

# Perceptions of Quality of Life among Face Transplant Recipients: A Qualitative Content Analysis

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**Background:** The aim of facial transplantation (FT) was to enhance quality of life (QoL) for individuals living with severe facial disfigurement. Yet QoL has proved challenging to assess, as the field lacks a unified approach for incorporating FT recipients' perspectives into meaningful QoL measures. In this study, we review FT recipients' self-reported QoL through a qualitative analysis of publicly available posttransplant interviews to identify the aspects of QoL they report as meaningful. **Methods:** A conventional qualitative content analysis was conducted through a comprehensive review of publicly available interviews with FT recipients. Data sources included English language audio, video, and online print interviews from 2008 to 2019. Recipient interview data were obtained for both partial and full FT recipients located in North America through Google and YouTube searches. Audio and video interviews were transcribed, and an inductive content analysis was used to develop and apply a coding scheme to all interview transcripts. Codes were subsequently grouped into categories and interpreted into themes.

**Results:** In total, 81 interviews representing 12 North American, English-speaking face transplant recipients were collected from internet sources, of which 74 interviews remained after exclusion criteria were applied. Three themes emerged representing the dimensions of QoL emphasized by FT recipients: (1) reconstitution and re-embodiment of physical/corporeal selfhood, (2) integrity of cognitive/emotional selfhood, and (3) social selfhood and the importance of social integration.

**Conclusions:** This study provides an insight into North American FT recipients' experiences, values, and goals and illuminates critical aspects of QoL that are meaningful to this unique patient population, which may not be fully captured by currently available assessment tools. The themes developed in this study link facets of QoL to the overall significance of embodied selfhood among FT recipients and will help inform the future development of FT-specific patient-reported QoL outcome measures. (*Plast Reconstr Surg Glob Open* 2020;8:e2956; doi: [10.1097/GOX.0000000000002956](https://doi.org/10.1097/GOX.0000000000002956); Published online 17 August 2020.)

## INTRODUCTION

Facial transplantation (FT) aims to improve the quality of life (QoL) of individuals living with severe facial disfigurement. The World Health Organization defines QoL

as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment.”<sup>1</sup> The field of FT is yet to reach a consensus on how to best define and evaluate QoL for FT recipients; furthermore, targeted measures incorporating recipients’ perspectives and reflecting their lived experiences of FT have not yet been developed.<sup>2</sup>

In a recent report, Aycart et al<sup>3</sup> identified over 25 different instruments that have been previously used to evaluate QoL after FT. The wide variety of available tools

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not only reflects the complexity and multidisciplinary nature of this procedure, but also implies that no one essential tool exists for comprehensive QoL assessment. Determination of what constitutes a successful outcome should ideally reflect the physical, psychological, and social domains of QoL and should incorporate FT recipients' values and goals. The optimal approach to assessing QoL in FT must therefore be sufficiently flexible to account for individual variations and sensitive enough to capture the nuances that are meaningful to each FT recipient.

The use of patient-reported outcome metrics (PROMs) represents one potential QoL assessment approach, which centers on patients' perspectives. Interest in PROM has increased exponentially over the past 15 years and includes quantitative and/or qualitative components.<sup>4,5</sup> Previous studies have shown the importance of qualitative analysis in providing a framework for PROM production.<sup>6-8</sup> However, the limited number and heterogeneity of FT procedures performed to date make it particularly challenging to recruit the research sample that would be needed to develop PROMs specific to FT recipients. Until a large enough sample of FT recipients exists to conduct prospective in-depth qualitative research, first-hand accounts of patient experiences articulated through publicly available print and video media represent a substantial source of data that may shed light on post-FT QoL. To date, these data have not yet been examined systematically. Through secondary analysis of publicly available interview data, this study illuminates facets of FT recipients' lived experiences expressed through their own words, which in turn may inform the future development of meaningful FT-specific QoL PROMs.

## METHODS

### Conventional Qualitative Content Analysis

Conventional qualitative content analysis is focused on providing a description of a phenomenon, in this case FT recipients' perceptions of QoL following FT.<sup>3,9</sup> Content analysis originated as a quantitative approach to analyzing textual data in areas such as communication.<sup>10</sup> Subsequently, the method was adapted for use in qualitative analysis and for interpretation of interviews and textual data to develop novel understanding of complex concepts. The methodological approach is typically systematized as follows: (1) a coding phase that involves the coding and categorization of meaning units from interview transcripts, and (2) a theme development phase during which investigators interpret categories into themes that enrich the understanding of a phenomenon.<sup>9</sup> This research design is particularly relevant to areas in which theory or research is limited<sup>9</sup> and is therefore well-suited to the exploration of FT recipients' perspectives on posttransplant QoL. The investigators were guided by a broad conceptualization of QoL, as articulated by the World Health Organization,<sup>1</sup> which informed the study design.

### Data Collection Strategies

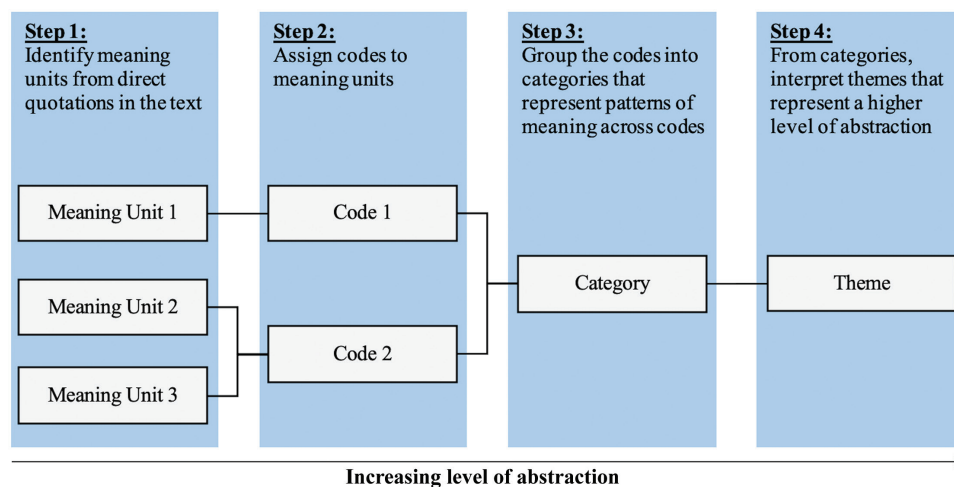
English-language posttransplant interviews of FT recipients whose FT procedures were conducted in North America and published online before September 27, 2019, were included in this study. Two investigators (J.A.G. and O.L.) performed comprehensive Google and YouTube searches to obtain publicly available interviews with FT recipients. Systematic searches were conducted for each FT recipient using the keywords: “[Recipient Name],” “[Recipient Name] face transplant,” “[Recipient Name] face transplant interview,” “[Hospital Name] face transplant,” and “[Hospital Name] face transplant interview.” All English-language online print, video, and audio interviews of FT recipients were considered for this study. Duplicate interviews were excluded, as were interviews that did not reference QoL. Video and audio files were then transcribed into written form.

### Data Analysis

Study data were analyzed following a conventional qualitative content analysis protocol.<sup>9</sup> After transcription, 2 investigators (J.A.G. and L.L.K.) independently read all the transcripts to achieve immersion and to develop a holistic understanding of the phenomenon of QoL as reported by FT recipients. Portions of the transcripts pertaining to QoL were highlighted, and notes were used to capture key information and concepts. Throughout this process, patterns across responses were observed, and the 2 researchers created codes to label novel and recurring concepts. Codes were gathered across all transcripts to produce a codebook, where each code included is a word or phrase that represents a different thought articulated by FT recipients. The codebook was developed using an inductive approach to identify preliminary coding structures from the interview data. Following completion of the codebook, the 2 investigators independently coded all transcripts. The coded transcripts were then reviewed together, and preliminary categories were generated by grouping the codes to reflect common code patterns. The 2 researchers reread the transcripts in their entirety and interpreted the identified categories into themes, representing a further level of abstraction. In addition, all co-authors of this study provided feedback in developing categories and themes, as well as reviewing the study findings. [Figure 1](#) shows the hierarchical organization of level of interpretation from meaning units (direct quotations), to codes, categories, and themes.

## RESULTS

In total, 81 posttransplant interviews from 12 FT recipients (77% men; 77% full face transplants; and average age, 39 ± 12.28 years) were identified, and 74 interviews met inclusion criteria after removing duplicates. Of these 74 interviews, there were 48 audio and video interviews and 26 print interviews. A comprehensive review of the transcripts led to the development of 57 codes referring to QoL. The codes identified were grouped into 10 categories that represented patterns of meaning across codes. The frequency of individual categories per recipient was



**Fig. 1.** Schematic of hierarchical organization of conventional qualitative content analysis and methodology—from meaning units (direct quotations), to codes, categories, and themes.

indicative of the aspects of QoL that gained focus. The categories established were then interpreted to formulate 3 themes (Table 1): “reconstitution and re-embodiment of physical/corporeal selfhood,” “integrity of cognitive/emotional selfhood,” and “social selfhood and the importance of social integration.”

#### **Reconstitution and Re-embodiment of Physical/Corporeal Selfhood**

The categories developed in this section were interpreted as expressing the ways in which FT recipients navigated their physical and aesthetic sense of embodied selfhood following FT. For some, regaining their former physical self-concept before FT was an express desire. Others reported a process of adjusting to FT and reintegrating a sense of embodied selfhood, or “wholeness,” that was in some ways distinct from their previous sense of self, yet recognizable. FT recipients’ characterization of their post-FT physical selves and sense of bodily integrity in relation to their former corporeal sense of self was expressed across categories. FT recipients emphasized several outcomes relating to their physical function and aesthetic appearance. These were referenced explicitly through regaining both motor and sensory function, significant changes in aesthetic features of the face, and physical challenges during transplant recovery. All FT recipients regarded regaining motor function, sensory function, or both as impacting their postoperative QoL. These features typically had direct implication for other areas of QoL, such as the ability to communicate and function independently. Eight of 12 FT recipients discussed specific aesthetic features, and 4 of these recipients cited undergoing multiple aesthetic surgical revision procedures. Additionally, 8 FT recipients discussed physical resemblance to their former self as important. Finally, overcoming specific complications, such as immune rejection, and persevering through significant pain and discomfort during recovery were significant physical challenges that 6 FT recipients reported as meaningful. Despite these cited physical challenges, the majority of FT recipients reported feeling positive about their aesthetic and functional outcomes.

#### **Integrity of Cognitive/Emotional Selfhood**

The dialogue of psychological state, emotional well-being, and sense of self illustrated the significance of cognitive and emotional aspects of selfhood. The psychological and emotional well-being of FT recipients represented an important dimension of QoL across all transcripts. Statements that either directly or indirectly referenced recognition of self and/or resemblance to the donor were detected among 9 of the 12 FT recipients. Nearly all FT recipients described perceiving their new face as themselves, with some describing the core of their sense of self as a constant internal element not tied to malleable external features. Psychological and emotional well-being and mental illness were separated categorically according to the “2 continua” model of mental health, which allows for differentiation of the presence or absence of mental illness and psychological, emotional, and social well-being (in this study, social well-being was captured within the third theme).<sup>11</sup> One FT recipient indicated that mental illness and maintaining mental health posed continuous challenges in their daily life. However, 7 of the 12 recipients reported that “life is good,” and 6 recipients indicated they were happier than before undergoing FT.

#### **Social Selfhood and the Importance of Social Integration**

The face represents a critical social feature that is important for communication, independence, and public blending.<sup>2,12</sup> Living with facial disfigurement causes many FT recipients to live in isolation from their family, friends, and society before transplantation. The combination of social stigma and resultant social withdrawal often leads to adverse mental health outcomes, including depression, anxiety, and even suicidal ideation or suicide attempts.<sup>13–15</sup> Analysis of the transcripts showed that social recovery in some form or the other was important for QoL among FT recipients. Eight of the 12 recipients mentioned that they were socially ostracized in public before undergoing FT and described the distress they experienced as a result of social stigma. All FT recipients included in this study reported improved social reintegration through

**Table 1. Analysis of Meaning Units, Codes, and Categories that Resulted in the Identification of 3 Themes**

Example Meaning Unit	Codes	Category (Category Frequency)*	Theme
<p>“I have regained more sensation in the past year than I anticipated. I can use my face quite a bit more than what I had expected. I am, as was one of my desires, able to feel my daughter’s kisses now, which brought me to tears on more than one occasion.”—Dallas Wiens</p> <p>“Right. It’s not like it used to be. But, after you live with something you hate for 14 years, and you look at something in the mirror and look as great as I look now, I’m totally satisfied right now.”—Patrick Hardison</p> <p>“All face transplants have shown signs of rejection at one time or another. I’ve had 3 episodes. They usually happen in the winter months. Sometimes I put a steroid cream on my face, and sometimes my medication is increased. It usually takes about 6 weeks for the biopsies to return to normal. It’s nothing to get upset about.”—Carmen Blandin Tarleton</p>	<p><i>Motor</i>: eating, speaking, breathing, blinking, facial expression, drinking, kissing, general functional improvement</p> <p><i>Sensory</i>: facial sensation, smell, taste, visual acuity, hearing</p> <p>positive/negative facial feature attitude, revisionary procedures, physical resemblance to former face, general aesthetic features, specific aesthetic features (nose, mouth, eyes, skin, facial hair, scalp hair, scarring, teeth)</p> <p>Pain, swelling, discomfort, rejection, nausea, sleep</p>	<p>Regaining physical function (12 FT recipients)</p> <p>Aesthetic changes (8 FT recipients)</p> <p>Physical symptoms (6 FT recipients)</p>	<p>Reconstituting and re-embodiment physical/corporeal selfhood</p>
<p>“Well, I had never contemplated my identity prior to this. Now that I had the experience of being a disfigured person and then having a new face, it has been quite strange to look in the mirror nowadays. I actually had my first dream last week, and in my dream, me with my new face. And I hadn’t had a dream yet. So, we are very connected to our identity through our face. I have always concentrated on the core of who I am because my looks have changed so dramatically over a short period of time.”—Carmen Blandin Tarleton</p> <p>I: “Do you still struggle with depression?” C: “Yeah ... occasionally. It’s not a daily fight anymore. But yeah, there are still days when I feel depressed.”—Cameron Underwood</p> <p>“I want to be positive. I want to move on. That’s what I said. Everything’s going to be great from here on out. It’s going to be good.”—Connie Culp</p>	<p>Resemblance to former face/donor face, new face as self, acceptance of new face, identity as internal</p> <p>Depression, suicidal ideations, anxiety</p> <p>Happiness, insecurity, adjustment to change, life is good, general psychological change, gratitude (to donor and donor family), overcoming adversity, perseverance</p>	<p>Recognition of self (12 FT recipients)</p> <p>Mental illness (1 FT recipient)</p> <p>Psychological and emotional well-being (7 FT recipients)</p>	<p>Integrity of cognitive/emotional selfhood</p>
<p>“The biggest difference is just being able to go out without a mask and without people staring at me.”—Cameron Underwood</p> <p>“I spend time with my dogs. I spend time with my family. I love my life. It’s different where I’m from. I’m from Virginia and the Blue Ridge Mountains. I am able to live now. You know before my transplant I lived in my bedroom. Now I go out, we go on dates, and we enjoy family time.”—Richard Norris</p> <p>“When people see me, I’m just the guy that’s walking down the street. I’m not the injured fireman anymore or the guy that’s face is burned. I’m not him anymore. I’m just a normal guy.”—Patrick Hardison</p> <p>“There’s no part of me that’s uncomfortable anymore. When I’m walking into a restaurant, I’m not uncomfortable. Or going to a store or see the kids or anybody that used to scare me. There’s no situation that I don’t want to be in anymore.”—Andy Sandness</p>	<p>Whispers, staring, pointing, fear, mocking</p> <p>Relationships with family, friends, donor family, care team, romantic relationships</p> <p>Blending in public, normalcy, independence</p> <p>Going to public places, employment, education, hobbies</p>	<p>Social ostracism (8 FT recipients)</p> <p>Interpersonal relationships (9 FT recipients)</p> <p>Regaining “normalcy” (6 FT recipients)</p> <p>Resuming social/daily activities (12 FT recipients)</p>	<p>Social selfhood and the importance of social integration</p>

\*Each frequency represents the number of FT recipients who mentioned each category at least once.

a reduction or mitigation of social ostracism following FT. Moreover, FT recipients discussed the importance of reestablishing, or engaging in new ways, in interpersonal relationships, returning to normalcy, and resuming social activities, including developing new hobbies. Nine recipients cited reestablishing interpersonal relationships with their children, family, and friends as important gains following FT. Six FT recipients used the term “normal” or “normalcy” to express an intense relief at being perceived as again “normal” following FT. Seven FT recipients expressed that regaining employment and/or pursuing further education were important goals they hoped to achieve following FT. All FT recipients discussed wanting to resume or having resumed various daily and social activities that they previously enjoyed, including hobbies, going to public places, and spending time with friends.

## DISCUSSION

### Recipients' Perceptions of Quality of Life in FT

In this study, we identified 3 overarching themes relating to QoL articulated by FT recipients: reconstitution and re-embodiment of physical/corporeal selfhood, integrity of cognitive/emotional selfhood, and social selfhood and the importance of social integration. Health has traditionally been conceptualized around physical, psychological, and social components.<sup>1</sup> In FT, these themes converge to reflect the ways in which QoL is linked to one's sense of identity.<sup>16</sup> The primary purpose of FT is to improve the QoL of individuals living with severe facial disfigurement. Unlike solid organ transplantation procedures that are typically considered life-saving, FT is generally referred to as “life-enhancing” as it is not meant to extend life. In fact, the potential side effects and inherent risks of immunosuppressive therapy can often shorten recipients' life expectancy. In this context, reliably achieving and substantiating improvement in QoL is of utmost importance to ensure that risks are acceptable when weighed against the anticipated benefits of the procedure. As of the time of this writing, the field has yet to establish a clear approach to defining and assessing QoL for FT candidates and recipients, although there is growing recognition of the need to develop QoL measures that incorporate recipients' goals and values and that are adaptable to each recipient's unique circumstances.<sup>2</sup> Beyond the limitations of the field, the heterogeneity of the tools used in the FT literature reflects a need for a clearer appreciation of the fundamental features of QoL as experienced by FT recipients. Our findings suggest that studies focusing on the physical, psychological, and social components of QoL should consider these dimensions as linked conceptually both by their interrelation and by their contributions to an individual's sense of identity as embodied selfhood.

Multidisciplinary literature rooted in the humanities and social sciences explores the concept of embodied selfhood from a variety of perspectives. Through this exploration, we determine that this concept is central to FT recipients' perceived QoL. From philosophers such as Maurice Merleau-Ponty and Paul Ricoeur (who strove

to conceptualize the relationship between the body and the self), to sociologist Erving Goffman (who examined the relationship between social stigma and identity), to contemporary anthropologist Lesley Sharp, postmodern feminist philosopher-bioethicist Margrit Shildrick, and philosophy of medicine/medical humanities scholar Frederik Svenaeus (who write extensively on embodied selfhood and organ transplantation), these authors offer compelling perspectives on embodiment, meaning-making, significance of the self, and the limitations of traditional medically and surgically driven outcomes measures in capturing the facets of QoL that are meaningful to FT recipients and reflect their experiences and priorities.<sup>2,16-24</sup>

It is important to prioritize recipients' perceptions of QoL in FT and highlight the need for qualitative research approaches to better understand how recipients make meaning of their lived experiences of FT procedures and explore the impact of FT on embodied selfhood.<sup>2,22-24</sup> As noted previously, prospective qualitative research on FT candidates and recipients is hindered by the limited number of FT recipients, as well as the unique nature of each FT procedure. Recipients' individual characteristics also present further complexity, including the native physiology of the recipient and the donor, and the etiology of the injury or disfigurement.<sup>2</sup> In the absence of a sufficient pool of FT recipients to allow for comprehensive, prospective, qualitative research examining QoL in this specific population, the data collected in this study represent the most extensive aggregation and analysis of patient-reported QoL outcomes in FT. The themes identified in this study can serve to inform future qualitative research and eventual development of PROMs for FT that focus on FT recipients' needs, goals, values, and experiences of the impact of FT on various dimensions of QoL as it relates to embodiment, identity, and meaning-making.

### Future Directions for QoL Assessment in FT

To develop and validate an FT-specific patient-reported outcome instrument that effectively captures recipients' perspectives on QoL, several challenges remain. First, more prospective qualitative research is needed, necessitating extensive cross-institutional collaboration to mitigate the limitations imposed by the low volume of FT procedures performed worldwide. Collaboration on prospective qualitative research as well as retrospective data sharing across FT programs would increase the likelihood of achieving a sufficient sample size to fully explore dimensions of QoL that are important to FT recipients. Both qualitative and quantitative approaches can enrich our understanding of the daily realities of FT recipients, and previous studies have discussed the importance of a mixed methods approach in informing future PROMs.<sup>25</sup> This will enable the development of an instrument that reflects those domains of QoL that are specific to severe facial disfigurement and optimally address its multidimensional considerations as they relate to FT.<sup>3,12</sup>

### Limitations

Several limitations must be noted. The first is composition of the sample. Each FT procedure is unique and

specifically tailored to a given recipient's functional and aesthetic needs, rendering generalization across FT recipients challenging. In addition, all interviews included in this sample were from English-speaking, North American recipients. The themes identified are limited to this population and may not fully reflect the experiences of FT recipients in other areas of the world. Furthermore, recipients may articulate their experiences differently, and comprehensiveness may differ across interviews, particularly throughout the continuum of posttransplant recovery. Analysis of secondary data sources from various time points presents a further challenge. Researchers are constrained by the questions posed during interview sessions and cannot ask targeted questions or control for the variety of factors that may impact responses. Because of this limitation, it is important to note that, although a given interview transcript may not address a certain dimension of QoL, it does not necessarily mean that the recipient is not affected by that particular issue. In addition, recipients' interview responses may be influenced by the nature and circumstances of the interview context, including the purpose of the interview, questions asked, dynamics between interviewer and interviewee, and the post-interview editorial process preceding public release of content. For example, many interviews in the sample were conducted through the hospital in which the FT procedure was performed, and recipients may have felt inclined to speak on particular factors of public interest or to focus on positive results, while feeling less able to address possible areas of concern. Due to these limitations, the category frequencies reported do not reflect the statistical significance or meaning of each category.

Finally, researchers conducting qualitative work bring their own perspectives and experiences to bear on all aspects of the study design and implementation; to some extent, research results will reflect the frames of reference of the researchers. A number of strategies were used to ensure trustworthiness of the study findings.<sup>26,27</sup> Codes were developed independently by 2 researchers (J.A.G. and L.L.K.) and subsequently merged through an iterative process of peer debriefing to address inconsistencies or discrepancies and to evaluate precision and ensure inclusivity of all potential QoL meaning units. All transcripts were then coded independently by these same researchers using a similar iterative peer debriefing approach. Categorization and theme development were also performed through an initial process of independent interpretation followed by extensive collaborative peer discussion and synthesis, with input from other study team members to further refine thematic development.

## CONCLUSIONS

QoL for FT recipients is a multidimensional construct that incorporates numerous subjective elements and cannot be entirely captured by conventional assessment methods. There is a need for standardized PROMs specific to FT that incorporate FT recipients' perspectives and can be used across institutions and for FT procedures. In the absence of extensive, prospective

qualitative scholarship in this area, a qualitative content analysis that directly examines FT recipients' experiences, values, and goals, expressed through posttransplant interviews, represents one strategy to illuminate the critical facets of QoL that are meaningful to recipients, which are not fully captured by QoL assessment tools currently in use. The 3 themes developed in this study link the facets of QoL to the overall significance of embodied identity to English-speaking, North American FT recipients. Still, more qualitative research is needed to further characterize the long-term implications of the themes identified. These themes can inform further qualitative research, guide future PROM development, and provide insight into the QoL dimensions that are meaningful to FT recipients to better serve this unique patient population.

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