Theor Med Bioeth (2008) 29:331–340
DOI 10.1007/s11017-008-9084-y

HIV/AIDS reduces the relevance of the principle of individual medical confidentiality among the Bantu people of Southern Africa

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Published online: 2 December 2008

Abstract The principle of individual medical confidentiality is one of the moral principles that Africa inherited unquestioningly from the West as part of Western medicine. The HIV/AIDS pandemic in Southern Africa has reduced the relevance of the principle of individual medical confidentiality. Individual medical confidentiality has especially presented challenges for practitioners among the Bantu communities that are well known for their social inter-connectedness and the way they value their extended family relations. Individual confidentiality has raised several unforeseen problems for persons living with HIV/AIDS, ranging from stigma and isolation to feelings of dejection as it drives them away from their families as a way of trying to keep information about their conditions confidential. The involvement of family members in treatment decisions is in line with the philosophy of Ubuntu and serves to respect patients' and families' autonomy while at the same time benefiting the individual patient.

Keywords Medical confidentiality · Bantu · Ubuntu · HIV/AIDS · Autonomy

Introduction

HIV/AIDS has presented new ethical challenges to health professionals and to the field of bioethics. Most of the debates have been focused on the area of public health concerning the protection of third parties. Practitioners and governments are still debating on the issue of disclosure for HIV/AIDS [1–5]. The issue of disclosure, which relates to the concept of individual medical confidentiality, has been even more problematic among the Bantu communities who dominate the region of Southern

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Africa. The Bantu peoples share some very important similarities in their cultures and health practices. While debates elsewhere have been focused on the rights and autonomy of the person living with HIV and the need to protect third parties, among the Bantu peoples, focus has been on benefiting the patient by disclosing HIV status to family and relatives. The Bantu people live a communal life based on connectedness, and life problems are solved as a family, not as individuals. The connectedness of the Bantu people stretches from birth to death and even continues beyond death [6]. This connectedness has led to some challenges related to the application of the concept of individual medical confidentiality, which is one of the most important moral rules of medical practice. To the Bantu communities, an individual's sickness affects both the family and the community, and other family and community members have to take an active part in one member's sickness [7].

The Bantu peoples and Ubuntu

The Bantu people are a group with over 400 linguistically-related languages spoken in Central, Eastern, and Southern Africa, including Swahili, Kinyarwanda, Kirundi, Tonga, Chewa, Shona, Zulu, Xhosa, and others. Many of the Bantu languages share the word "*muntu*" and "*Bantu*" to refer to person and people respectively. This word appears in slightly different forms in the various languages, including the following: *umuntu, munhu, vanhu, mutu, andu, atu, motho, batho, antu*, and others [8]. In several of the Bantu languages, a person is referred to as "*umuntu*" and personhood as "*ubuntu.*" In IsiXhosa and IsiZulu, they also say "*Umuntu ngumuntu ngabantu,*" meaning that a person can only be a person with and among other persons. This means that a person who is living on an island with baboons and gorillas and not behaving like a human being ceases to be a human being [9].

The Bantu communities are guided by Ubuntu, which is a centuries-old philosophy of life that represents personhood, humanity, humaneness, and morality. It is a metaphor that describes group solidarity where such group solidarity is central to the survival of communities facing a scarcity of resources. With Ubuntu, the individual's existence is relative to that of the group. This is manifested in anti-individualistic conduct towards the survival of the group. Ubuntu is seen as that which separates men and women from beasts and is actually the potential of being human. Ubuntu is characterized by group solidarity, conformity, and compassion. Ubuntu stresses respect, human dignity, humanistic orientation, collective unity, mutual support, while de-emphasizing individualism and hence, a person can only be a person through others. Ubuntu emphasizes human relationships in pursuit of the survival of society, and individuals are challenged by others to achieve self-fulfillment through a set of social ideals [10].

Individual medical confidentiality and autonomy

Rules concerning individual medical confidentiality are common in codes of medical ethics from as early as the Hippocratic oath to the Declaration of Geneva by

the World Medical Association. The concept of individual medical confidentiality is one of the tenets of the ethical principle of respect for persons. The principle of respect for persons is born out of the assumptions that the individual is the supreme governor of body, mind, behavior, and actions [11]. The individual is seen as a central figure, a distinct, independent, and sovereign unit living in society, and the role of society is to produce an environment in which the individual can reach his or her full potential. The individual belongs to society only as a distinct, independent person [12, 13]. The idea of autonomy emphasizes self-determination, individual rights, and freedom, which provide the opportunity to act independently. Individual actions are directed toward goals that are exclusively one's own. Individuals are viewed as autonomous agents with freedom of will and freedom of action, who are therefore entitled to control information about themselves [14].

According to the concept of individual medical confidentiality, doctors may not reveal what they learn about the patient without the patient's consent except to other health professionals when necessary to help the patient and as required by law, specifically in circumstances where there is concern for the safety of other specific persons or concerns for public welfare, as in the case of communicable diseases [11]. In the Western model of medicine, confidentiality is important in building and maintaining trust between the physician and the patient and is meant to ensure that the patient feels comfortable in discussing his or her problems with the physician. The honesty that confidentiality helps facilitate enables the physician to decide on the best treatment alternative. Emphasis is placed on keeping or respecting patients' or clients' information secret on the premise that this information will only be used for therapeutic purposes [15].

Medical confidentiality is based on several moral grounds, including the welfare of society. Without confidentiality, diseases like sexually transmitted infections would be difficult to control because people would shy away from practitioners. The general expectation of confidentiality in medicine encourages patients to be open with their physicians so that they can effectively assist them [11]. Confidentiality reduces the fear patients might have about disclosing some embarrassing details. Confidentiality therefore assists both society and the individual patient. Confidentiality is also based on the right of the individuals to determine what information others can have access to. Confidentiality gives patients a sense of control over private or personal information about themselves or their lives [16]. It also gives them control over who knows about them because what is known about them may harm them in various ways through stigma, discrimination, and other ways [17]. Individual confidentiality is based more on the principle of nonmaleficence, because it seeks to avoid social harm to the individual. On the other hand, it is also based on the principle of beneficence in that it encourages patients to open up to professionals so that professionals may be in a better position to assist them.

Ubuntu and "autonomy"

Bantu cultures do not share many of the assumptions implicit in the Western autonomy-based approach to bioethical deliberations. On the contrary, most African

cultures take a community-based approach rather than an individual rights-based approach [7]. Greater value and meaning rests in the interdependence of family, which transcends self-determination. This centuries-old tradition emphasizes the value of viewing persons holistically by affirming the importance of community, society, and the family. This community-based approach differs from the Western approach, which emphasizes the individual, his freedom and his rights. In Bantu culture, the family and community always come first. The individual is born out of and into the community. The individual is socialized to become a part of the community and remains a part of the community [17].

In Bantu cultures, individual interests are balanced with and at times subordinated to those of the community. An individual is guided and regulated by rules of interdependence governing participation and identity. Birth is seen as a way of inserting a person into a social structure with many strong linkages. The individual members in the family, community, or clan are known by relational terms such as uncle, brother, sister grandmother, aunt, and other such terms. The individual's sense of personal security and self worth comes from a person's place in the group rather than from personal success or failures. The individual has a name that differentiates him or herself from others as well as talents, which delineate personal identity. These talents complement or have to be complemented by others in the community. Each person preserves his or her originality without denying or contradicting that of others [18]. It is common for people not to refer to each other using first names but rather by family names and totems [16]. Two other writers have also observed the same ideas among the Chewa in Malawi and the Gikuyu people in Kenya, respectively. The two writers separately observed that the uniqueness of an individual is secondary in Bantu cultures and that first and foremost, the individual is several people's relative and several people's contemporary [19, 20]. Godfrey Tangwa, a Cameroonian philosopher, also notes the same philosophy among the Nso people of Cameroon [21].

The notion of communalism is exemplified in proverbs that are common in most Bantu languages such as "A single tree cannot withstand wind," "Knowledge is like the baobab tree—no single person can embrace it." These proverbs are used in daily speech among the various tribes in Africa. There are also common Shona proverbs such as "*Zano ndega akasiya jira mumasese.*" This saying means that a person who was planning by himself ended up in trouble because he did not consult others. Another commonly used proverb, "*Chara chimwe hachitsvanye inda,*" means that one finger cannot crush a louse. "*Zano vaviri*" is used to reflect the fact that two or more individuals can come up with better ideas, while "*Kutsva kwendebvu varume vanodzimurana*" literally means that when their beards catch fire, men help each other extinguish the fire. Individualistic people are looked down upon and are called names, which serve as labels meant to discourage individualism and selfish behavior.

Whenever one discusses the issue of culture, it is safe to always throw in a word of caution. If one reads a lot of literature on African culture, particularly writings of anthropologists, he or she may be left with the impression that African cultures have been stagnant over time [22]. But this is false. We would point out that there is much diversity in Bantu communities as a result of urbanization, education,

industrialization, and time. African societies continue to face change each and every day as a result of urbanization and development. Some individuals in Bantu communities are moving away from communitarian values to individualistic values. The important issue to note is that the majority of the population in Southern Africa still lives in rural areas where communitarian values are still dominant.

Most of the urban poor have remained resistant to Westernization, viewing cities as a temporary places to live while working in urban areas. Most of the working people in Africa maintain two homes: the rural home where all the relatives live, and the urban home where they go to work while maintaining close links with their rural kin. Upon retirement, most working-class people move back to the rural areas where life is less stressful so that they can spend the remaining part of their lives relaxing in a familiar environment among familiar faces. When individuals die while staying in urban areas, their bodies are transported for burial in rural areas, where their ancestors are buried. This symbolizes the fact that even with the individualistic behaviors that come with urbanization, communal values are still dominant.

Examples of Ubuntu in action

To clearly point out the role of Ubuntu philosophy in Bantu societies today, we will proceed to give some examples of Ubuntu in action. At funerals in Southern Africa, all members of the community are welcome. Since an individual is a part of a broader community, there is no need to send formal invitations for others to attend. It is common to find more than a thousand people gathered at funeral of an ordinary person or even a child, and a beast has to be slaughtered to feed the multitudes. When it comes to marriage, the extended families from both sides are involved. On the day that the union is traditionally formalized, members from both sides gather over food and drink as a way of cementing the relationship between the two separate families and the two families now become related. Before people can think about divorce, they have to involve their aunties and uncles and even parents in a *dare remusha* (family court). Only when the family gathering has failed to resolve the differences can the pair then proceed with the divorce. In the daily life, relatives do not need to make appointments to visit relatives' homes or even workplaces during working hours. At least every year the members from the extended family get together for a *Bira*, which is a ceremony to communicate with ancestors.

Ubuntu, ill health and individual medical confidentiality

The communal approach to life even extends to illness. Bantu communities look at illness not as an individual affair, but as a family or community affair requiring a family or community solution [23]. The role of medical insurance is very limited in Africa and family and relatives usually provide assistance in times of hardship. In Africa, "family" is taken to include the extended family, and when Bantu people talk about "the family," they talk about the extended family, since they are

connected as a family through the totem, family name, ancestors, traditional religious beliefs, and communal life. When a person is sick, the whole extended family has to be informed about the nature of the illness so that they can participate in decisions as well as in the illness. The relatives have to be informed not only of the nature of the problem, but also its extent, as well as possible causes of the illness. Together, the family members decide where to go for treatment. Whichever option is chosen, family representatives must participate in the consultations. Members of the community are also free to visit the family and enquire about the person and may even suggest the best treatment option that the family might consider without being accused of interfering in a family or personal matter. Traditional healers from Bantu cultures do not practice individual medical confidentiality: consultations involve the families of patients [24].

Individual medical confidentiality for HIV/AIDS

Before the advent of HIV/AIDS, the concept of individual medical confidentiality was not very problematic. Patients were quite happy for doctors to inform their relatives about their conditions, except for sexually transmitted infections, and doctors were very happy to maintain medical confidentiality as required by codes of ethics. HIV/AIDS has presented a unique profile that requires it to be handled differently. One of the simple realities about HIV/AIDS is that it is very often family affair. The infection of a spouse may mean that the other spouse is also infected. The infection of a parent may also mean that the offspring are infected. There is still a lot of stigma surrounding HIV/AIDS in Africa. The stigma may be attributed to its link to promiscuity and death. During the early days of HIV/AIDS, it was associated with homosexuality and promiscuity before people realized that there were other ways in which HIV could be acquired such as unsafe blood, unsafe needles, vertical transmission, and other means. Currently there is no permanent solution for HIV/AIDS, since ARV treatments only serve to prolong life. In most African countries, where access to treatment is limited, life expectancy has been severely reduced as a result of HIV/AIDS. Debates about individual medical confidentiality for HIV/AIDS need to be taken within this context and it should be appreciated that the insistence on individual medical confidentiality continues to promote stigma and discrimination for people living with HIV [25].

For HIV/AIDS, there are several other reasons why individual medical confidentiality is rendered less relevant. One can also easily judge whether a person is HIV-infected by physical appearance. One can safely conclude the status of the spouse or even young children. Care and treatment takes months or even years and usually patients die at home since hospitals are failing to cope with large numbers of HIV/AIDS patients. With individual medical confidentiality, the chances of infecting the caregivers or spouse may be increased in cases of patients who choose not to inform their relatives. This concept also does not work well for drug adherence. Spouses and family members are known to play an important role in promoting adherence. Access to treatment for HIV/AIDS is still very limited and due to poverty, a majority of the patients cannot afford the high cost of medications.

The role of medical insurance in Africa is still limited and persons living with HIV/AIDS (PWLHA) have to be assisted by the extended family, especially in paying for treatments such as antiretroviral (ARV) drugs. Treatment using ARVs still remains expensive, even though the costs have been falling as a result of generics. Where government programs to provide free ARV treatment exist, those programs are still in their infancy and therefore access is not guaranteed. The family is therefore forced to play a major role in terms of care and treatment decisions. The family can only play a role if they are informed about the condition and how serious it is.

Over and above all these considerations, individual medical confidentiality does not work well with Ubuntu, which emphasizes family, community, and sharing and solving of life problems together. Medical confidentiality is about one's autonomy and one's right to control who has access to one's information. In medicine, it is generally acceptable to breach medical confidentiality on the grounds of "saving" third parties, especially where dangerous or risky patients are concerned. With Ubuntu, medical confidentiality has very little relevance since illness is viewed in a holistic way. For any illness, the Bantu healers look at both the biological and social causes and address the two sides when administering treatment. Family members and relatives accompanying the sick to the hospital often feel frustrated when they are requested to leave the consultation and the doctors do not tell them about the diagnosis. As far as they are concerned, they are a part of the illness and they have to be involved in assisting their relative.

Ubuntu and the doctor-patient Relationship

Family members often make medical decisions on behalf of their sick relatives. Patients place much trust in their families because of having been socialized into Ubuntu, which emphasizes loyalty, integrity, solidarity, and compassion [20]. This is not very applicable in Western societies that focus on individual autonomy, and hence discussions about surrogate decision makers, assisted suicide, euthanasia, advance directives and capacity to make decisions result. Within the African family, the hierarchical and communal pattern of decision-making usually takes precedence. The sense of well being depends less on a feeling of personal control but on being a part of a family. Within the doctor-patient relationship, elements such as loyalty, integrity, solidarity, respect, trust, and compassion are considered more important than autonomy. Patients do not question the medical doctor just as they would not question the wisdom of the traditional healer or the spirit medium.

Beyond individual medical confidentiality

With the challenge of HIV/AIDS, it has become evident that the concept of individual medical confidentiality is one of the moral principles that Africa inherited unquestioningly from the West as part of Western Medicine. Western medicine is well known for emphasizing individual confidentiality. Sickness is considered more of a personal issue since it is viewed as a form of malfunction

within the body. During the early years of the AIDS pandemic, medical doctors and other health practitioners in Africa were encouraged to stick to individual medical confidentiality. This approach has proven problematic and it has raised several unforeseen problems for persons living with HIV/AIDS (PLWHA) in Southern Africa, ranging from stigma and isolation to feelings of dejection as it drives them away from their families as a result of trying to keep information about their conditions confidential. Some advocates and medical practitioners in Africa now encourage the involvement of others in treatment decisions. A significant proportion of medical practitioners now invite relatives into consulting rooms during history-taking as well as during examinations, discussion of tests results, recommendations regarding treatment options, and the making of treatment decisions [26, 27]. Even when the patient is absent, it is now common to see a family member visiting the doctor to obtain new prescriptions and drugs. The new changes have been observed in interactions with people living with HIV/AIDS, relatives of PLWHA, and medical practitioners in various countries in sub-Saharan Africa.

This new phenomenon has its roots in the African philosophy of Ubuntu. There are various advantages to using this approach of openness, including the facts that care for PLWHA requires months or even years, patients usually die at home, and importantly, family members help in ensuring adherence to complicated drug regimens. The family assists by providing a good diet and encouraging the patient and assisting with the cleaning of clothes and general maintenance of hygiene. Decisions have to be made by the extended family on future care of the children and spouse after death of a patient and this approach also helps to ensure that the inheritance of the surviving spouse is disbursed or handled appropriately while at the same time helping to reduce the problem of stigma. This openness also assists in preparing relatives for the death of their loved one. It may even be further argued that the life of the patient, which can be extended through better care as a result of involving family, is better than it would be if the diagnosis were kept secret. Secrecy may result in the patient succumbing to an early death as a result of poor care due to the non-involvement of family members.

The World Health Organization (WHO) Guidelines on HIV/AIDS treatment now encourage patients to have a treatment buddy whose role is to encourage adherence [28]. This recommendation encourages openness by encouraging the involvement of other persons in the treatment of PLWHA. From experience, it has become evident that it is important for medical personnel to inform the appropriate members of family even against the wishes of the patient. This involvement of others, which is based on the grounds of both consequentialism and beneficence, ensures that the patient benefits through better treatment, family support and also helps the family to know more about the disease as well as how to take appropriate care of the sick person. This also assists the family and the patient in deciding together where the patient will die. Commonly, terminal patients among the Bantu and other groups in Africa request permission to leave the hospital so that they can die at home among loved ones and in a familiar environment and be buried in the same burial grounds as their ancestors. In this case, revising the idea of confidentiality enhances respect for the patient and also the family since it is appropriate for their culture.

Conclusion

In view of the communal and extended family culture, the approach of legitimizing family confidentiality and involving family members among the Bantu communities of Southern Africa as well as other cultures with a communitarian approach to life, is a noble one. Yet medical practitioners should ideally make decisions to involve appropriate members of family after careful consultation with the patients to obtain their consent. Broadening the concept of confidentiality has to do with an understanding of personhood and what it means to be a part of a family and community within the Bantu people and respect for the Bantu philosophy of Ubuntu. Medical practitioners need to respect patients' wishes as much as possible. In cases where the patient does not want some people to know, medical personnel have to weigh the risks and benefits to the patient and disclose only if third parties may be seriously harmed by that decision. Medical personnel need to be protected by legitimizing their roles and need to be trained in making judgements on the appropriate strategy to take.

Openness is the optimal way to go as it attempts to deal with the problem of stigma and discrimination for PLWHA. The current attempts by the governments to make ARVs available to the majority of patients will also go a long way in addressing the issue of stigma, since it has been proven elsewhere that stigma can be reduced by the availability of AIDS drugs. After dealing with stigma, AIDS would be considered in the same way as any other disease. Governments in Southern Africa need to adjust their AIDS policies accordingly to reflect this reality on the ground and health workers need to be trained in making judgements on the appropriate strategy to use in involving the family in treatment and care for PLWHA. Optimally, strategies should be based on respect for the patient, respect for culture, and also respect for the family, who bears the burdens of illness and who takes over after the person dies The bioethics community should therefore give consideration to the broadening of the concept of medical confidentiality as it is used in Bantu communities by lessening the emphasis on the individual patient and including the family.

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