

ETHICS CORNERED: DILEMMAS OF THE DEAF COMMUNITY AS A MINORITY PARADIGM ON THE COCHLEAR IMPLANT TECHNOLOGY DEBATE.

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Abstract

Introduction: The Deaf community is a group which has disputed the use of cochlear implant technology as a threat to its existence. Even if the group's arguments have met with logical, external or real hindrances, the case can be modeled for observation on ethics and mainstream worldviews with which it appears to be confronted.

Purpose: Instead of the modern "trial-and-error" paradigm, a time-consistent perspective can provide valuable criterial foundation on dilemmas of pursuing or not ethnicity recognition, special minority rights and mainstream convergence.

Method: With bioethics as a starting point, we provide explanations and predictions on the Deaf community case using philosophy of science, social psychology and commenting on the current spirit of the era.

Results: Ethnicity recognition and special minority rights are not cases which can be easily endorsed. However, mainstream convergence creates an opening.

Conclusions: The narrative of the Deaf community could be reformed by communicating its culture to the mainstream one, bridging the Deaf community with a non-stereotypical part of the mainstream. Furthermore, if bioethics fails in its mission as a common practice, the next era may not have a use for it.

INTRODUCTION

Technology has always affected humankind, not only by means of facilitating everyday life but also in the gradual change of the worldview. Like in the 17th century case of Galileo Galilei, populations do not shift their worldview in a fast or peaceful way, but through crises and turbulence- in that case, the confrontation with the established religious anthropological narratives that in turn led the Renaissance to the gradual detachment from capitulatory power. The consequences of a violent transition can be understood clearly in examples where the cost consists of the shrinkage or annihilation of people's ideologies, languages or practices and, sometimes, the people themselves. Advances in technology continue to happen in an exponential fashion. Genetics and medicine are evolving so fast that a sub-discipline was created to monitor and deal with the emerging crises: Bioethics' main target is to debate on the current scientific narratives and technological innovations that the people should be aware of, preventing the consequences of a baffled multitude.

A group of people claiming its existence is being threatened by such advances is the Deaf community. The Deaf appear to be confronted with the cochlear implant (CI) technology, which deprives deaf of the main physiological characteristic that has historically been the foundation of their coming together as a group: deafness. Moreover, if CIs were to be majorly installed, this could lead to the gradual demise and extinction of sign languages and Deaf culture. There were a few axes for this hypothesis that provided the fuel for the debate, such as the linguistic issue of characterizing deafness as a disability or the ethical issue of installing CIs in pre-lingually deaf children. In this paper, we discuss bioethics as such, minority influence and the spirit of the era, in an effort to provide valuable criterial foundation to the dilemmas of pursuing or not ethnicity recognition, special minority rights and mainstream convergence.

BIOETHICS

As an abstract concept, bioethics exists since ancient times, because it is the product of human thought and it positions itself on a meta-level of philosophical critique over life as a phenomenon. All that anyone needs to practice bioethics is to be living. Its systemization as a sub-discipline was established in the 1960s when the consequences of the eugenics experiments and the practices of exterminating entire social groups by the Nazis were addressed (Lekka, 2013, 1). This is not without value for us today: Ethical philosophy derives from anthropology and technology is its application (Maranto, 1996, 15). In other words, ethics defines its field from an anthropological foundation, which determines actions. For example, if deaf, blind and psychotic individuals are not sufficient for human standards, as they live a “life unworthy of living” (Binding & Hoche, 1920), then there is no ethical issue in sterilizing them, which is what National-Socialism tried to do. Anthropological narratives may appear in an extreme or less extreme fashion; nevertheless they are crucial for people’s belief system or tolerance. This is what propaganda can do: Worldviews are larger and stronger than laws and this is because they define people’s actions and reactions, bending laws when they are considered to be obsolete. A bioethics committee may do exactly that when brought forward to endorse a parliament bill. But, what is bioethics’ scope?

The two extremes of bioethics between which ethical issues are investigated are, on the one hand to decide ourselves about the future nature of humans making them without drives (Hudson, 2000) and on the other hand to not decide, unless absolutely medically necessary, since some consequences maybe irreversible (Altmann, 2001). Accordingly, the extremes of bioethics uncover a root of the problem: Are we sure, as a whole, about today’s anthropological narrative? If humans should be defined as biological super-humans, then we must strive to make people like that, without taking notes of culture, as it is an out-of-biology element of identity. One could hurry to deliberately address culture or history as obsolescent concepts. Unfortunately, without these concepts, one couldn’t possess the choice of “addressing” anything in the first place. An explanation is needed on what is the reason for bioethics’ future projections and current dilemmas.

ASYMMETRIES

When scientific practices shift towards a radical way of dealing with former problems, if this is radical enough, it will carry along notions, traditions, ontological generalities and values (Kuhn, 1962). This cannot be partially averted since it constitutes an organic whole-*Paradigm*. This Paradigm, which works its way through the scientific community towards problem solving, is brought against a theoretical dead-end, when the empirical practice and the observational language is unable to translate and outflanks the theoretical foundation of the Paradigm-an *anomaly*. This, hard-to-accept by the scientists, aberration will drive the existing Paradigm to a *crisis*, an area where language and notion lose their meaning-an *asymmetry*. Such a crisis can resolve within the existing Paradigm or move towards a new Paradigm, depending on the foundation’s capacity to assimilate the anomaly.

In the case of CIs and Deaf culture, one shouldn’t try to prioritize asymmetry only in whether deafness is a trait or a disability. The asymmetry is noted here to indicate that the whole anthropological narrative that defines people’s practices is asymmetrical: Whatever could happen in an evolutionary time spectrum for the human body, it is now done faster. Medical practices can intervene, by equipping the human body with selective advantages; and have done so in favor of health and well-being for most cases. However, people have proved that they can evolve not only faster, but also differently from natural laws. Humanity’s interest until recently was directed towards mutual respect, minority recognition and preservation, and, most importantly, sociability regularization through laws. Lately, the research appears to shift towards medicine and the meddling with physiology (Marschark, 2001), possibly with the same goal: If everybody shares similar brains, they will share similar

behavior. But, how do minorities behave, and how does the Deaf community influence this kind of crisis? The aforementioned asymmetries are partly what bioethics was conceived for, although behavior is another domain.

DEAF MINORITY INFLUENCE

Each human being is a member of at least one special cultural group, thus belonging to some national majority, even if it's common to apply this term unfavorably to minorities (Fenton, 2003, 165). Indeed, if there is an implication from the ancestry, values and institutions of the Deaf community, it is that their long term practices, including the struggles for legal recognition, could constitute in fact an ethnic history, which has specific collective narratives, such as the ASL speakers. However, the values and rules of the Deaf culture do not underlie something totally different from the mainstream anymore since they relate to, embody and transform it, especially within a historical period where the distinct characteristics of even national groups fade (Lane et.al, 2012, 27). Furthermore, culture consists of ideas, narratives and cannot be exclusive, because of some physiological characteristic (Levy, 2002, 147). No person is born with a pre-installed symbolic order, culture included, but with a predisposition towards language acquisition, through which, he/she is led to acquire identity and social roles.

"It is not so much the kind of person a man is as the kind of situation in which he finds himself that determines how he will act."

(Milgram, 1974, 205)

A main issue in a group is the amount of aggressiveness and prejudice with which each member chooses to defend the group's collective goals (Sheriff, 1966); in this case, goals that are mutually exclusive to the mainstream ones. Even if the group gains coherence and stability, members do not appear as a multitude of separate personalities, but as a collective that feels threatened proportionally to the threat against its core narrative. Specifically about intergroup conflict and minorities, the main elements that constitute an effective minority influence is *Diachronic Consistency* and *Synchronic Consistency*, which translates to the persistence of an idea over time and the rallying of the whole group around it, respectively (Moscovici et al., 1969). At first the minority would clash, proclaim its solution as the only compromise, and then would abate but keep its distance (Maass & Clark, 1984). Social psychology experiments show that the minority influence is augmented when the minority distinctions are singular, not dual, when members are investing in the process of influencing, when the minority is considered to be autonomous, and when its viewpoint is considered to be just and accordant to the spirit of the era for social rules (Mugny, 1982). The Deaf community fits well with the aforementioned model of a strong-influencing minority. However, does the spirit of the current era allow for considering the Deaf viewpoint as just?

THE SPIRIT OF THE ERA

"We live in an era that has declared health, normality, beauty, and profit to be the maxims of life"

(Hintermair & Albertini, 2005, 187)

Social narratives nowadays are not manufactured by scientists nor are shaped by ethics, but emerge as the result of a status-related consumerism, in terms of acquiring positional goods (Hansson, 2005, 524). The way free-market often functions within medical research is by creating new needs and providing the products; there isn't any "invisible hand of the market", automatically balancing what people need (Golub, 1996, 75). In the CI case, the commercialization of science

provides the mainstream with an underlying consumerist attitude, which views the Deaf viewpoint as unjust, for blocking “scientific progress”. This kind of utilitarian approach appears to be very closely related to a postmodern neoliberal utopia (Bourdieu, 1998, 94), which promises that, not only the market, but also the social structure will self-regulate.

Effectively enough, narratives influenced and dogmatized by the present free-market mindset could apply to children, hence narrowing the issue of choice in installing children with CIs down to a pragmatic answer: If CIs are considered useful for the 90% of the cases (deaf children of hearing parents), parents do not have any obligation towards the Deaf community to raise ethical dilemmas (Levy, 2002, 152).

“Children do not need perfection. Perfection is not about children. It’s about our own needs”.

(Maranto, 1996, 276)

The implication of the above is that the ones possessing the choice also possess the need for perfection, thus adding to the argument about commercialized science creating needs, based on a “normal” or superhuman narrative. The problem in the children’s case is not only the meddling with their physiology, but also the shaping of their worldview. There is no need to hypothesize in order to conceive how perfection-oriented individuals will treat the perceived as less-than-perfect ones in the future, because this is already the case. Perfection is highly unobtainable and a fantasizing concept, therefore it can lead to all kinds of irrationalities that characterize this era and relate to pathogenies, like consumerism. The same applies to an opposing concept, “suffering”, that could gradually emerge as the narrative for medical intervention (Hintermair & Albertini, 2005, 186). In this case, if suffering is to become a well-established criterion for medical intervention, then irrationalities may escalate to the extreme: The “people that suffer extremely”, may be deprived of a “life unworthy of living”. If this historical analogy is not shocking enough, we could picture a sales executive claiming that, if an unworthy life’s end is marketed effectively, then people will ask for it.

CONCLUSIONS

Technological products become freely and rapidly accessible by increasing groups of the population, a fact which appears difficult to regulate through carefully planned long-term research, since the corporations that benefit from these practices are in many cases the same that fund medical technologies research, adding again to the populations’ worldview through marketing. Accordingly, the dilemma of pursuing or not the elevation of Deaf culture as exceptionally important and in need of conservation is suppressed under the global market’s speed that leads to inequalities in interests and affects political or legal decisions through lobbying. This is the case with many minorities and languages in decline around the world. Deaf culture protection, ethnicity recognition, special minority rights (proxy consent), as separatist practices, are not cases that would be easily endorsed by legal procedures in the current era; lobbying for Deaf community brings no profit.

This brief analysis shows the way a minority collides with the mainstream, revealing the nature of two different worlds. However, stereotypes and attitudes change when individuals are exposed to information that disproves those (Brown, 1995). The way to do so is contact (Allport, 1954). To attempt this kind of convergence there should be an abatement of the Deaf culture narrative and also of the attachment the Deaf have to it. Furthermore, there should be institutional support for cultural contact with the mainstream. In the same way, a force that could turn the tables is a public opinion that detaches itself from science as a social narrative. It is a crucial dilemma whether Deaf culture should merge with the current mainstream and what that would mean. Maybe such an approach would mitigate the Deaf

community's position even more and threaten the group's coherence. Nevertheless, if the non-stereotypical parts of the mainstream identify with Deaf culture, they will defend it as their own. Such parts are those that understand and deny the underlying narratives of the spirit of the era, acting for progress with respect to the lessons of history. The criteria of identification arising from the analysis are not only cultural, but also, political and ethical. A main reason why this convergence might fail would be bioethics' inability to establish itself as common knowledge and practice amongst people, merging present with the past and the future.

What theoretical concepts can provide us with is an aspect of the possible regulative-repressive role of future ethics. Inside a new Paradigm, anomalies are to be regarded as natural events, but will have already led to society's destabilization. Bioethics is looked upon as the representative of vested interests and values. But, is it? If commercialized science is already the new religion of a postmodern era, this means that bioethics has partly failed (or worse) to debate a cultural balance. At this point, the Deaf community has intervened to defend its own culture. What we can deduce from the meta-analysis is that a Kuhnian crisis, where the human body is implanted or changed on a genetic level, has partly arrived. If this becomes part of the mainstream anthropological narrative, current ethics will be deprived of meaning. A new Paradigm may well be a barbaric one, but it will surely mean business as usual.

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