The Significance of Deaf Culture: A Bioethical Analysis of Pediatric Cochlear Implants

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Introduction

Deafness is a general term used to describe the inability to hear. There are four types of hearing loss: conductive hearing loss, sensorineural hearing loss, mixed hearing loss, and auditory neuropathy spectrum disorder. Conductive hearing loss results from an object preventing sound from passing through the outer or middle ear. Sensorineural hearing loss is caused by nerve damage to the inner ear, and mixed hearing loss is a combination of the two. Auditory neuropathy spectrum disorder involves the ability of the inner ear to detect sound, but the ineptness of sending said sounds to the brain in a way that is comprehensible. There also are degrees of hearing loss, which affects the capacity to hear. Hearing loss can range from slight to profound. Slight hearing loss ranges anywhere from 16 to 25 dB, mild hearing loss ranges anywhere from 26 to 40 dB, moderate hearing loss ranges anywhere from 41 to 55 dB, moderately severe hearing loss ranges anywhere from 56 to 70 dB, severe hearing loss ranges anywhere from 71 to 90 dB, and profound hearing loss ranges anywhere above 91 dB.

There are a number of ways to describe hearing loss: high-frequency versus low-frequency, bilateral versus unilateral, symmetrical versus asymmetrical, progressive versus sudden, and fluctuating versus stable. Medical intervention is often strongly encouraged to prevent further damage or any overall harm to the individual experiencing hearing loss. While this is seen as essential for the health and wellbeing of the individual by the medical community, it is often interpreted as unnecessary and offensive by the deaf community. The deaf community promotes deaf culture as a way of life, resisting *treatment* for their *disability,* as they are not *handicapped* and therefore do not require a *cure*. The discrepancy between the values of the medical community and the values of the deaf community can create ethical dilemmas, particularly when treating children who are deaf. This then imposes ethical considerations for parents who are deaf who are making decisions on behalf of their children who are deaf. The purpose of this paper is to explore ethical considerations related to the acceptance of medical advancements in children who are deaf with parents who are deaf compared to children who are deaf with parents who are hearing. The primary question explored in this paper is whether children benefit from medical interventions designed to help them belong to the hearing community or are harmed by being excluded from the deaf community (i.e., stripped of their cultural identity). To answer this question, modern medicine's perspective on deafness will be analyzed along with the deaf communities' response. Subsequently, ethical considerations and frameworks will be explored, and recommendations offered.

Deafness

According to the Global Burden of Disease Study (2015), hearing loss is ranked the fourth leading cause of disabilities and the most common form of sensory deficit worldwide. According to the Center for Disease Control and Prevention (CDC), two to five out of every 1,000 children in the United States are born with a detectable level of hearing loss in one or both ears (Vohr, 2003). An average of 90% of those children born with a detectable level of hearing loss in one or both ears are born to hearing parents (Mitchell et al., 2004).

Hearing loss can be subcategorized into genetic versus non-genetic. Furthermore, the genetic etiology can be subcategorized into simple Mendelian inheritance versus complex inheritance. Simple Mendelian inheritance can then be subdivided into syndromic versus non-syndromic, broken down moreover by inheritance pattern: autosomal dominant, autosomal recessive, X-linked, and mitochondrial (Shibata et al., 2015). The non-genetic etiology, on the other hand, describes the environmental causes for hearing loss. Environmental hearing loss is subcategorized into infectious versus noise induced. While hearing loss affects individuals regardless of their age, gender, race, or ethnicity, the number of recorded cases is significantly higher in low to middle income countries than in high income countries, as access to diagnosis, prevention, and treatment may be limited in resource-poor settings.

Deafness is usually the result of inner ear or nerve damage that results in partial or complete hearing loss. According to the National Institute on Deafness and Other Communication Disorders (NIDCD), it is estimated that 28.8 million American citizens could benefit from the use of hearing aids, but only 16 percent of adults ages 20 to 69 take advantage of medical intervention (Hoffman et al., 2017). As of 2012, only 324,000 cochlear implants were administered worldwide. In the United States alone, 96,000 cochlear implants were administered, accounting for nearly 30 percent worldwide (NIH, 2016).

Modern Medicine's Perspective on Deafness

Medical Model of Deafness

There are essentially three models of deafness: the cultural model, the social model, and the medical model (Power, 2015). The medical model is a far more physiological and traditional construct than the other two. From the medical neurophysiological position, hearing loss is the outcome of an auditory disease that stems from specific histological and/or cytological disorders. According to the University of Bolton's Library Publication on Deaf Awareness (2013), the medical model defines deafness as an illness and a disability. The same publication describes deaf people as "cases for treatment" by medical professionals via medication, surgery, or training. The medical model has dominated the media for years because of the prestige of scientific medicine and medical professionals. According to Griffith University's Centre for Applied Studies of Deafness (as cited in Hyde et. al., 2005) the medical model is referred to as "a hearing world view of congenital deafness" (p. 417). Since a majority of hearing people have little to no association with people who are deaf, it is difficult to perceive deafness as *normal*. Instead, hearing people tend to see the inability to communicate via spoken language as walls and/or barriers that prevent conventional social interactions (Hyde et. al., 2005).

Hearing Aids

The two main courses of treatment for deafness are hearing aids and cochlear implants (Hearing loss, 2019). Hearing aids are most commonly used when hearing loss is mild to profound. According to the Mayo Clinic (2019), hearing aids are considered to be most beneficial if the hearing loss experienced by an individual is the result of damage to the inner ear. This would be an example of sensorineural hearing loss, meaning that it stems from the inner ear or auditory nerve. Hearing aids are often favorable to cochlear implants as they do not require surgery in addition to being much more cost effective and time sensitive. If the individual has a better understanding of speech or their condition is unilateral, then hearing aids may be prescribed over cochlear implants (Hearing loss, 2019).

Cochlear Implants

Cochlear implants are considered to be the best treatment method for congenital profound deafness (Hearing loss, 2019). The Mayo Clinic (2019) defines cochlear implants as electronic devices that partially restore hearing. Individuals tend to seek out cochlear implants when suffering from hearing loss resulting from inner-ear damage so severe that the use of hearing aids no longer helps. Unlike hearing aids, which amplify sound, cochlear implants bypass damaged portions of the ear to deliver sound signals to the auditory nerve. They utilize a processor to capture sound signals that are then relayed to a receiver implanted under the skin directly behind the ear. This receiver sends the signals to electrodes implanted in the cochlea, which stimulates the auditory nerve to direct said signals to the brain. Once there, the brain is able to interpret those signals as sounds. Obviously, this option is much more complex than the former, as it requires a surgical procedure.

Deaf Communities' Response to Modern Medicine

Deaf Culture

The idea that people who are deaf have their own cultural identity was first officially recognized in 1965 by William Stokoe, Carl Croneberg, and Dorothy Casterline at which time deaf culture was written into the Dictionary of American Sign Language (ASL; 1965). According to Gallaudet University's Laurent Clerc National Deaf Education Center on American Deaf Culture, deaf culture centers on the use of ASL to provide a sense of identification and unity with other people who are deaf (American Deaf Culture, 2015). The values, behaviors, and traditions of deaf culture include promoting an environment that supports vision as the primary sense used for communication at school, at home, and in the community (American Deaf Culture, 2015). Vision is relied on most heavily for sensory input about the environment, especially in the case of people who are deaf and rely on visual communication in the form of sign language (Muir, 2005).

One example of the importance that language plays in establishing a sense of cultural identity can be seen by the deaf bilingual-bicultural community. The deaf bilingual-bicultural community calls this form of social intimacy the bi-bi approach. The bi-bi approach claims that people who are deaf should only use ASL as their mode of "spoken language" (Tucker, 1998, p. 7). This is mostly due in part to the fact that the deaf community views hearing loss as a means of communication, self-expression, and a way of life. Furthermore, the deaf community has a specific set of customs, values, and attitudes that is seen as a birthright or means of bonding together, just like any other racial or tribal minority. In the 1980's, the deaf cultural movement gained increasing momentum, resulting in a revolutionary shift in deaf education away from the medical model to the socio-cultural model (Chen, 2015). The socio-cultural theory of cognitive development draws upon the other two models: cultural and social. Specifically, the cultural model intends to remove the stigma of being infirm that is associated with the deaf community, while the social model seeks to explain the negative repercussions that this stigma has on the deaf community and the difficulties this community experiences as a direct result. By claiming that a person's identity is the product of both their cultural opportunities and the restrictions that are placed upon them, the socio-cultural theory of cognitive development, with the help of the deaf cultural movement, initiated an increase in the rights and dignity of people who are deaf.

The Deaf Identity Development Model (DIDM) was first proposed by Glickman (1993). This model stemmed from Minority Identity Development Theory, which was first coined by Cross in the 1970's (Yakushko et. al., 2010). The DIDM describes the processes by which people who are deaf may acquire deaf culture. This paradigm consists of four stages (Glickman, 1993): culturally hearing, culturally marginal, immersion identity, and bicultural deafness. Culturally hearing refers to people who hold attitudes and beliefs that are dominant within the culture. People with a hearing identity perceive deafness as a medical pathology and the hearing world as their reference for normality, value spoken language, and claim to have hearing loss rather than being deaf. Culturally marginal refers to people who experience shifting loyalties between the deaf and hearing worlds. People with a marginal identity feel as if they do not belong to either community or tend not to immerse themselves in either society. Immersion identity refers to people with a radical stance. People with an immersion identity have a positive connotation associated with deafness and the use of sign language. Bicultural deafness includes balancing deaf pride with humanity. People with a bicultural identity identify with the deaf community, but value and feel comfortable in the hearing community.

Goldblat and Most (2018) examined the relationship between cultural identity, severity of healing loss, and the use of cochlear implants. The adolescents and young adults sampled were divided into three groups: deaf with cochlear implants, deaf without cochlear implants, and hard of hearing. Participants were asked to identify with either the hearing, deaf, marginal, bicultural-hearing, or bicultural-deaf culture. The gender, parents' hearing status, educational setting, and mode of communication were considered. Findings revealed that participants with cochlear implants had stronger bicultural-deaf identity than participants without cochlear implants. Researchers also concluded that of the participants with hearing loss who had hearing parents, most tended to lean toward a hearing identity. On the other hand, participants with hearing loss who had parents who were deaf tended to lean toward a deaf identity (Goldblat & Most, 2018). One explanation for this could be that children who are deaf, but raised in hearing households, grew up immersed in hearing society via spoken language, causing them to adopt the medical model.

Resistance to Cochlear Implants within the Deaf Community

As previously stated, cochlear implants are the best form of treatment for congenital profound deafness, but members of the deaf community do not see deafness as a condition that warrants remedy. In many cases, members of the deaf community actually see this as a means of decimating their intrinsic values and stripping them of their individual liberties. Using derogatory terms like *handicapped* or *disabled* are offensive and imply that deaf society is somehow inferior to the hearing world. Members of the deaf community claim that attempting to *cure* deafness could even harm those who have chosen to identify with deaf culture, decimating the community as a whole. This negative connotation has caused the deaf community to view medical intervention as an unnecessary means, especially when it comes to a seriously invasive treatment such as cochlear implantation. According to the National Association of the Deaf (2015), many members of the deaf community like being deaf (see position statement on Early Cognitive and Language Development and Education of Deaf and Hard of Hearing Children, 2015). Members of the deaf community are proud of their culture and view their *personal diversity* as their right, a right for which they will continue to challenge the medical community. The fight for freedom in the deaf community continues to reflect the social model described previously. According to the University of Bolton's Library Publication on Deaf Awareness (2013), people who are deaf are only *disabled* by barriers and walls created by other people.

In 2007, a video of a six-month-old boy who was deaf being able to hear for the first time after undergoing cochlear implantation was uploaded on YouTube, sparking controversy over the resistance to cochlear implants within the deaf community (Cooper, 2019). Similar videos titled "Baby Aida Reacts to Hearing Her Parents' Voices for the First Time" and "Hearing My Husband Say I Love You for the First Time" began circulating (Cooper, 2019), receiving praise and admiration from the hearing community, but condemnation from the deaf community. The deaf community does not see cochlear implants as the *miracle cure* they are portrayed as by the media. Instead of being an awe-inspiring medical advancement, cochlear implants are depicted as demeaning to members of the deaf community.

Lilit Marcus, a member of the deaf activist community and the daughter of two parents who are deaf, expressed her disdain for the overly emotional videos on the same platform, claiming that sensationalizing and romanticizing cochlear implants suppresses the struggles recipients face (Marcus, 2014). The activation of cochlear implants is highly sensitive and should be a private and personal moment for the individual and their loved ones. Oftentimes, the act itself evokes a shock and horror response from the sudden flood of sensory inputs (Cooper, 2019). It may take months to years for the individual to have fully functioning cochlear implants, as it takes the brain time to rewire itself before it can entirely comprehend what is happening. Cochlear implants are meant so serve as *tools*, not a cure, to deafness. The most inaccurate message proposed by these videos is the idea that cochlear implants convert people who are deaf into hearing. The ‘one-size-fits-all’ fallacy is an erroneous misconception that causes potential negative implications, especially with pediatric patients who are deaf.

Ethical Considerations for Physicians Treating Children who are Deaf and Living in Deaf Households

Wildes (2007) claimed that the controversies in bioethics illustrate the challenges of addressing morality within a morally pluralistic society:

> “We cannot categorize the perspectives on the cochlear implant controversy as ethically ‘right’ or ‘wrong’. We can, however, accept moral ambiguity and cultivate open-mindedness and empathy” (p. 37).

Keeping this in mind, we explore ethical considerations for children who are deaf and living in deaf households from the perspective of the American Medical Association Code of Medical Ethics (hereafter referred to as the AMA Code of Medical Ethics), which was first adopted in 1847, and articulates the values to which physicians commit themselves as members of the professional medical community (Code of Medical Ethics Overview, 1995). Although the AMA Code of Medical Ethics is organized around nine principles, in the sections to follow, we highlight only those relevant to questions surrounding cochlear implants for children who are deaf and living in deaf households.

Ethics of Patient-Physician Relationships

According to Chapter One of the AMA Code of Medical Ethics, doctor-patient relationships are strengthened by the practice of medical ethics, as it assists in creating better communication and making better health care decisions (Code of Medical Ethics Overview, 1995). Within the context of thinking about pediatric cochlear implants, Miziara (2012) emphasizes that, from the standpoint of ethics, physicians must be able to offer their pediatric patients various possible outcomes of the medical procedure(s) pertaining to their case, even though it is ultimately the patients' guardians who make the final decision. The patient-physician relationship is critical here, as physicians have the power to impact the decision of the parent/guardian. Therefore, physicians should carefully analyze each case based on ethical standards before offering their medical opinion (Miziara, 2012). It is important for the patient to know all available options, so that their treatment is not limited by unfavorable social and/or economic circumstances (Miziara, 2012). It should be the goal of both the parent and physician to offer their child/patient what is referred to as an "open future" (Miziara, 2012, p. 78). The idea of an open future suggests these children should be able to pick the community they wish to belong to upon entering adulthood. As Miziara (2012) notes:

> "ENT physicians have the moral duty and ethical obligation of offering their patients the best treatment available, providing parents/guardians with information on all options available – and their pros and cons – without trying to influence them by acting in an unbiased manner and presenting options consistent with medical and scientific knowledge" (p. 78).

Even when parents are biased by their own ideas on the matter, physicians must proceed with caution to avoid adopting a paternalist stance. Instead, physicians should remain strictly professional.

Ethics of Consent, Communication, and Decision-Making

According to Chapter Two of the AMA Code of Medical Ethics, it is a doctors' responsibility to help their patient make well thought-out decisions about their course of treatment by having them research medical ethics of consent (Code of Medical Ethics Overview, 1995). In the case of pediatric patients, it is a doctors' job to encourage the patients' parent/guardian to make well thought-out decisions in the best interest of the child. When treating adolescents, it is important for physicians (and parents) to recognize and respect the adolescents emerging autonomy. As Walker (2002) notes:

> "… ensuring patient choice enhances patient compliance and facilitates goal achievement, two elements associated with treatment success. Researchers who had reviewed a series of studies concluded that minors who were involved in treatment decisions differed in several ways from those who were not involved: (a) improved psychological and physical recovery from surgery, (b) more rapid recovery, (c) increased compliance with professionals' recommendations, and (d) improved perceptions of treatment efficacy" (p. 278).

Furthermore, encouraging an open line of communication between patient, physician, and parents allows for the child to be treated with dignity. According to Walker (2002), dignity gives cause to build citizenship and facilitate children's developmental skills, specifically when it comes to personal decision making. This principle is important for physicians working with children who are deaf in that inclusion promotes a positive environment for all parties involved, especially the minor patient.

Ethics of Privacy, Confidentiality & Medical Records

According to Chapter Three of the AMA Code of Medical Ethics, respecting patients' privacy is crucial in order to build trust, foster thoughtful decision making, and improve quality of care (Code of Medical Ethics Overview, 1995). The Health Insurance Portability and Accountability Act of 1996 (HIPAA) required the creation of national standards to protect sensitive patient health information from being disclosed without the patient's consent. There are provisions of the rule as they apply to the confidentiality of adolescents, however the Privacy Rule generally allows a parent to have access to their child's medical records (HIPPA, 2018). There are three situations in which the parent would not be the minor's personal representative: (a) when the minor is the one who consents to care and the consent of the parent is not required under state law (e.g., in states that allow minor adolescents to consent to testing and treatment for sexually transmitted infections), (b) when the minor obtains care at the direction of a court or person appointed by the court, and (c) when the parent agrees that the minor and the health care provider may have a confidential relationship (HIPPA, 2018). This principle is important for physicians working with children who are deaf in that the child is protected by law rather than solely by a parent or guardian. In the case of children who are deaf with parents who are hearing, this principle may help to elevate certain biases held by the authority figure(s) and how they ultimately impact the child.

Ethics of Medical Research & Innovation

According to Chapter Seven of the AMA Code of Medical Ethics, physicians who are involved in clinical research have additional responsibilities to protect the rights, safety, and welfare of research participants by informing them of matters, including the study design and participant selection and obtaining informed consent (Code of Medical Ethics Overview, 1995). In general, minors cannot “consent”, however, they can “assent”. According to the U.S. Department of Health and Human Services, assent is the willingness to agree to participate in research for which parental consent has been obtained. Gupta (2013) defines informed consent as the process by which potential participants are informed of the purpose and nature of a study so that they can make a voluntary decision about whether or not to participate. Informed consent resides on three essential elements: (a) voluntarism, (b) information disclosure, and (c) decision-making capacity (Gupta, 2013). Voluntarism is defined as the ability of an individual to judge freely, independently, and in the absence of coercion, what is good, right, and best subjected to his/her own situation, values, and prior history (Roberts, 2002). Specifications for informed consent and assent are included in the Federal Policy for the Protection of Human Subjects (45 CFR 46), also known as the Common Rule, a U.S. policy designed to protect human participants engaged in biomedical and behavioral research and which serves as the basis for institutional review boards’ rules and regulations (Protections, 2016).

Waivers of parental consent may be granted when (a) doing so will not adversely affect the welfare or rights of the adolescent involved, (b) the risks associated with partaking in the research study are minimal, (c) the research study would not be capable of being executed without obtaining a waiver, and, in certain cases, (d) an adolescent has been neglected or abused by his or her guardian (Protections, 2016). The American Academy of Pediatrics, Committee on Bioethics (1995) developed specific guidelines to assist physicians in obtaining informed consent, parental permission, child assent, and addressing conflict (Sanci et al., 2004). These guidelines acknowledge the idea of the mature-minor principle, assessing children by their maturity level rather than their age when it comes to making medical decisions (Sanci et al., 2004). This principle is important for physicians conducting research with children who are deaf.

Ethics of Physicians & the Health of the Community

According to Chapter Eight of the AMA Code of Medical Ethics, a doctor's job does not simply stop at individual care, but instead extends to the health of the community (Code of Medical Ethics Overview, 1995). In short, it is the moral obligation of the health care system to provide every individual with equal opportunity of treatment and preventative care. According to Pick (2013), the deaf community struggles with significant health disparities, as they are often excluded from health surveillances, outreach programs, and mass media healthcare messages. Pick (2013) contributes this to cultural and language barriers, putting people who are deaf at a higher risk of poor health knowledge and inequitable access to medical care. As Pick (2013) notes:

> "These barriers directly translate to inadequate assessment, limited access to treatment, insufficient follow-up and poorer outcomes. For example, in the deaf population compared with the hearing population there are lower rates of individuals accessing preventative services, worse cardiovascular health outcomes and higher rates of obesity"

It all starts with early education. If members of the deaf community are not presented with direct access to health information early on in life, they are more likely to feel helpless and less likely to seek it out due to the cultural and language barriers. This principle is important for physicians working with children who are deaf in that treating an entire community provides a greater understanding of their culture. Physicians treating a member of the deaf community should be knowledgeable on the patient's background and have a certain level of respect for the reasons behind decision making related to treatment.

Protection Versus Autonomy

It is well established that a patient's meaningful involvement in their treatment is important. This is also true for pediatric patients, especially adolescents whose autonomy is emerging as they prepare to enter adulthood, at which time they will be responsible for their medical care. However, parents/guardians and many physicians may value protection over autonomy. As Walker (2002) notes:

> "… on both ethical and pragmatic grounds there are sound reasons for including children in the medical decisions that affect them. Historically, however, medical decisions regarding minors have been fertile ground for conflict between the competing rights of children, their parents, and the state" (p. 279).

The idea of morality versus practicality then allows for the introduction of the best interest approach. Taylor (2016) provides four distinct interpretations of the best interest approach: (a) best interest as determined by the patient's clinical needs, (b) best interest taking into account a subjective evaluation of the patient's wider social and welfare preferences, separately and subsequent to the doctor's determination of clinical interests, (c) best interest as an objective evaluation of what the 'reasonable' patient's preferences would be, if their views were unknown, and (d) best interest as a fusion of clinical and wider welfare issues.

Parental Consent as Protection

First and foremost, it is important to mention that protection and respect for autonomy are not mutually exclusive. Children are vulnerable citizens, and the power of consent ultimately falls on the parent/guardian. This vulnerability contributes to a loss of autonomy, stripping pediatric patients of their right to exercise free will. However, if overprotection can cause harm, then so can under protection. Israel (1992), a genetic counselor at Gallaudet University, claims that many deaf families are not interested in fixing or curing deafness. In certain instances, couples have even chosen not to have children if they are not likely to be born deaf. These parents want to protect their children by fitting them into their world, in which they feel safe. The Americans with Disabilities Amendments Act of 2008 prevents discrimination on the basis of disability but does not provide for people with “voluntary” disabilities. This then introduces the longstanding argument of whether or not it is selfish for the parents of children who are deaf to reject the use of cochlear implants simply as a means of preserving their own sense of deaf culture. Melissa Chaikof, the mother of a child with cochlear implants, reported that her concern for her daughters’ future far outweighed her concern for the future of deaf society (Tucker, 1998). However, other parents in the deaf community feel differently. When working with minor children who are deaf, understanding how parents view protection (and protection from what) is important.

Child Assent as Autonomy

The United Nations established the Convention on the Rights of the Child (CRC) in 1989 to formally codify an international bill of rights for children, and to address the unique concerns and needs of children under the age of 18 (General Assembly of the United Nations, 1990). The basic human rights of children include the right to (a) survival; (b) develop to the fullest; (c) be protected from harmful influences, abuse, and exploitation; and (d) full participation in family, social, and cultural life (General Assembly of the United Nations, 1990). The established rights are built on the four pillars of the CRC: nondiscrimination; commitment to the best interests of children; the right to life, survival, and development; and respect for the views of children (General Assembly of the United Nations, 1990). Specifically, Article 12 of the CRC ensures that children capable of forming and expressing their opinions should be afforded the right to do so (United Nations, 1989). It is also important that those opinions be acknowledged in the context of the child's age and maturity, so that it is within the rights of children to advocate for themselves in a developmentally appropriate way (United Nations, 1989). In the context of thinking about treatment for children who are deaf, physicians should keep these basic human rights in mind, especially the ability to fully participate in cultural life. If the child who is deaf is born to parents who are deaf, they may be encouraged to embrace deaf culture as opposed to hearing culture, even though they are entitled to whichever they so choose to accept.

Ethical Frameworks for Healthcare Professionals Working with Children who are Deaf and Living in Deaf Households

Model for Balancing Protection and Autonomy

Given that sound justifications exist for both ends of the protection versus autonomy continuum, there exists a need to balance these extremes. Autonomists question *who* should be making the decisions, while protectionists question *what* decisions should be made, presumably in the best interest of the child (Chenneville, 2015). The answers to these questions should take into account the decisional capacity of the minor in question, as opposed to the opinion of their authority figure, whether that be their parent or their physician.

Chenneville et al. (2010) introduced a model for balancing protection and autonomy among minors. Although Chenneville et al.'s (2010) model focused on work with patients living with HIV, it applies to minor adolescents with other health conditions. In this model, the *who* and the *what* associated with the decisional capacity of minors is based on data obtained from a series of questions in the form of an assessment rather than the viewpoint of an authority figure, whether that be a physician or a parent (Chenneville, 2010). Applying this model to working with children who are deaf, healthcare professionals should allow adolescent patients to be autonomous to whatever extent possible, assuming their decisional capacity is high. As long as the child's voice is respected and incorporated in an appropriate way, it is assumed that autonomy is advantageous, even when protection is warranted.

An assessment of decisional capacity is central to Chenneville et al.'s (2010) model for balancing autonomy and protecting when working with minors. According to experts in the fields of psychology, law, and bioethics (Dunn, Nowrangi, Palmer, Jeste, & Saks, 2006; Grisso & Appelbaum, 1988), decisional capacity is comprised of four components: (a) understanding, (b) appreciation, (c) reasoning, and (d) the ability to express a choice. The Veterans Health Administration defines decisional capacity of an individual as the ability to understand and appreciate the nature and consequences of health decisions and to formulate and communicate decisions concerning health care (Informed Consent for Treatment and Procedures, 2009). In this context, the word *understanding* refers to the extent to which an individual is able to comprehend the meaning of the information being communicated to them (Palmer & Harmell, 2016). This includes any potential risks and benefits of the proposed treatment and its alternatives. *Appreciation* involves the ability to apply relevant information to one's self and their own personal situation (Palmer & Harmell, 2016). The *reasoning* component associated with health care decision making refers to evidence that the patient's choice reflects the presence of a sound thought process (Palmer & Harmell, 2016). A physician is able to determine if a patient's choice is reasonable if they are able to manipulate the information rationally. At the most basic level, the *ability* to express a choice simply means the ability to communicate a decision, however, some authors emphasize the need to be clear and consistent (Palmer & Harmell, 2016).

Goodness-of-Fit Ethics

The goodness of fit ethical (GFE) framework was originally meant to illustrate the balance between respecting the rights of those with mental impairments as autonomous members of the community with the need to ensure that incompetence or ill-informed decision making will not jeopardize their welfare (Fisher, 2003). Simply put, this model conceptualizes consent vulnerability in terms of patient characteristics and consent context. Fisher (2003) claims that, when using the GFE model for informed consent, or assent in the case of minor, a child’s vulnerability in life creates vulnerability in the context of treatment or research. Treatment or research vulnerability is the failure of research procedures to protect patients or research participants (Fisher, 2003). The GFE model suggests the need to build upon a patient’s assets while minimizing harm. In this case, requiring parental or guardian permission, which is intended to protect adolescents, may actually serve as a barrier to adolescents’ participation in research that may have implications for their health. The GFE framework applies to treatment as well. Fisher et al. (2017) applies the importance of participant consent strengths and vulnerabilities specifically to treating pediatric patients with HIV, but the same applies to children who are deaf. Medical practice is shifting away from medical paternalism, or the idea that physicians are the primary decision-makers for patients, and toward more collaborative models of decision-making (Fisher et al., 2017). According to Fisher et al. (2017), the GFE model requires medical professionals to design informed consent procedures that reflect all of the following: (1) an understanding of developmental and health-related factors influencing minors’ ability to provide an informed, rationale, and voluntary participation; (2) an understanding of guardians’ comprehension of the child’s health condition and, in this instance, general deaf literacy; (3) an understanding of the cultural context and preferred modes of family healthcare decision-making; and (4) an understanding of the unique characteristics of the specific treatment. Following this framework may minimize the shame and stigma surrounding a child who is deaf choosing to adapt a hearing identity when their parents are in strong support of deaf culture.

Recommendations

Physicians and other healthcare professions should be encouraged to access decisional capacity and involve youth in decision making about treatment to the extent that they are capable, which is consistent with the protection-autonomy model. It could also be beneficial for physicians and other healthcare professionals to access patient/family characteristics and context within working with children who are deaf and their families, which is consistent with the goodness-of-fit ethical framework.

Valuing children who are deaf is important for preserving deaf culture. This entails providing support for the bilingual ASL/English education of children who are deaf, so they are competent in both languages. The dual competency also eliminates the cultural and language barriers that prevent equal access to health care. Additionally, continued support for the Association of Medical Professionals with Hearing Losses, which was formed to include all medical professionals with hearing loss, poses potential advantages in terms of equal opportunity. The Association of Medical Professionals with Hearing Losses provides information, promotes advocacy and mentorship, and creates a network for individuals with hearing loss interested in or working in health care fields.

Conclusion and Future Direction

While medical intervention for hearing loss is often strongly encouraged by health care professionals, it may be seen as unnecessary and offensive by the deaf community. From the medical perspective, hearing loss is an auditory disease resulting from a histological or cytological disorder. From the socio-cultural perspective, society needs to remove the pessimistic stigma associated with deafness, as it has negative repercussions on the deaf community as a whole. Physicians are encouraged to familiarize themselves with the Deaf Identity Development Model in order to better understand deaf and hearing cultures. Physicians also are encouraged to consider the ways in which AMA Ethics Code applies to their work with children who are deaf and living in deaf households. Finally, physicians and other healthcare professionals working with this population should familiarize themselves with ethical frameworks such as the Protection-Autonomy Model (Chenneville, 2010) and Goodness-of-Fit Ethics (Fisher, 2003) in order to ensure the best outcome for the children and families they serve. Ultimately, it is the parent who makes the final decision on behalf of the child, but the physician plays a large role in determining the parents' choice. Respecting the voice of children is important, especially for minor adolescents. Both parents and healthcare professionals should primarily be concerned with providing the child an open future, so that they can pick which community they wish to be a part of upon entering adulthood. This instills the idea that the child can benefit from medical intervention without being worried about whether or not belonging to the hearing community will strip them of their cultural identity.

Future research is needed to explore the extent to which deaf culture impacts medical decision making within the deaf community and how to involve the deaf community in research around deafness. This could potentially be initiated by increasing deaf community representation and participation in the hearing community via committees or boards meant to spread medical information and research opportunities. Overall, the aim should be to minimize health disparities by improving health literacy among the deaf community and to exclude cultural biases when treating patients or conducting research.

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