

authoritative overseers and to the public, but are at risk of benign neglect. In contrast, Toronto General Hospital's surgical innovation committee gains unmediated attention (McKneally and Daar 2003; McKneally and others 2011). It is chaired by the Surgeon-in-Chief who has enforcing authority over surgical practice, equipment, operating rooms, personnel and budgets (Das and McKneally 2019).

Innovations such as WET and FT help hospitals develop coordinated networks of patient care. Such hospitals are ideally suited for research as well as innovation, activities that help to attract patients, staff and donors and encourage further innovation across disciplines. Sharing innovation experience and lessons learned shortens learning curves, reduces the misadventures inherent in exploring beyond the leading edge of established practice, accelerates advances in patient care and encourages a spirit of pride in caregivers.

Publications like this thoughtful target article and its appearance in the American Journal of Bioethics will advance cross-disciplinary discourse with surgeons and promote progress in managing responsibility and sharing accountability for surgical innovations.

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OPEN PEER COMMENTARIES



Putting a Face on WET Recipients

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I have at least four close friends who seem to be ideal qualified recipients of WET. My friends have a variety of eyes: some prosthetic, some wandering, some misaligned, some absent, some shrouded with dark glasses, and some convincingly sighted. All have excellent navigation skills, some use braille or guide dogs, and all use white canes. None of my friends understand themselves as “afflicted with vision loss” (Laspro et al. 2024, 60) Rather, they all have a very high quality of life guided by the slogan “We are the blind

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leading the blind and proud of it!” the motto of Lighthouse for the Blind in San Francisco. They all understand themselves not as having lost sight but rather having gained blindness. My friends’ psychosocial sturdiness, successful adaptation to blindness, and good lives have nothing to do with the functional or esthetic status of their eyeballs.

My friends’ lives fall into a category of being sociological researchers call the “disability paradox,” described in anthropological literature in 1999 as

“high quality of life against all odds” and briefly noted in Laspro et al. (2024). Their lives appear paradoxical or against the odds only to sighted and other nondisabled people who view my blind friends’ lives through the perspective of the sighted majority rather than from within the experience and logic of such lives lived well with blindness. Several of my blind friends claim that blindness enhances their lives by occasioning opportunities for resourcefulness and strong community. As the blind bioethicist Adrienne Asch noted decades ago, disability does not necessarily determine quality of life (Parens and Asch 1999). Human flourishing depends not on being sighted, hearing, or nondisabled, but rather on living in an environment that sustains the particular form, function, and needs of our bodies. This sustaining environment offers humans the ground for happiness and high life quality (Garland-Thomson 2019, 2020). Such an environment provides secure caring relationships, adequate economic resources, suitable material supports, meaningful work, appropriate technology, proper accommodations, supportive communities, and access to healthcare. To maintain their high quality of life, none of my friends need eyeballs.

REDEFINING THE DISABILITY PARADOX

The disability paradox is not that blind or disabled people are happy rather than miserable with their lives but rather that the nondisabled majority often seem unwilling to recognize that one can lead a good life as a blind or disabled person. The lived testimonies of my blind and disabled friends suggest a different approach to evaluating the ethical considerations of such experimental treatments as WET. Rather than investments in experimental surgeries resulting in certain harm, further research into the misunderstandings of the “disability paradox” is a more ethical approach. Such research may reveal that this paradox springs from bias and lack of understanding by the nondisabled majority about how people with disabilities can experience well-being, high quality of life, and satisfaction with our lives equal to or exceeding life satisfaction or happiness experienced by the nondisabled. This apparently frequent inability among the nondisabled majority to appreciate or recognize that quality of life and happiness are not necessarily determined by disability status is suggested in two recent studies by the Harvard physician Lisa Iezzoni that found many physicians unaware, perplexed, and uncomfortable about how to treat patients with disabilities (Iezzoni et al. 2021, 2022).

The more subtle disability paradox can be extracted from Laspro et al.’s requirements for the appropriate WET “recipient” capable of granting fully informed consent for this experimental surgery. The appropriate WET patient recipient must be a psychosocially stable, intellectually competent subject with the capacity to understand mounds of technical information, manage media attention, be free from the taint of mental illness, and fully comprehend and accept what the target article consistently refers to as “risks” but that are clear harms. These harms are the surgery itself, the longevity of the transplant, a lifetime of harmful immunosuppressants, the burden of managing media attention, and the psychoemotional realism to minimize the “false hope of vision restoration” (Laspro et al. 2024, 62).

My blind friends are all “optimal surgical candidates” particularly qualified to navigate the “thorough informed consent process” Laspro et al. describe for the WET experimental surgery (Laspro et al. 2024, 65). However, their high quality of life and well-being challenge the assumption that “vision restoration” is both the appropriate ethical and medical goal of surgical treatment. Despite their seemingly excellent qualifications as recipients, none would consider consenting to this experimental surgery that imposes unavoidable harms on the WET patient. My friends’ reasonable resistance to WET suggests that a fully qualified recipient would in truth be a vulnerable subject of medical research. The disability paradox here is that anyone capable of granting consent after fully understanding that the “risks” of this experimental surgical procedure, especially that these harms cannot be “appropriately mitigated,” is a vulnerable subject needing protection from medical exploitation and unwarranted harm (Laspro et al. 2024; Koenig 2014).

How does Laspro et al.’s seemingly sensible ethical analysis mute the unavoidable harms of WET in contrast to its trivial and uncertain benefits? One way is the common use of distancing, dehumanizing medical acronyms. Laspro et al.’s ethical analysis is swept along rhetorically by the early introduction of this common medical shorthand. The first paragraph reduces the procedure of experimental whole eyeball transplantation surgery to WET and later to the even more distancing acronym FT-WET. Such abbreviations shift readers’ imaginations away from the actual human experience of eyeballs extracted from recently dead human faces and implanted into other human faces, both of which helped shape meaningful human lives. Distancing acronyms permit the surgical perspective to overtake the patient perspective, making

the WET potential recipient vulnerable to the inherent “rhetoric of hope” and the “feel-good narrative” that can fire imagined restoration of lost human capacities and biological integrity (Shildrick 2015). Medical literature and healthcare conversations littered with such dehumanizing shorthand are not distinctive to VAS; for instance, the unsettling metaphor PVS identifies unconscious human beings through the language of vegetables.

PROTECTING THE VULNERABLE SUBJECT OF RESEARCH

This “blind spot” in the medical perspective about the lives of people who would make appropriate recipients of WET exists because the medical perspective has overtaken the perspective of blind people such as my friends. This seemingly objective medical “view from nowhere” obscures the announced aim of WET (Nagel 1986). The explicit goal of WET is “further advancement in the field of vision restoration” not helping blind people to have a higher quality of life (Laspro et al. 2024, 69). This objective goes unquestioned in the ethical examination under consideration, and the beneficiaries of this enterprise remain obscured. The most significant potential benefits accrue to medical science itself, specifically to the surgeons and researchers credited with developing and carrying out WET. The “view” from my blind friends’ perspective is most frequently overwhelmed in medical literature by statistical profiles of people with disabilities such as QUALYS and other reductive accounts of disability (National Council on Disability 2019). Medical case studies and statistical evidence often outnumber complex narrative accounts from people living with disabilities embedded in lives and relationships. In other words, the announced aim of achieving a “balance between innovation, ethics, and patient safety” is unachievable in the WET experimental surgery (Laspro et al. 2024, 68).

A full account of the acceptable recipient of WET as a vulnerable subject of medical experimentation escapes Laspro et al.’s analysis. The briefest revisitation of the history of bioethics would remind us that protecting people from becoming subjects of medical experimentation was the initial mission of bioethics that arose from the Nuremberg doctor’s trial of 1946 and the eventual establishing of the Nuremberg Code, which aims to protect people from the harms of medical experimentation (Alexander 1949). The proposed implement of protection for vulnerable subjects of medical treatment and research is “the voluntary consent” of the individual. That voluntary

consent requires that the experimental subject receive “sufficient knowledge and comprehension of the elements of the subject matter involved, as to enable him to make an understanding and enlightened decision” (Nuremberg Code).

Based on the requirements and premises of the Nuremberg Code, the prospective recipient of WET is a vulnerable subject who needs to be protected from the narrow range of perspectives and information available in the routine process of granting consent. Most important, any potential WET patient should be fully informed about the crucial distinction, mentioned nowhere in LASPRO et al., between whole eyeball transplantation surgery and established solid organ transplants such as liver, kidney, or even heart transplants. Solid organ transplants aim to delay imminent patient death by replacing a failing organ necessary for life. In contrast, vascularized composite-tissue allotransplantation, reduced in the target article to the distancing acronym VCA, aims only to improve the patient’s quality of life, a goal unsupported by sufficient sociological and psychological research.

The “seduction of restoration,” especially among people who are newly blind, might be so powerful as to compromise even an ideal informed consent process (Dobbs 2019). To give full voluntary consent, the prospective recipient should also be capable of and required to comprehend “sufficient knowledge” about transplantation from outside of the medical perspective. For instance, the recipient should be made aware of the cultural history of medicine to understand the limits of the benefits of restoration to this imagined state of normalcy (Davis 1995; Hacking 1990) or what the philosopher Erik Parens calls the “goodness of fragility” (Parens 1995). Prospective patients should be informed about psychological harms of medical normalization, what one philosopher has called the “the persistence of the other within the self” in all transplant surgeries as well as the “profound ontological uncertainty” occasioned by the psychoemotional entanglement between a recipient and the donor who must die not so the recipient can live but only perhaps have vision (Parens 2008; Shildrick 2015). The information provided to perspective recipients should include quality, long form investigative reporting such as the *Wired Magazine* article on “the devastating allure of medical miracles” that centers patient perspectives rather than medical perspectives of VSA (Dobbs 2019). Moreover, potential patients should be fully informed about the recent studies in the medical journal *Health Affairs* reporting doctors’

negative attitudes about patients with disabilities and their lack of knowledge about accommodations for disability and disability rights legislation in the United States (Iezzoni et al. 2021, 2022).

The most important information a prospective patient requires to be fully informed about WET is to know about and perhaps even meet my blind friends (Girma 2019; Kleege 1999). Laspro et al.'s ethical analysis mutes, if not erases, the fact that WET recipients are harmed if they do not recognize the lives lived by my blind friends and other people with disabilities who have good lives. Furthermore, WET doctors and medical practitioners are subject to moral harm from participating in such experimental surgeries. The subjects of medical research deemed appropriate recipients of WET are indeed mannequins stripped of their complex human particularity. These potential recipients risk being reduced to vulnerable medical subjects whose full humanity is overdetermined by prejudicial stereotypes about blindness often held by the sighted majority and upheld by the entire logic of medical experimentation. Indeed, a more just distribution of resources would be investments that improve the lives of blind people through a range of social services and cultural supports, perhaps launching a program of training expert blind people as dou-las to accompany newly blind people through medical and social encounters. Such programs would no doubt come from rehabilitation medicine rather than surgery and from philanthropy and government grants, not from investments in experimental, unavoidably harmful normalization surgery.

JUSTICE

How might we put a face on the vulnerable subjects of medical research I am describing here? Bringing a broad range of literature from disability bioethics, healthcare ethics, and health humanities into medical education broadly understood is one enterprise already underway. Integrating this material into curriculum, medical journals, professional development, conferences, workshops, and across all knowledge making activities of medical science, particularly bioethics. Perhaps most important, medical training and practice should introduce if not create a more capacious understanding of the bioethical principle of justice. Such an interpretation of justice would emphasize the balance between harm and benefit in medical treatment, technology development, and medical scientific practice in the broadest sense. This is what Laspro et al. call for as “the ethical stewardship of resources” regarding

WET (Laspro et al. 2024, 61). This is an ambitious ethical call that many healthcare experts, scholars, and patients contribute to today (Catapano and Garland-Thomson 2019; Cureton and Wasserman 2020; Reynolds and Wieseler 2022).

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Disability Bioethics, Social Inclusion, and Whole-Eye Transplantation

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Matteo Laspro et al. (2024) provide a thought-provoking review of the ethical issues surrounding Whole-Eye Transplantation (WET). In this commentary, we expand on three of the concerns they raise in the context of disability bioethics to articulate priorities for future debate as WET evolves from experimental procedure to clinical practice. First, we worry that surgeons' ableist biases might unduly influence patients with a significant eye injury or visual impairments to prioritize WET as a normalizing procedure over other therapeutic or social interventions to improve their quality of life. Second, given that currently WET's potential benefits are mainly cosmetic, we think that the bioethics community needs to be carefully reflective about how WET should be prioritized against interventions that assist someone in feeling more comfortable with their disabled body and the limitations (and gifts) that accompany disabled embodiment. Third, we suggest that some of the advantages the authors claim for WET are exaggerated in ways that reinforce ableist assumptions about eyes as the main locus of social interaction. While the authors acknowledge these considerations, they deserve continued attention and discussion.

We agree with the authors that patients who want to undergo WET should normally be allowed to do

so, granted that they are fully informed about risks and benefits. Much like in the ethical debates surrounding cochlear implants or disability-selective abortion, a commitment to individual autonomy requires that individuals not be prevented from accessing WET on the grounds that it *might* reinforce disability-related stigma (Kittay 2019; Levy 2002; Sparrow 2005). Navigating the world with a significant eye injury and visual impairment is difficult and would likely still be so even if the built environment were better designed for people with these disabilities. As long as sufficient medical evidence exists to support the safety and efficacy of WET, there are strong reasons of autonomy to allow individuals to pursue it as a personal enhancement for their disability.

However, in the section devoted to disability bioethics concerns, the authors come to the rather weak conclusion that society can simultaneously prioritize personal enhancements in line with a medical model of disability while also pursuing status enhancements in line with the social model of disability. This conclusion, while plausible, does not fully reflect the normative force of a social model critique of WET. Concerns about the over-medicalization of disability and the social barriers that people with disabilities confront in