AMA Journal of Ethics®
June 2023, Volume 25, Number 6: E391-397

CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Surgeons Approach Gender-Affirming Surgery Revisions When Patients Were Not, Perhaps, Well Informed in Prior Counseling?

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Abstract

Surgeons often encounter patients with realistic goals yet who desire unrealistic means of achieving them. This tension is compounded when surgeons consult with patients eager to revise a prior gender-affirming procedure completed by another surgeon. Two key factors of ethical and clinical relevance are that (1) a consulting surgeon's job is complicated when a population-specific evidence base is lacking and (2) a patient's marginalization is exacerbated by their having suffered the downstream effects of compromised initial access to comprehensive, realistic surgical care. This case commentary about revision of gender-affirming phalloplasty canvasses the pitfalls of a limited evidence base and focuses on strategies surgeons can use to help guide consultation. In particular, informed consent discussion may need to reframe a patient's expectations about clinical accountability for irreversible interventions.

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Case

T is a 32-year-old transgender man who presented to Dr D, a reconstructive urologist. Five years ago, he underwent an abdominal phalloplasty and scrotoplasty, along with partial colpocleisis and hysterectomy, in a different state, and now he wishes to pursue urethral lengthening to the tip of the penis, which was previously constructed without a urethra. Dr D recognizes urethroplasty in abdominal phalloplasty (UAP) as a revision procedure with high risk for complications, which is why a radial forearm flap phalloplasty (RFFP) is the typical recommendation for patients desiring urethral lengthening.

On further discussion with T, T clarifies that he was never told about the relative advantages of RFFP or the broad consensus that abdominal phalloplasty was incompatible with urethral lengthening. T tells Dr D that he has always wanted urethral lengthening as a goal but that he does not recall discussing this with the surgeon prior to the first phalloplasty. T is dismayed by the information from Dr D, but after

contemplation of the risks and burdens of treatment presented still wishes to proceed with urethral lengthening while avoiding any additional donor sites, such as would be required for RFFP. Dr D mentions that other phalloplasty patients have had skin grafting procedures to reconstruct the urethra after phalloplasty. On examination, Dr D believes that the revision surgery would be unsafe for T and would fail to reach his expectations. Considering T's unfortunate past experiences, Dr D knows that he must approach his recommendations both sensitively and scientifically, providing continued care with multidisciplinary support.

Commentary

Given Dr D's previous experiences with UAP and knowledge of the literature and analogous procedures, he feels that the revision surgery would not achieve the patient's goals. Considering the less robust blood supply after local tissue transfer and decreased pliability of the abdominal tissue, Dr D suggests that an additional donor site, such as the forearm, is needed and believes that urethral lengthening on the abdominal phalloplasty would result in an unacceptably high rate of stricture and fistula above the already high rate expected in standard procedures such as RFFP.[1]

First, Dr D should clarify the goals of surgical treatment with T. Potential goals that can be addressed without urethroplasty to the tip of the phallus should be elucidated, such as creating the appearance of a urethral meatus[2,3] or closure of the vaginal canal.[4] If T desires these non-urologic changes in addition to standing micturition, treatments to meet these goals should also be discussed. For the specific goal of standing micturition, we would recommend that Dr D offer T a free flap phalloplasty using the radial forearm. In this option, T's existing penis would be disassembled and could potentially be repurposed as the skin envelope of the penis.[5] Alternatively, T could forgo surgery and use an assistive device to stand to urinate. Both options require T to compromise, either by undergoing much more extensive surgery than originally anticipated or by not achieving his goal of urinating from the tip of the penis. To best support T in moving forward, the surgeon must honestly face the disappointment intrinsic to this compromise.

We begin this commentary by describing preliminary scientific evidence and our own clinical experience with gender-affirming surgery generally; we do not perform UAP revision surgery routinely. Realistic expectations for treatment outcomes with UAP must then be communicated to the patient. A shared decision-making process can begin once the patient understands the potential outcomes, thereby ensuring autonomous and maximally informed consent.

Synthesizing Preliminary Evidence and Clinical Experience

Although access to gender-affirming care has been increasing, case volume remains too low and procedures too heterogeneous to perform statistically powered studies for many of the interventions included in phalloplasty.[6] Tools like the IDEAL (idea, development, exploration, assessment, long-term) framework for surgical innovation adapt traditional hierarchies of evidence quality to surgical care and can maximize the utility of preliminary evidence for informing clinical decision making.[7,8] Based on the limited available evidence, UAP has a high rate of urethral complications.[9,10] When surgeons are faced with immediate clinical questions and insufficient evidence, they can supplement data on the techniques under consideration by extrapolating from research on analogous procedures, such as a 2-stage Johansson urethroplasty described in T's request for urethroplasty, and clinical experience.

Dr D has limited options that he would feel comfortable offering the patient, and this information must now be communicated. We recommend that Dr D remain grounded in what is known rather than addressing the unknowns inherent in the initial request: the patient's anatomy differs from the majority of urethroplasty patients from our own practice and in the literature, as UAP relies on collateral blood supply rather than a robust vascular pedicle.[10,11,12] Although the exact outcome of such a surgery is debatable, what Dr D knows is that UAP is not as safe and reliable as urethral lengthening after other types of phalloplasty.

Guiding patient decisions based on limited research and clinical experience has multiple ethical implications. Although the surgeon may estimate that the likelihood of adverse outcomes is too high to justify the benefits and thus that proceeding with surgery would violate the principle of nonmaleficence, multiple frames of reference for risk acceptance must be considered in surgery. Cisgender individuals living with a condition that could require reconstructive treatment have been shown to be more risk tolerant than surgeons offering the operation.[13] The role of the surgeon is to guide clinical decision making by offering greater knowledge and experience. Even if T had the same professional knowledge and experience as Dr D, he might still judge the potential benefits to outweigh potential risks.

Ethical principles, such as centering T's autonomy, help to guide decision making but do not inherently compel the surgeon to act in accordance with the patient's wishes.[14] Consistent with the concept of "surgical buy-in," or relational autonomy of patient and surgeon as described by Schwarze et al, surgeons conceptualize themselves as taking accountability for all steps of clinical care necessary to help patients reach their surgical goal.[15] In T's case, Dr D believes that T's surgical goal is unachievable, so T should be encouraged to consult with other surgeons who may have differing clinical experience or risk acceptance. In suggesting a second opinion, Dr D should recommend other surgeons who he specifically believes are best equipped to offer expert guidance and clarify that he is open to seeing T again for further discussion if he decides to pursue additional consultations. Connecting the patient to trans-affirming mental health clinicians for decisional support would provide an additional source of professional guidance, although perpetuating the history of mental health clinicians' gatekeeping for gender-affirming surgery must be avoided.[16] Neuropsychiatric evaluation might be required for patients with a questionable capacity to consent.

Setting Realistic Expectations

It will be difficult for T to learn that his current outcome might have been prevented with more thorough counseling, and Dr D must acknowledge this circumstance without assuming that the original surgeon was ill-intentioned or neglectful in order to establish a therapeutic relationship with T. The initial clinical documentation could elucidate what information was provided to T, enabling Dr D to assess whether T understood and recalled it. In T's case, the initial discussion of the risks and benefits of alternative treatments and a request for urethral lengthening were not documented.

To help T set realistic expectations, Dr D might wish to assess the veracity of T's nonclinical information sources, as one small survey found that 94% of transgender respondents reported receiving surgical information from the internet.[17] In addition, some patients and clinicians lack access to reliable information due to a legacy of exclusion from academic medicine, which is important for understanding the historical context of current injustice in health care. T's prior residence and health plan may also

have contributed to his seeking a revision procedure, as a lack of trained surgeons and barriers to insurance coverage have led some patients to access care that may be less comprehensive.[18,19] Dr D has potentially encountered these downstream effects of social marginalization as experienced by T and other transgender patients. Although Dr D cannot single-handedly reverse the unjust distribution of research attention and medical resources, he can acknowledge their maldistribution to build an alliance with his patient.

Alternatively, the first surgeon may have counseled T that future urethroplasty would be ill-advised but T did not retain this information[19] or may have misunderstood his goals. For patients like T who initially lacked a realistic understanding of outcomes, surgeons like Dr D who are considering revision must carefully reset patient expectations. To communicate surgical risk, we recommend that surgeons use the Best Case/Worst Case framework, which involves detailing the best possible, worst possible, and most likely outcomes for each potential treatment using storytelling to illustrate the burdens of treatment (ie, catheterization on the scale of weeks or months until urethroplasty is complete), the expected negative consequences (such as additional scarring to the donor site), and a full picture of the end state if realized.[20] The Best-Case outcome of standing micturition after free flap phalloplasty still includes the potential lifelong need for specialized urological care, as strictures can occur years after surgery.[21]

Discussion of undesired trade-offs of a desired intervention may be one of the most difficult parts of the consultation for patients, as it requires them to surrender how they had imagined their future. Although balancing sensitivity and compassion with a scientific, clinical rationale can be difficult, both are crucial to providing the best possible counseling. In T's case, Dr D should continually validate the legitimacy of T's current treatment priorities by expressing that T's desire for urethroplasty is due to T's real understanding of the potential benefits and that he would offer it to T if it were safe. Dr D should then explain that the method T has requested has too great a potential for adverse outcomes; with presently available techniques, urethroplasty with his current penis is not possible though another treatment option might provide a viable solution.

Sharing Surgical Decisions and Informed Consent

In T's case, we would hesitate to book any surgical revision of phalloplasty immediately after the consultation. Given the emotional gravity of resetting T's expectations, Dr D should offer the opportunity for additional consultation to reach a final, shared decision. Such caution is valuable, as an overly confident surgeon and an overly optimistic patient can together reach a shared, yet poor decision.

Furthermore, informed consent is not a rigid, final destination on a checklist; it is an ongoing and iterative process that should center what the individual patient most values.[22] Although the practice of maximally informed consent is still limited by many practical factors, there is a minimum acceptable standard for a surgeon to meet when proceeding with irreversible treatments.[23] Gender-affirming surgery aims to improve quality of life, so it is patient satisfaction, rather than externally observable endpoints such as nonrecurrence of cancer, that is the arbiter of success. Given a lack of patient-directed research on gender-affirming surgery outcomes,[24] however, surgeons may not have immediate access to information requested by patients to best predict their own satisfaction.[25]

Although the surgeon is accountable for establishing informed consent, information that contributes to consent does not only come from the surgeon. In addition to recommending that T consult mental health professionals, Dr D might offer to connect T with other patients who have had a complete revision of phalloplasty with a new free flap, as this is a uniquely challenging experience. T's further contact with primary care and mental health professionals who have been provided with information described in the Best Case/Worst Case scenario framework may also help T to manage his expectations regarding further surgery.

Conclusion

Patient autonomy is an important ethical tenet, but it does not compel surgeons to perform interventions they deem unsafe. Communicating surgical risk to patients seeking revision must be done sensitively, acknowledging the potential for prior medical trauma. Best Case/Worst Case scenario storytelling can help the surgeon to establish more robust informed consent, along with multidisciplinary care coordination and connections to other patients who have previously faced the same decisions.

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Editor's Note

The case to which this commentary is a response was developed by the editorial staff.

Citation

AMA J Ethics. 2023;25(6):E391-397.

DOI

10.1001/amajethics.2023.391.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

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ISSN 2376-6980