully. I don't have any complaints whatsoever."</i></p> <p><i>"One of the things I've been interested in is it is a bit of a roller coaster ride. So generally, after they wake up from the surgery they're really excited because they're physically restored. But then they go through this sort of valley where they're not functional. They're actually decreasing in their overall function. And it would be nice to better understand that so that we can frame the expectations in future patients."</i></p>
Satisfaction with Sensation	2	7	<p><i>"...Quality of life is better with the hand transplant because [I can] touch..."</i></p> <p><i>"When this person got sensation, he was as happy as can be."</i></p> <p><i>"[Transplanted hands] don't look like your hands, [they] don't move like your hands, [other people] see that."</i></p> <p><i>"It has always been important for me to have new real hands and not plastic or silicone hands."</i></p>
Satisfaction with Hand Aesthetics	2	12	<p><i>"And in fact we'll often see patients feel super-satisfied with a result in their upper limb, the moment it aesthetically looks better, even if it far falls short of our functional goals for them, because they'll say ah, job well done, you know, this looks like a hand."</i></p> <p><i>"[I have heard recipients say things like] I just, I'd like to have something that makes me look a little more normal, and I'll feel more comfortable going out in public settings. And even if I need to roll my sleeves down because I have scars, it's okay, it'll still look better than, you know, having a prosthetic, which tends to really stick out, you know, or not having a limb at all."</i></p>
Post-Surgical Challenges and Complications	5	12	<p><i>"The hand transplant physically is great, the medication with the transplant really messed up my kidneys though..."</i></p> <p><i>"I have had a couple of episodes where they have given me massive [steroids] and... it makes you feel bad..."</i></p>

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			<p>"[The patient] had multiple [instances of antibody-mediated rejection] which were really hard to treat. And this was I think ... really, really hard because [it] was constant or [the patient] was repetitively hospitalized. And this was something [the patient] did not anticipate also in their decision of getting the hand transplant."</p>
			<p><i>"I don't like steroids. The steroids make you feel icky."</i></p> <p><i>"Because of the cortisone...my face was not the same...I was very fat [in my] face."</i></p> <p><i>"I went through dialysis and had to have a kidney transplant."</i></p> <p>"Now I have diabetes. Now I have skin cancer. Now I have renal failure."</p> <p>"Like with the prednisone on steroids you can gain weight, have insomnia and not sleep as well."</p> <p>"There's many different side effects. I mean one of the most obvious ones, particularly when you're thinking about function of an extremity, is tremor."</p>
Medication (Immunosuppression) side effects	4	7	
			<p><i>"The pain...is not as strong."</i></p> <p>"They will have pain because of scar build up, tightness. So physical therapy is not comfortable either. Therapy pushed them mentally and also its painful."</p> <p><i>"The hand therapy was extensive – hours and hours a day – just doing small things with my hands like, picking up small items or gripping things...it was 3 hours a day every day for 3 years."</i></p> <p>"For all of the gain in function, [or] maybe it's just even the aesthetics of actually going out in public and having a hand, so now there's all the doctor visits and now there's all the medicines and now there's all the going to the therapy and there's the blood tests and there's the complications of the immunosuppression."</p> <p>"And I think the lack of compliance with either medication or therapy of course has detrimental effects."</p>
Pain Interference	1	5	
Treatment Adherence	4	12	

Note: **Bold** text indicates domains or subdomains that are novel to UE transplant as compared to other traumatic injury/amputation populations.

Table 5. Social Health & Participation: Participant-reported HRQOL domains with exemplar quotes

Domain	Mentioned in Recipient Interviews (n = 5)	Mentioned in Clinician Focus Groups (n = 13)	Sample Quotes from <i>Recipients of UET</i> and UET Clinicians
Ability to Participate in SRA	5	13	<p><u>"With my new hands, I am able to go outside and to get a social life."</u></p> <p><u>"After my injury, I could not work for about 10 years. There is no way I could have gone back to work without transplant."</u></p> <p>"I think another component that has been important that we're noticing in our patients is the impact – the impact that the hand has caused on them, which, in addition, affects their relationships with the people around them, if that makes sense, which in all of them, at least in all of our case areas, has had an impact, with not only the caregivers, but at work or in their social setting with friends and extended family."</p> <p>"And then sort of top-tier [benefits of the transplant are things like], can I touch and hold my kid's hand, and shake hands with someone else at church, and feel like they're feeling skin when they're shaking my hand?"</p>
Satisfaction with SRA	5	4	<p><u>"I am very happy to go outside, to go to the restaurant, to go and to do shopping."</u></p> <p>"...[T]he autonomy and independence of the human connection is always the thing that was the most stark, for me when I met patients, took care of the patients, and sort of saw how they were interacting with people in the room."</p>
Independence	5	13	<p><u>"[In] the four years before I had the transplant, I was very dependent on my [family member], and since receiving the limbs, I've become independent."</u></p> <p><u>"I almost don't have to ask people for anything. I really feel free."</u></p> <p>"With our last transplant [recipient], it was a matter of being independent. She was a quadruple amputee, and [before the transplant] she's not able to escape a fire, she's not able to put her prosthesis on."</p>

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Asking for Help	3	9	<p><u>"The relationship [with my family member] has gotten better because the relationship is not judged anymore on the fact that I have to ask [for help with things or not]."</u></p> <p><u>"I have noticed that since the hand transplants, I almost don't have to ask people for anything."</u></p> <p>"It seems, sometimes, that they reverted to the relationship they had when they were maybe 13 years old, where she was, wanting to be more independent but could not be. She was dependent on her mother, and her mother still wanted some level of control over her life and decision-making, and she was obviously actively involved in daily care."</p>
Economic QOL	1	11	<p><u>"I bought an apartment 2 years ago." [recipient, after describing her ability to work after her transplant]</u></p> <p>"All this unforeseen sort of ancillary financial stress about it is not insignificant.... I mean, there have been people where this person's a pretty good candidate, but they just are going to be massively overburdened financially..."</p> <p>"Finances also make a difference. There is no health insurance in America that recognizes hand transplant as a treatment."</p> <p>"If you're able to earn a wage, that's a huge step forward to feeling more normalcy, and being back into society."</p>
Social Support	2	12	<p><u>"I had a very good support system, I really did not, I had mostly the same friends. My wife was always great, you know support for me."</u></p> <p>"The other thing I think that we look [for] is social support, the social network, are they embedded in...family support or [a spouse], that really could help them get through this."</p>
Intimate Relationships	2	8	<p><u>"I can put my hand on [my partner] and I can touch him or feel him or touch his hair or things like that."</u></p> <p><u>"I can touch [my partner], I can feel him in my hands, and so I can hold his hands and things like that change a lot in my perception, and I think also in his perception, I mean if it fits him or not him in the perception of a man like to have a girlfriend who has hands and to have a girlfriend that does not have hands, I am sure it might change in his mind like, it's natural."</u></p> <p>"...So, the hand actually plays an important role, because we express intimacy, we touch the face, we hold the hand, we gesture with our hands."</p> <p>"Your patients talk about holding hands with their spouse, and feeling like they're making contact with a body part."</p>

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Table 6. HRQOL Themes Identified as Important for UET

	Physical/Medical Health	Mental/Emotional	Social Participation
Themes Novel to UET	Sensation of the Hand Satisfaction with Hand	Expectations Fitting In	
<i>Themes that are novel to UE transplant as compared to other traumatic injury/amputation populations</i>	Satisfaction with Hand Function Satisfaction with Hand Sensation Satisfaction with Hand Aesthetics UET Treatment Adherence UET Post-Surgical Challenges & Complications UET Medication Side Effects	Integration & Assimilation of Transplant	
Other Relevant Themes	Pain Interference ^{a,d,e} Upper Extremity Function ^b Fine Motor Function ^c Self-Care ^c	Anger ^{a,e} Anxiety/Fear ^{a,b,d,e} Body Image ^f Depression ^{a,b,d,e} Grief/Loss ^{d,e} Health-related Self-efficacy ^a Positive Affect & Well-being ^{b,d,e} Psychological Trauma ^{d,e} Resilience/Grit ^{d,e} Self-esteem ^{d,e} Stigma ^{b,d,e}	Ability to Participate in SRA ^{a,b,d,e} Social Support ^a Satisfaction with SRA ^{a,b,d,e} Asking for Help ^{d,e} Independence ^{d,e} Economic QOL ⁵⁶ Intimate Relationships & Sexual Function ^a

Note: UET = Upper Extremity Transplant; SRA = Social Roles & Activities

Overlap with existing HRQOL measurement systems is noted as follows: ^aPROMIS, ^bNeuro-QoL, ^cSCI-FI, ^dSCI-QOL, ^eTBI-QOL, ^fItem bank in development