Ethics Principles of Translational Audiology

Subjects: Audiology & Speech-language Pathology

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The idea behind translational research in audiology is to improve the quality of medical care for patients with hearing impairment. Although lofty and deserving of the highest recognition, this idea should never be implemented at an individual's expense in the research procedure. The inalienable dignity of the human being requires researchers and physicians to act for the benefit of the subject, limit the harm, maximize the benefits, and respect the autonomous decisions of the subject. What may serve as signposts indicating the ethical way of conducting translational research in audiology and taking care of patients with hearing impairment are the principles of beneficence, nonmaleficence, autonomy, and justice.

Keywords: ethics ; audiology ; deafness

1. Introduction

Audiology is a large branch of medicine concerned with disorders such as hearing loss, hyperacusis (distorted loudness perception causing several noises unbearable and painfully loud to the affected person [1]), tinnitus (the perception of sounds without actual acoustic stimuli [2]), or misophonia (an emotional reaction to sounds [3]). Another branch of audiology deals with vestibular dysfunctions originating from the inner ear [4][5][6].

Hearing loss may have congenital or acquired origins [7], and several therapeutic options were developed to treat the affected patients. These options depend on the site of the pathological changes (outer, middle, inner ear; brainstem or central auditory system) and on the degree of the hearing loss (mild, moderate, or severe) [8]. The National Health Service should support people who are hard of hearing and help to early detect hearing impairment [9].

2. The Principles of Beneficence and Nonmaleficence

The principle of beneficence is the obligation of the physician to act for the benefit of the patient, prevent harm, remove conditions that will cause harm and help persons with disabilities. It is worth emphasizing that, in distinction to nonmaleficence, the language here is one of the positive requirements. The principle calls for not just avoiding harm, but also to benefit patients and to promote their welfare.

The practical application of nonmaleficence is for the physician to analyze the benefits and losses of the proposed interventions and therapies. The physician is obliged by this principle to avoid those that are inappropriate and chose the best procedure for the patient.

The application of the principle of beneficence in clinical trials refers to a researcher's obligation to maximize the benefits of the research and minimize the risk of harm to its participants. Therefore, this principle also includes the principle of nonmaleficence, which sets specific limits for the activities of researchers. It prohibits taking any action that may cause intentional evil or harm to the participants of the research, whereby both physical wrong or harm, i.e., one concerning the state of somatic health, as well as emotional and financial harm, must be included.

A key measure ensuring compliance with the principle of beneficence in scientific research is the analysis and assessment of the risk-benefit ratio of a research participant. Research should not impose risks and burdens disproportionate to the expected benefits of participating in it. In the case of experimental research involving sick persons, which gives participants a chance to obtain a direct diagnostic, therapeutic or prophylactic benefit, the benefit-risk balance of the new intervention cannot be assumed to be less favorable than that of the existing best-proven interventions. In the case of scientific research that does not provide direct diagnostic, therapeutic or prophylactic benefits to participants, the accompanying risk should be estimated proportionally to the scientific value intended to be obtained in connection with the implementation of the research. Such tests are allowed only if they involve risks and burdens that are not greater than acceptable [10].

It should be noted here that participation in scientific research is always associated with the risk of the subject coming to harm. The most frequently mentioned risks include incurring physical, mental, and socioeconomic harm. Research in biomedical sciences often exposes the subject to minor pain, discomfort, or harm caused by medication side effects, and these harms are examples of the physical type of harm. Among the psychological harms, attention should be paid to undesirable changes in the research participants' thought processes and emotional states, e.g., episodes of depression, confusion or hallucinations after taking the drug, feelings of stress, guilt, and loss of self-esteem. These changes may be temporary, recurrent, or permanent. Potential socioeconomic harms include violations of the right to privacy and intimacy of research participants, job loss, and stigmatization. Moreover, information relating to alcohol or drug abuse, mental illness, illegal activities, and sexual behavior creates areas highly prone to abuse [11].

Applying the principle of beneficence and nonmaleficence, the researcher should assess the significance of the potential benefits and harms and, on this basis, decide on the participation of the subject; bearing in mind the principle according to which a research participant should never be the object of an action or a means to achieve an end. However, as an end in itself, the researcher should assess the moral acceptability of his action.

3. The Principle of Autonomy

Compliance with the principle of autonomy is based on respecting the patient's opinion and will. It refers to the freedom of the patient to choose the method of treatment and the need to obtain informed consent from the research participants. Autonomy in bioethics and medicine emphasizes respect for the person and their dignity, including the medic, the patient, and the researcher alike.

On the one hand, hearing loss or deafness requires a specialist or researcher, who will provide the patient/research participant with information about the procedure, side effects, risks, benefits, and costs necessary to make an autonomous decision; on the other hand, the patient or his or her parents have the opportunity to make decisions based on their beliefs and after consulting specialists or other deaf people. The physician or the researcher in his or her actions is guided by evidence-based medicine and the good of the patient/research participant; nevertheless, he or she is obliged to respect the individual's will, even if it is not in line with his or her point of view. Involving the patient in the decision-making process is a desirable phenomenon that proves that the principle of autonomy is respected [12][13].

Regarding audiology and the needs of young patients for implant provision, preserving the child's autonomy is also an essential aspect of medical practice. To maintain the principle of the child's autonomy, with the literal meaning attributed to it, the intervention decision could be postponed until an older age. However, it should be remembered that for the proper sensorimotor and speech development, it is important to take appropriate action as early as possible [14]. It is also crucial for supporting a child's psychosocial development.

4. The Principle of Justice

Another principle of research ethics is the principle of justice. Suppose justice means treating everyone morally and appropriately, including the benefits of participating in the research for all community members. In that case, one should expect equal access for both researchers and, above all, deaf patients to the most modern hearing aids or implants at the best time for a given person. This means that everybody should equally be able to participate in research regardless of, for instance, gender. Another benefit of participating in research is the application to community members that do not participate in research and to broaden the knowledge and social skills. However, is it so? It seems that both in translational audiology and other fields, especially in modern areas of medicine, the principle of justice functions insufficiently. The application of justice in research should be reflected in social life and the availability of the most appropriate solutions for the patient [15]. Justice in research emphasizes the fundamental principle of "health for all" [14]. This means access to health, regardless of gender, ethnicity, place of birth, political beliefs, religion, economic or social status. Applying the principle of justice in translational audiology could prevent the marginalization of a society. Every researcher in each community would have to provide the best possible equipment implants for the patient, regardless of the patient's place of residence or economic status.

Consequently, each patient would have the same opportunity to develop communication. It does not always have to be verbal communication; this could involve a sign language interpreter. In the context of the principle of justice, it is essential to inform the patient from the very beginning what solutions they are entitled to regarding the implant and what methods of communication they have at their disposal. Researchers in their daily work should apply the principle of justice. A drawback is that this often leads to the research group being less numerous than if patients were only offered one method of assessment and therapy. Therefore, bearing in mind that clinical trials usually have their origin in medical practice, the

ideal solution is if the principle of justice accompanies the researcher from the very beginning of their activity, including conceptualization, practice, and research. However, this is not always the case in everyday life. A body that is responsible for safeguarding, so to speak, the principles of ethics, including justice [16], is the bioethics committee. Therefore, an audiologist who is a researcher has several roles in conducting the research. First of all, he or she should take into account the patient's well-being and health, as well as the patient's ethical perspective. Secondly, they must consider factors influencing moral judgment, sensitivity, motivation, courage, and cultural dimensions of ethical practice in audiology [17].

The multifaceted nature of the issues related to deafness also leads to serious moral dilemmas related primarily to reproductive medicine and the treatment of hearing loss. In the case of reproductive medicine, the dilemma may concern the acceptability of donor selection and the selection of an embryo burdened with deafness. Such a situation took place in the USA, where a deaf lesbian couple deliberately created a deaf child. Sharon Duchesneau and Candy McCullough used their sperm donor, a deaf friend with five generations of deafness in his family. Duchesneau and McCullough do not see deafness as a disability. They see being deaf as defining their cultural identity and witness signing as a sophisticated, unique form of communication [18][19][20][21]. The moral dilemma concerns the dispute over the understanding of deafness and the concept of care related to the ethical principles discussed above.

Furthermore, although this problem is not new in ethics, a similar situation occurs when parents do not agree to have a child's life saved by refusing blood transfusions because of their faith. For this case also, an extremely problem of rapidly developing research and gene therapies and their applications should be resolved. The question arises whether genetic testing techniques designed to reduce disease and improve the quality of life can be used to deliberate defective embryos. It should be remembered that deafness does mean not only a lack of hearing, which can actually be perceived in a cultural context, but also several comorbidities, including an increased risk of dementia [22]. This dilemma seems to be difficult to resolve from the principles described above. All perspectives boil down to whether it is good that a sick child has been brought into the world. The arguments from one side point to the use of preimplantation genetic diagnostics as incompatible with its objectives. However, it should be remembered that Gauvin, the son of a pair of deaf women, was born thanks to the knowledge in medical genetics.

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