

Virtual Mentor

American Medical Association Journal of Ethics
May 2010, Volume 12, Number 5: 367-372.

CLINICAL CASE 2

Outer Ear Construction: Is Advocacy Part of Treatment?

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Jonathan was born with unilateral right-sided grade III microtia; his external ear was absent, with a peanut-sized structure in its place and the external ear canal and ear drum also missing. Testing showed that his right inner ear was intact and his hearing was normal on the left side. A CT scan revealed that his right ear canal did exist. Jonathan's parents were counseled to wait until he turned 8 years old to pursue reconstructive surgery, so his ear would be closer to adult size.

Shortly after his 8th birthday, Jonathan's parents made an appointment with Dr. Cavanaugh, who had completed both otolaryngology residency and a plastic and reconstructive surgery fellowship. After discussing the risks and benefits of the procedure, Dr. Cavanaugh performed a rib cartilage graft reconstruction procedure on Jonathan. Dr. Cavanaugh had completed the first two stages of her three-stage reconstruction when Jonathan's insurance company denied preoperative clearance for the third stage, deeming it an elective enhancement procedure not sufficiently related to ear function.

Dr. Cavanaugh helped Jonathan's parents appeal the insurance company's decision, but they were rejected twice. Understandably, they were frustrated, and began investigating alternatives. They were informed that other insurance companies also considered the third surgery an elective procedure ineligible for coverage. They decided to seek media publicity to either help raise funds for the final operation or to convince the insurance company to "do the right thing" for the sake of public relations. Jonathan's parents found a television station that would air their story if they could persuade the doctor to appear on camera or at least comment on the insurance company's decision.

Commentary

In taking the Hippocratic Oath, every graduating medical student pledges to "apply, for the benefit of the sick, all measures [that] are required, avoiding those twin traps of overtreatment and therapeutic nihilism" [1]. Simply put, by exercising our knowledge of physiology and anatomy and our skills in therapeutic maneuvers, we administer to those who are sick so that they may be made whole again. Furthermore, we have also sworn to "respect the privacy of [our] patients, for their problems are not disclosed to [us] that the world may know" [1].

However, patients can certainly choose to disseminate private medical information if they wish. Disclosing one's condition to the world is like signing a waiver of

confidentiality; the information becomes public. Therefore, if this patient asks his or her physician to assist in the disclosure by providing medical and technical information, professional opinions, and advocacy, the doctor will not be violating the patient's confidentiality if he or she agrees to help. But what is the goal of such public display of health information, and does the physician have an ethical responsibility to participate? The family in the case scenario is "going public" with medical information in an attempt to pressure the third-party payor to cover the costs of their son's operation. Strictly speaking, the family's attempt to secure reimbursement is not part of their son's treatment. It can be argued that, because this kind of public disclosure is not part of the treatment, the physician should take no part in it.

That, however, is a simplistic view of the situation. In the current medical system, much delivery of care depends on third-party payors, whether they are private insurers, HMOs, or the government. Often these third-party payors have stringent and arcane rules regarding which procedures are covered, and these rules may not be based on medical facts [2, 3]. Nonetheless, their "pre-approval" is required to guarantee payment for the surgeon's service and for the hospital and operating room fees. Many hospitals do not allow or cannot afford to schedule cases without guarantee of financial reimbursement, and most Americans are not able to pay for such surgical procedures out-of-pocket.

Studies on uninsured adolescents and young adults have shown that health insurance coverage is a significant determinant of access to health services [4]; those without health care coverage are more likely to have an unmet medical or prescription medication need. [5]. More specifically, children with special health care needs are more likely to have access to medical, dental, and mental health care if they are insured [6]. Taking into account the current imperfect system of medical care delivery, obtaining payment for treatment becomes essential to obtaining the treatment itself.

A publicity campaign to pressure the third party has been shown to be an effective option to secure payment, and thus treatment [7]. A doctor faced with a possibly beneficial procedure versus no treatment for a patient who wants to be treated for a medical need should therefore pursue this option for his or her patient, if the patient requests it. However, such a course of action is not without caveats.

Going public requires that the patient waive his or her confidentiality and right to privacy. It becomes more complicated when the patient is a minor. In this case, the decision to give up confidentiality was made by the parents and not the patient. Even if the child were to voluntarily state the desire to pursue this public appeal, how do we judge his understanding of the situation? A physician who is approached by a patient—or parents—about such publicity campaigns should not blindly agree, but should sit down with the responsible party and discuss these issues carefully, just as he or she would obtain informed consent for any treatment with a thorough discussion of potential risks and benefits. When a child is involved, it may be

prudent to ask for a psychiatrist's or social services' evaluations as well. Even if the physician participates in this publicity campaign, he or she should be careful not to divulge any more medical information than is absolutely necessary.

Second, since the parents' perceived need to take their plea to the media is a byproduct of our medical system and not a medical treatment in the strict sense, the physician should never actively recommend it. While we no longer practice the paternalistic medicine of generations past, it has been shown that patients put their trust in physicians' recommendations, and they are more apt to weigh the benefits of their physicians' recommended treatments highly [8, 9]. Therefore, a physician's recommendation to resort to a publicity campaign may influence a patient to unwittingly waive more confidentiality than he or she is prepared to give up.

Finally, prior to pursuing this desperate measure, the physician should have exhausted the usual channels: writing and appealing to the insurance companies directly, including contacting its medical directors.

Case Specifics: Microtia and Ear Construction

Microtia is a congenital condition in which the external auricle is not formed. There are different levels of severity, classically grouped into grades I, II, and III (for more on microtia staging and treatment, see the [clinical pearl](#) section in this issue of *Virtual Mentor*). In grade III microtia, all elements of the external auricle are missing, and in its place is a protrusion of soft tissue with or without underlying cartilage [10, 11]. The middle and inner ear elements may or may not be malformed or absent [11, 12].

An auricle can be formed from the patient's own skin and cartilage [13], or from commercially available products [14]. Since the patient was not born with an ear, this procedure—called ear *reconstruction* in the plastic surgery literature—is better termed, as Dr. John Mulliken put it to me, ear *construction*. Construction takes at least 2-4 separate operations [15]. Dr. Cavanaugh should have explained this when applying for authorization for the procedure from the insurance company. If the insurance company has approved the first two stages, it is not unreasonable to presume that they implicitly approved the complete ear construction process. Nevertheless, it would be prudent for the surgeon to verify approval for complete construction before performing the first operation.

While not essential to life like the heart or kidneys, the auricle serves several important functions. It plays a role in the localization of sound [16, 17]. Most glasses rely on the presence of ears to hold them in place, and the psychological ramifications—especially in young children and adolescents who appear different from their peers—are significant [18, 19]. Studies have shown that obvious physical deformities affect socialization and integration in society [20]. Moreover, there is strong evidence that society equates a normal facial appearance with increased intelligence, attractiveness, and other positive social attributes [21]. The quality of life of a patient with obvious, uncorrected craniofacial deformities is apt to be

negatively affected. Many health insurance plans cover so-called lifestyle medications for older men with erectile dysfunction who are usually not seeking to have children [22, 23]. Lack of sexual function in this population does not impair procreation, is not life-threatening, and is purely a quality-of-life issue. It is not stigmatizing in the casual social situation, as a child's lack of external ear is likely to be—yet it is covered by insurance.

Furthermore, the common perception that ear construction is “enhancement” surgery is errant. A breast augmentation is enhancement of existing breasts, and rhinoplasty can be an enhancement of the nose. But a patient with microtia was born *without* an ear. Constructing such an ear is therefore not enhancement surgery. It is more analogous to a cleft lip repair than a face-lift.

In summary, the perception that correction of congenital conditions that affect facial appearance provides enhancement for the patient is incorrect. Furthermore, an auricle serves both physical and psychological functions. In an imperfect medical system, the economics dictate access to care, and, if the patient knowingly and willingly chooses to give up medical confidentiality to obtain financing for treatment, the physician has both an ethical and professional obligation to help.

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Further Reading

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