

Face transplants: What role for lived experience in assessments?

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Depression, anxiety, post-traumatic stress and suicidal thoughts are mental health risks exacerbated by the extreme social isolation that results from severe facial disfigurement. Facial transplantation can help recipients reengage with their friends and communities and restore their social identities.

Yet for all of the procedure's benefits, the facial transplantation field still has not settled on how to best define and measure quality of life (QoL) for candidates and recipients in ways that account for their lived experiences. A group of clinician experts, including a surgeon who has performed several face transplants, explored the importance of qualitative research to understanding what is meaningful to candidates and recipients and how the field might develop standardized assessment tools.

Following are highlights from an [article](#) published in the *AMA Journal of Ethics*[®] ([@JournalofEthics](#)) by Rami S. Kantar, MD, surgery resident, Laura L. Kimberly, MSW, MBE, assistant research scientist, Elie P. Ramly, MD, surgery resident, and Eduardo D. Rodriguez, MD, DDS, plastic surgeon, at NYU Langone Health, as well as Arthur L. Caplan, PhD, professor of bioethics, and Allyson R. Alfonso, medical student, at NYU School of Medicine.

They argued that assessing quality of life in facial transplantation “must be grounded in patients’ experiences of living with severe facial disfigurement if QoL measures are to be useful in responding to the full scope of patients’ needs.”

The [November issue](#) of *AMA Journal of Ethics* further explores, in print and podcast, quality of life in reconstructive transplantation ethics.

Few patients, many instruments

Despite the small number of face transplants that have been performed—just over 40 to date—the authors noted that more than two dozen instruments have been used to measure and report on the

procedure's influence on patients' quality of life assessments. And while quality of life was reported overall to improve post-transplant, comparison and generalizability of results are limited by the scarcity of reported outcomes, bias, variability in evaluators and variation in assessment time points.

The number of tools to assess quality of life "likely reflects not only the lack of a standardized instrument validated for use in this population, but also differing perspectives about which dimensions of QoL are most significant," the authors wrote. They added that some dimensions of patients' lived experiences of facial disfigurement and transplantation are not amenable to traditional measurement approaches.

Where to start

Qualitative research can help identify dimensions of quality of life most relevant and meaningful to facial transplantation candidates and recipients. The authors noted that, as facial transplantation programs work to integrate patients' lived experiences in definitions and measures of quality of life, they will need to account for variation in those experiences.

"For instance, because demographic differences among patient populations can influence perceptions of QoL, the FT [facial transplantation] field will need to determine how such variations should be accommodated or accounted for when validating assessment tools," they wrote. "Traditional approaches to validating standardized tools might not be feasible given the small number of FT candidates and recipients."

The key, the authors advised, is for facial transplantation programs to collaborate.

"Given that each FT procedure is unique and that few procedures are performed, programs should commit to sharing outcomes data and approaches to QoL assessment and monitoring to ensure ethical and sustainable progression of the field," they wrote.

The Organ Procurement and Transplantation Network encourages data reporting for vascularized composite allotransplantation. In addition, the Chauvet Workgroup, which brings together representatives from transplant centers, has considered standardizing psychosocial assessment for vascularized composite allotransplantation, including measures of quality of life. It has reported preliminary findings for upper extremity grafted patients.

"The field of FT must integrate multiple epistemological stances and include a range of experiences to ensure that QoL assessment captures data that are meaningful and useful for FT programs, payers, candidates and recipients," the authors wrote.

Modified since the approaches are not only quantitative.