

# Prophylactic Desexualizing Mastectomy for an Intellectually Disabled Woman: Protective Measure or Disregard for Autonomy?

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**Summary:** Historically, sterilization of the so-called feeble-minded has been advocated in the name of eugenics. Surrogate decision-making that impacts sexuality of the intellectually disabled presents significant ethical dilemmas. We describe a 19-year-old intellectually disabled woman who presented with her legal decision-maker for surgical correction of her asymmetric chest and hypoplastic breast. The decision-maker requested a mastectomy to make the patient's breasts as inconspicuous as possible, and to reduce the risk of sexual assault and pregnancy. This case covers the ethical considerations on whether or not to prophylactically desexualize an intellectually disabled woman. (*Plast Reconstr Surg Glob Open* 2022;10:e4347; doi: 10.1097/GOX.0000000000004347; Published online 23 May 2022.)

Unilateral breast hypoplasia and asymmetric breast anomalies are congenital conditions resulting in mild to severe breast deformity. These conditions frequently go unnoticed until puberty. If left untreated, the adolescent may experience anxiety, low self-esteem, and depression.<sup>1</sup> It is therefore important to consider early surgical intervention to avoid any potential psychological harms and associated decreases in quality of life.

The primary goal of surgical management is to restore cosmesis through achieving breast symmetry. Most commonly, surgery augments the hypoplastic breast to symmetrize to the contralateral breast. Reconstructive surgery often consists of a two-stage breast reconstruction utilizing breast tissue expanders and the subsequent placement of breast implants.

Breast symmetry may alternatively be achieved through reduction of the unaffected breast to match the size of the hypoplastic breast; this approach may confer less postoperative risk but is less commonly practiced. Regardless of the method chosen, this decision must be made congruently by the surgeon and the patient, and in line with the patient's own beliefs regarding the tradeoffs of a surgical intervention to achieve cosmesis.

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## CASE

The patient was a 19-year-old woman with a history of intellectual disability, generalized epilepsy, and breast asymmetry. The patient was adopted from Eastern Europe at 18 months old. Childhood neurocognitive testing indicated a Full-Scale IQ of 54, denoted as intellectually disabled and impaired. She was accompanied by her adoptive mother, who is her legal guardian and decision-maker. Because the patient is unable to appropriately communicate with providers, her mother provided the medical history. The patient's mother stated that the patient has been expressing feelings of distress and embarrassment due to her asymmetric breasts, especially in public. The patient would often attempt to symmetrize her breasts with homemade breast inlets.

On physical examination, severe left breast hypoplasia with poor inframammary fold definition was noted; the right breast was significantly larger with grade I ptosis (Fig. 1). Options for symmetrization were discussed with the patient's mother, emphasizing left breast implant augmentation as the most common approach. However, the patient's mother believed that the augmentation of the patient's breasts might result in an increased risk of sexual assault should her daughter ever live in an assisted care setting. Instead, she would prefer the patient's breasts be as inconspicuous as possible. The mother therefore asked the surgeon to perform a symmetrizing right "mastectomy" with cosmetic preservation of the nipple to reduce the patient's sexuality.

Given the recent advances and growing social awareness within plastic surgery, there is a significant increase in new ethical considerations; furthermore, a recent review illustrated that plastic surgeons ought to be more comprehensive when encountering ethical dilemmas.<sup>2</sup>

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**Fig. 1.** Patient's marked left breast hypoplasia, and asymmetrical chest.

There are multiple theoretical surgical options to correct this deformity; however, the focus of this article is to illustrate the challenges in providing nonlife-saving elective care in the absence of patient input and autonomy.

### ETHICS SUPPORTING THE MASTECTOMY

A mastectomy and free nipple graft for the patient may be a valid recommendation. This decision is supported by the principles of beneficence and nonmaleficence, as well as by the 2004 Pillow Angel Case.

To respect beneficence and nonmaleficence, the net benefits must outweigh the possible harms of the procedure. Potential benefits of a mastectomy are symmetrical chest contour and that this option aligns with the mother's perceived belief of future risk reduction of sexual assault. The associated risks include bleeding, infection, skin necrosis, loss of nipple sensation, and complete nipple loss.<sup>3</sup>

A similar argument was made in the 2004 Pillow Angel case, where the parents of an impaired prepubescent girl successfully petitioned Seattle's Children's Hospital to perform several medical and surgical interventions—including bilateral mastectomy—to prevent the potential "sexualization" of the patient's breasts by future caregivers.<sup>4</sup> This concern is not without cause; Bureau of Justice data illustrate that intellectually disabled women are at a 12-fold increased risk for sexual assault compared with the average person.<sup>5</sup> Therefore, it may be argued that it is within reason to perform the mastectomy to "desexualize" the patient.

### ETHICS AGAINST PERFORMING THE MASTECTOMY

Mastectomy and free nipple graft for the primary purpose of "desexualizing" a patient may be considered

unreasonable based on the principles of autonomy, beneficence, and nonmaleficence, and a modern understanding of the 1927 Supreme Court case of *Buck v. Bell*.

In our case, while the patient was deemed incompetent based on cognitive testing, this does not discredit either her opinion or her desires. Indeed, autonomy and intellectual disability are not mutually exclusive; the previous literature has demonstrated that intellectually disabled patients are still able to voice their autonomy for inclusion in society.<sup>5</sup>

Therefore, the argument can be made that any intervention should adhere most closely to the patient's—rather than the mother's—wishes. The patient complained to her mother that she felt uncomfortable in public due to her breast asymmetry; however, she expressed no preference among the procedural options to achieve breast symmetry. Therefore, the decision to choose a less-common option solely to appease the mother's concerns would run against the patient's autonomy.

Additionally, it must be noted that this is a complex procedure that poses the possibility for significant complications, including graft loss, necrosis, and infection. Furthermore, this patient would lose nipple sensation and the ability to breastfeed, a central component of motherhood, rendering the possibility for this procedure to be labeled a soft sterilization.

Similar sterilizations were a central tenet of the eugenics movement in the United States, including the infamous 1927 *Buck v. Bell* Supreme Court case.<sup>6</sup> Carrie Buck was a "feeble-minded woman" committed to a Virginia mental institution, whose condition had run in her family for three generations. A Virginia law at the time allowed for the sexual sterilization of inmates like Buck to promote the "health of the patient and the welfare of society." The Supreme Court ultimately upheld Buck's sterilization, with Justice Holmes declaring that, "being swamped with incompetence...Three generations of imbeciles are enough."

The decision in *Buck v. Bell* has been widely renounced as running counter to the principles of autonomy, beneficence, and nonmaleficence. Therefore, mastectomy should not be performed for this patient, as the justifications for doing so are unethical.

### CONCLUSIONS

Unilateral breast hypoplasia and asymmetric breast anomalies are benign conditions that can have significant negative psychological impacts if left untreated. This case highlights the complicated ethical challenge of whether to perform a mastectomy with a free nipple graft for an intellectually disabled woman. It should be noted that mastectomy and augmentation were not the only available surgical approaches in this case. Breast reduction is another option that could have minimized surgical risk and might have been discussed in a subsequent visit. However, the patient and her mother ultimately did not follow up after the plastic surgeon expressed his concern and need for further ethical intervention and discussion before surgery.

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