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LETTER FROM THE EDITOR

Assessing Quality of Life in Reconstructive Transplantation

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When we met as graduate students at the University of Pittsburgh, both of us pursuing an MA in bioethics concurrently with a PhD in communication, we often found ourselves together in courses and colloquia. As mutual concerns and interests arose through classroom encounters, we recognized that many of our most dissatisfying—and often most heated—discussions with peers and professors circled around questions of what constitutes a particular quality of life (QoL) or health, from whose perspective QoL or health is assessed, and what values or measurements QoL or health is based on. We recall several early seminar-style conversations about disability and quality of life in which the second author (J.B.) would ask of our readings and of the group, "Where are the patient perspectives? Where are the voices of people with this condition?" In communication studies and in bioethics—but especially in bioethics—the insights of persons affected by a condition or a medical intervention were in many cases elided, replaced by less descriptive, "sanitized" medical terminology or ruled out by academic research journals' preference for objective, quantitative data.

For this theme issue of the *AMA Journal of Ethics*, we wanted to open a multidisciplinary conversation on the related issues of QoL, representation of outcomes, and knowledge generation in vascularized composite allotransplantation (VCA) using a wide range of empirical and conceptual tools. We have been gratified in our efforts to bring together voices from bioethics, surgery, psychiatry and behavioral health, disability studies, communication and rhetoric, religious studies, and the VCA patient population (in the form of oral history data collected by the first author, E.H.).[1] We believe the convergence of diverse viewpoints on the multifaceted nature of VCA bioethics is useful both practically (for generating productive discourse) and symbolically (for underscoring the multiple points of view that can be relevant if not critical to a holistic bioethics of VCA).

VCA, sometimes called reconstructive transplantation—which includes transplants of the hand, face, penis, larynx, and uterus—is primarily conducted to improve a patient's quality of life. Yet ethical inquiry into QoL aspects of VCA is lacking, even though it is relevant to topics such as patients' lived outcomes, the impact of social acceptance or stigma on recipients' experiences of physical disfigurement or functioning, and the effects of disparate access to personal and financial support on a person's candidacy for VCA. For one thing, as authors in this theme issue point out, developing "objective" scientific assessments of QoL in the field of VCA faces challenges, including low numbers of geographically isolated patients (fewer than

200 VCA surgeries have been performed worldwide as of 2015[2]) and the complicated, long-term nature of these interventions. For another, the patient's QoL is not the priority of every stakeholder. As discussed in one of the essays that follows, although it may seem "intuitive and self-evident that VCA candidates' and recipients' QoL and autonomy should be priorities in decisions about engaging in or disengaging from experimental surgery," competing interests can arise when the goals of medical researchers, institutions, and patients differ and are not recognized openly (eg, patients harboring undisclosed restoration fantasies or professionals or programs targeting scientific endpoints).

For all of these reasons, in cases in which patients have experienced burdensome side effects or adverse results in the long postoperative phase of the VCA process, which lasts the rest of the recipient's life or as long as the allograft is retained, VCA surgeons must navigate difficult decisions about whether and how to share unfolding information about participants' QoL with their peers and the public. For instance, should researchers publish data that are measurable by existing tools for assessing QoL, or would narrative methods be more useful for understanding how possible complications played out in the course of treatment? Because VCA has intensive postoperative requirements (eg, immunosuppression, rehabilitation) and a lifelong risk burden for participants, several contributors to this issue argue that narrative data from patients receiving these treatments can be germane to understanding how well or poorly treatment protocols promoted the health and QoL of VCA patients.

The second author's background as a member of a vulnerable group and as a researcher who works almost exclusively with narratives from marginalized populations proved valuable in informing the development of this issue. The small number of VCA patients is significant not only because this paucity makes quantifying outcomes problematic (highlighting the importance of individual narratives) but also because the medical research context privileges perspectives of surgeons. And the smaller is the number of people receiving treatment, the less likely they are to be able to find each other and share their stories in spaces unmarked by the language, power, or expectations of medical researchers. As feminist bioethicist and disability scholar Margrit Shildrick and collaborators have written, "transplant professionals need to question the limits of what is seen as unproblematically therapeutic, and to look beyond conventional data."[3]

Taken together, the essays in this theme issue comprise a unique and timely collection of perspectives on VCA bioethics; considered individually, they address perennial challenges to authentic representation of vulnerable others that are germane to other areas of research and health care ethics. It is our sincere hope that, in addition to contributing to the literature on VCA ethics and medical ethics, this theme issue of the *AMA Journal of Ethics* will draw attention to why quality of life is an area of inquiry that can help us both challenge our assumptions about what data count in a particular setting and reorient studies of bioethics and medical practice to the importance of subjective, contextualized narrative data.

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