

COMMENT

Diagnosis of autism, abortion and the ethics of childcare in Yoruba culture

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Abstract

*This paper examines the ethics of childcare in Yoruba culture in the contexts of autism and abortion. The traditional Yoruba moral principles of *ibikojuibi* (equality of humans at birth) and *ajowapo* (solidarity) have been theoretically developed to establish the personhood of autistic children and provide a justification for not aborting fetuses with autism. Despite these justifications, this paper argues that there is a need for contextual rethinking, which would allow for: (i) prenatal genetic testing, as well as abortion of fetuses with a high risk of the autism mutation, and (ii) early clinical diagnosis and treatment of autistic children in contemporary Yoruba society.*

Introduction

The development of medical technologies is beginning to change the classical perceptions of mental disorders such as autism. Hitherto unknown aetiologies and prognoses of neuropathological disorders are now being better understood, and there has been a great improvement in the diagnosis of and treatment options for these disorders. For instance, besides prenatal genetic testing, which offers parents the choice of aborting a foetus with the autism mutation; we can now opt for pharmaceutical and medical technological interventions to help “children with autism communicate, observe appropriate behaviour, and learn social interaction skills” (1). Some examples of such interventions are augmentative and alternative communication devices (AACs), video modelling (VM), virtual reality (VR) and several diet therapies. It is now also possible to improve human cognitive capacity in non-pathological cases through the use of chemical and mechanical forms of neurotechnology, including psycho-pharmaceuticals, neuronal tissue implants, brain-computer interfaces and a host of other novel methods (2).

The emerging medical technologies raise a few moral concerns of considerable importance. As knowledge and advancements in neurology make inroads into developing states such as those in Africa, some of which have different cultural dispositions as well as a dearth of research work on autism, we need to understand the ethics of parental decisions regarding the diagnosis of autism and the care of autistic children. What impact does culture have on people’s understanding of the diagnosis and treatment of autism spectrum disorders in children? What are the traditional responsibilities of caregivers to autistic children? Are there any

ethical justifications for such responsibilities? Should a foetus with autism mutation be aborted?

This paper is an ethical assessment of a case report on the Yoruba cultural outlook on the care of autistic children. The Yoruba people are one of the major ethnic cultural groups in southwest Nigeria and southern Benin, West Africa. An attempt has been made to keep the assessment within the framework of the Yoruba ethical mores regarding childcare.

The case

Mrs A, a 29-year-old trader, was married to Mr A, a 40-year-old farmer who was a member of a Yoruba rural community in southwest Nigeria. When his wife remained childless till seven years after the marriage, Mr A’s extended family got him married to a second woman, Mrs B, who was a traditional birth attendant. In the following year, Mrs B gave birth to male twins, X and Y. When the twins were four years old, symptoms of autism were observed in Y, while X was without symptoms. After persistent but unsuccessful attempts to treat the child with herbal medication, the family was advised to consult the priest for a traditional diagnosis. The child’s neurological inactivity was diagnosed as a non-pathological result of the gods’ wishes, something which was considered incurable. Since there was now no question of treatment, the only option left was that of care. A few months after the family members had managed to convince themselves that Y’s neurological condition was the handiwork of the gods, the family’s traditional physician confirmed that Mrs A was pregnant. This was after about 11 years of being unable to bear a child and facing stigmatisation for her barrenness. Mrs A was looked after by the family’s traditional physician and the entire household. Her husband’s younger brother, Mr C, felt that she should undergo prenatal genetic screening and have the delivery outside the village to be on the safe side. Initially, Mr A was in favour of his wife receiving prenatal care in the house itself. However, due to the family elders’ efforts to persuade him and the trust he had in his brother, Mr A agreed to Mr C’s request. The screening revealed that the foetus had a high risk of autism. The amniocentesis carried out later confirmed the chromosomal abnormality. Mr A was not only unable to understand the results of the screening and amniocentesis, but was also reluctant to accept the medical advice that the pregnancy be terminated to prevent the likelihood of having another autistic child. Mr C made an attempt to educate Mr A on the implications of the results and the options available,

and given Mr A's trust in his brother, he eventually decided to terminate the pregnancy. However, Mrs A did not believe the diagnosis; with the backing of many of her husband's family members, she refused to terminate the pregnancy.

Ethical considerations

Informed consent was obtained for the collection and reporting of the data for this study. In line with the terms of consent agreed upon with the family, the identities of the family members and traditional physician, as well as the name and location of the clinical laboratory, were not disclosed so as to maintain confidentiality. Only the researcher listened to the audio recording.

Case analysis

It is common to find such cases among Yoruba families and the traditional healthcare system. Yoruba culture, like many others in Africa, centres on the need to have children as an important value of life (3). Rearing children is the responsibility not only of the biological parents, but also of other caregivers in the family, ie non-biological parents in the family clan. Thus, the word "caregivers" refers to the biological parents and all the members of the extended family. "Care", in general, connotes attitudes and actions that help to maintain, mend and improve human conditions, and in this context, the child's world. Besides being members of the family, caregivers "assume the role of health caregivers, acting as de facto nurses, physician assistants, medication dispensers, etc" (4).

Family members have a critical role to play in the holistic development of children. In the case of Y, the family caregivers were disturbed about his health and abnormal social behaviour. While Y's symptoms were simply those of autism, this medical term was never used to refer to his condition. Autism is a complex neurological disorder that impedes or prevents effective verbal communication and effective social interaction, and hinders appropriate behaviour (5). A term used to denote such a condition in the Yoruba language is *arindin*. *Arindin* is a collective term used to describe neurological disorders without the distinctions that are made in modern neurology. In Y's case, caregivers initially believed that his condition was curable. Hence they were actively discharging their duty to ensure his complete well-being. The strong hopes in Y's holistic neurological activity and development were dampened with the outcome of the traditional spiritual diagnosis.

In Yoruba society, there are certain cultural priorities regarding children's developmental skills. Unusual but harmless behaviours among children with neurological problems are not considered a serious health condition that warrants treatment at all costs. In the case of the family described above, the capacity for social interaction was given greater priority than having a high level of intelligence. This was because the family believed that if a person lacks intelligence, the problem can be remedied by making him/her associate closely with wise and intelligent people. Thus, the family accorded lower

priority to improving Y's level of intelligence than to the deficit in the area of social interaction, with which his symptom of avoiding eye contact is traditionally associated. These priorities stem from the fact that the Yoruba community sets great store by social ties.

In the absence of scientific explanations, many biological and neurological conditions, such as albinism, Down syndrome and sickle cell anaemia, are attributed to the gods in traditional Yoruba culture. Thus, there is an urgent need to educate people such as Mrs A's family on the importance of prenatal genetic screening and diagnosis. Termination of pregnancy is generally frowned upon in Yoruba culture (6), since it is believed that abortion disrupts the natural order, which may wreak further havoc.

As there was no life-threatening condition in the case of Mrs A, the family opposed the idea of an abortion on the basis of a genetic diagnosis. In their view, it would be better for Mrs A to go ahead and give birth to the baby and then, if necessary, take the steps required to cope with the baby's condition and care for it in the tradition of Yoruba culture. However, this attitude may be adjudged problematic. Owing to a lack of reflective moral sensitivity, and especially the lack of scientific information on autism, the fundamental question of what was in the best interest of Y and the potential baby was relegated to the background. Instead, the focus fell on the superfluous question of who should decide on the dilemma and on fulfilling Mrs A's intense wish for a child.

This case raises two pertinent questions. First, what is the ethical justification behind the perceived responsibility of the family caregivers to autistic children among the Yorubas? Second, what is the Yorubas' ethical view of personhood and on the abortion of fetuses with autism mutation? These questions are addressed in separate sections.

The Yorubas' ethical views on childcare and autism

Yoruba society is based on the extended family structure, a network of kinship. The biological parents as well as the members of the extended family play vital roles in the rearing and total development of the children. Children are seen as "ours" and not "mine". This sense of collective ownership has strong implications in terms of responsibilities towards children. The Yoruba norms of childcare are generally guided by two fundamental principles: *ibikojuibi* (equality of humans at birth) and *ajowapo* (solidarity).

The principle of *ibikojuibi* states that the primary premise of the norms of action in human relations should be an unbiased approach to the way human beings are born, with all people being considered equal. The emphasis is on coming into the world the same way, ie by being given birth to by a woman, and not on equal rights. Though there may be favourable or unfavourable circumstances surrounding birth, all human beings are thought of as equal by virtue of the gift of life. The principle of *ibikojuibi* serves as a guarantee against discriminatory treatment.

From the principle of *ibikojuibi*, there flow obligations and responsibilities aimed at curbing inequalities among human beings and minimising disparities between disadvantaged and advantaged individuals. The disadvantages could be physical or mental, economic, sexual, and temporary or permanent.

In line with this strong belief in the norm of equity, an action is considered right insofar as it respects equality of birth, and is sensitive to natural, artificial or social conditions that create differences among human beings. Initially, it was perhaps the desire to redistribute communal resources to address varying needs and differences in the condition of different individuals that gave rise to the spirit of "togetherness" in Yoruba culture.

The principle of *ajowapo* (literally "we exist together") connotes the positive obligation to act in such a way as to assist others in the framework of a system of mutual obligations, sacrifices and responsibilities. Obligations resulting from mutuality are anchored in the belief that "a person is a person through other persons or I am because we are" (7). The object of shared interest is the well-being of the community and its constituents. Hence, that which connects people and helps build solidarity among them to enable them to improve their well-being is morally right, and that which damages the social bond and collective well-being is wrong.

How do these two traditional moral principles impact on the responsibilities of family caregivers in the context of the diagnosis and treatment of autism? The principle of *ajowapo* suggests that caregivers have the moral obligation to care for autistic children so as to facilitate their integration into society.

The principle of *ibikojuibi*, in this context, posits that to avoid inequality, autistic children deserve more care and attention than children without the disorder. As far as the obligation of caregivers is concerned, justice is not determined by equality of all children's entitlement to care; rather, it entails ensuring that the least advantaged receive more care so as not to be worse off and to receive equal opportunities. The average traditional Yoruba views autism as neither a just, nor unjust health condition because it is believed to be beyond the personal control of the affected children, caregivers, traditional physician and priest, and in the hands of the gods. What is just or unjust, fair or unfair is the caregivers' disposition to care or not care for the autistic child.

The Yorubas' ideas regarding caregivers' responsibility to children with neurological differences allow them to refrain from discriminating between children with and without neurological disorders. While both categories of children are cared for and loved, the lack of discrimination against children with neurological disorders is often seen as a form of social understanding of human diversity.

On the basis of the principles of *ajowapo* and *ibikojuibi*, it can be argued that the Yoruba perception of caregivers' responsibilities to care for autistic children is justified. By fulfilling their collective moral obligations, the family caregivers would not only be giving the child a meaningful and fair chance in life and instilling a sense of duty towards the

community, but would also be creating scope for the inflow of potential benefits in the future. The logic behind this is that if we look after our children (whether with neurological disorders or not) now, when they grow into adulthood, it will be their duty to reciprocate and look after us when we are old.

Notwithstanding the foregoing justification of caring for autistic children among the Yoruba, it does not necessarily follow that there is justified obligation to diagnose autism mutation during pregnancy. Against this backdrop, there is need for contextual rethinking of the mores of childcare in traditional Yoruba culture to allow for not only prenatal genetic testing, early clinical diagnosis and treatment of autistic children but also an abortion of foetuses with a high risk of the autism mutation.

The Yorubas' ethical ideas on aborting foetuses with autism

Let us now consider the Yorubas' ethical views on personhood and the abortion of foetuses with autism mutation. One may ask whether the abortion of a foetus diagnosed with autism is considered morally right or wrong in the Yoruba ethical system, and on what basis. Associated with this, are the moral values relating to severely autistic children in Yoruba culture. These questions have been the subject of serious debate in western bioethical discourse.

In the Yoruba ethical framework, personhood is understood in terms of the degree of a person's moral status, which is reflected in the individual's humanness, dignity and personal identity a subject and object of a "direct" duty. As an object, it means the "being in question can be wronged" and as a subject, can wrong others. Personhood is not fixed, intrinsic, individualistic, nor an equally bestowed essence. The nature of the logical relationship between a being and the community is not necessarily symmetrical, nor parasitically asymmetrical, but just non-symmetrical. As mentioned earlier, personhood is seen in terms of degrees: the more a person develops his/her potential to form a part of a caring relationship, the greater his/her moral personhood. Those who could be a part of such a relationship in principle, but are contingently unable or permanently vulnerable, have only a degree of moral status.

According to the Yoruba notion of personhood, therefore, the moral status of autistic adults may be equivalent to that of normal adults if they are able to coordinate their actions with those of others, do what is likely to benefit others and act for the sake of others. On the other hand, autistic children who are mentally severely handicapped are considered to lack the dignity that others have, for they are incapable of being involved in communal relations (8). However, this does not mean that they have no moral status at all; the difference is only a matter of degree with little or no significance in real-life relationships. By the same logic, newborns have a higher moral status and greater personhood than foetuses because the former are out in the world and thus, are more readily conceived of as a "we", who receive the sympathy and help of other humans beings (8).

As for the Yorubas' ethical views on the abortion of embryos diagnosed with autism, many see it as a condemnable act. The logic of this value judgment is usually not elucidated. Abortion is construed as any intentional action leading to the loss of either the embryo or the foetus. In the western debate on abortion, one's position on abortion is often contingent on one's view of what constitutes personhood. The Yoruba worldview, however, is based on a metaphysical and anthropological framework of human existence that is independent of the normative explanation of personhood. According to the Yorubas' metaphysical conception of a being, human beings are composed of three elements: the *ara* (body), *emi* (spirit) and *ori* (human destiny). Different divinities work harmoniously on these three elements. *Olodumare* (supreme divinity) is responsible for the spirit of life; *Orisanla* is responsible for making the human body, while *Ajala* is responsible for moulding the different destinies that each being chooses from prenatally. In the absence of this tripartite conjunction of elements, a being cannot be conceived or biologically born. The worldview of the Yoruba – that life begins at conception and that the foetus is a potential human being which has a right to life from the moment of creation – is consistent with this myth of creation. "A human's moral status increases as it develops from the embryonic to foetal to neonatal stages" (8).

Returning to the Yoruba notion of personhood, it may not be "problematic accepting that at a certain point, foetuses are organisms with the capacity to feel pain and hence, to be an object of solidarity. Though they still cannot be subjects of a relationship of identity and solidarity, they can be objects of them to some meaningful degree" (8). However, it may be argued that the foetus is neither a subject, nor an object of communal relations at this early stage and that as such, it lacks moral status. While this argument appears sensible, it is redundant in the context of the Yorubas' metaphysical and anthropological framework, which is independent of the normative conception of moral status.

Given the Yorubas' metaphysical–anthropological worldview, the abortion of an embryo diagnosed with autism is morally condemnable (6). This is because the being has life from the time of conception and its subsequent development up to the neonatal stage is only the physical manifestation of all that has transpired in the metaphysical realm.

Conclusion

It is important to make efforts to convince the Yoruba people about the necessity of abortion in certain cases, for example, when a foetus has been diagnosed to have a high risk of

autism. Yoruba caregivers need to do some rethinking on the scope of their responsibilities to the unborn in situations in which there is a high risk of some disorder due to a hereditary predisposition. Steps are necessary to ensure that the Yoruba people should have a scientific understanding of prenatal screening and the diagnosis of chromosomal disorders, as well as the preventive and therapeutic measures available due to the advances in biotechnology and neuropharmacology. To promote the best interest of the unborn child with a high risk of autism, it is only logical that all stakeholders in the family should consent to abortion.

Family caregivers' responsibilities towards autistic children should not be determined by age-old traditions of empathic care alone. Early clinical diagnosis is necessary and the child must be treated. The attitude to children's neurological disorders should not be guided by utopian ideas of human biodiversity which requires no therapeutic efforts, as is often the case in traditional Yoruba culture. To ensure the overall well-being of the would-be autistic child and autistic children, it is the responsibility of family caregivers to educate themselves on preventive measures, as well as modern methods of treatment and care.

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