

“When the Seagulls Cry”? Biobanks and Local Tradition

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Abstract

This article aims to present the proposal which demonstrates – on the example of a specific country - how local tradition can help to adopt “globalized” initiatives such as the idea of biobanks.

Keywords: biobanks, developing countries, mental disorders

Streszczenie

Artykuł ten ma na celu prezentację propozycji, która demonstruje - na przykładzie konkretnego kraju - jak lokalna tradycja może pomóc w przyswajaniu „zglobalizowanych” inicjatyw takich jak idea biobanków.

Słowa kluczowe: biobanki, kraje rozwijające się, zaburzenia psychiczne

Introduction

Research on Schizophrenia requires complex, multifaceted explorations among which genetic and proteomic studies on various physiological metabolic pathways are very important (there are many significant findings, for example Neuregulin-1 (NRG1) and Disrupted-in-Schizophrenia-1 (DISC1) are considered as hopeful susceptibility factors for Schizophrenia [1]; Dihydropyrimidinase-like 2 and Alpha-crystallin are interesting potential biomarker candidates [2], and this finding might lead to the development of new therapeutic strategies as well as blaze a trail for their possible use as peripheral blood markers that may contribute to early Schizophrenia detection[3]).

The expansion of research on human tissues and cells is crucial for developing better treatment and earlier detection of Schizophrenia and other numerous diseases. An easy access for researchers to numerous samples of bodily materials can significantly contribute to this progress. That is why the institutions of biobanks are so promising and their establishment is associated with great expectations of scientists, specialists from translational research and medical practitioners. However, the advantages of biobanks have yet to be clear and recognized by laypeople. Thus, the question arises how to launch this project effectively and safely.

To establish a bank it is not only necessary to secure financial capital, but first and foremost it is indispensable

to engraft the sense of reliability and trust in potential customers. And to establish a biobank, except for the mentioned conditions, it is essential to find a special, suitable framework which can encourage potentially interested laypeople to take part in this venture.

Biobanks already exist in various parts of the world. Particularly, a net of well-structured bio-repositories is placed in Europe, but also in America and Asia. However, very little attention is devoted to poor parts of the world - South American and African countries.

In this article I will focus on Nigerian case and the framework which can be used to establish a net of bio-repositories in this country. Such biobanks can accelerate the progress of research on disorders such as Schizophrenia and on many other serious diseases. Let me bring you closer to this engrossing issue.

One Overriding Aim

The aim of my paper is to investigate how biobanks can be introduced into the Nigerian context in the most effective way, convenient for laypeople. It should be done by means of assimilation rather than imposition of western, extraneous ideas in the Nigerian settings.

Looking for some framework which can be suitable for embedding biobanks, I have found a very interesting thought of Emmanuel Onyechere Osigwe Anyiam-Osigwe, a Nigerian sage philosopher. The process of bringing the

indigenous thoughts of Osigwe to the level of praxis in the case of biobanks might result in effective solutions.

This challenge can be explored at three levels: 1) the level of an individual person, 2) the level of a local community, 3) the level of the nation. In this paper I will discuss only the first, individual level, to make my statement clearer.

I also will show how to prepare individuals for participating in biobanking initiatives. The true intricacy is how to identify and remove obstacles lying in the way of this process. I will discuss it in the final part of my paper. Now let me start this stirring exploration.

The Level of a Person

The Holistic Approach to Life of Emmanuel Onyechere Osigwe Anyiam-Osigwe includes three pillars: 1) development of personal values, personal awareness and self-mastery; 2) enhancement of socio-political existence and order; 3) economic existence, awareness and responsibility [4]. The mentioned pillars are most crucial for the process of state's development. I have chosen Osigwe, because his thought is universal enough to overcome various animosities (religious, political) existing in Nigerian society. I will now delve into the first pillar.

The realm of an individual reveals various intricacies and problems. One of the crucial statements of Osigwe is that a person can gain access to one's own "innate endowments" and can apply for holistic development [5]. An important thing in this area is to examine the argument which claims: the development of a person cannot be done apart from raising the awareness and responsibility for one's own "intellectual property", which here is understood as the uniqueness of genes contained in human "bodily material".

The welfare of a person consists of one's "intellectual properties", particularly embedded in the amazing genotype. This "treasury of knowledge" has to be taken care of and should be explored with respect because each human being is a precious gem. However, let me ask what the deficiencies related to the personal level are?

The person facing the dilemma whether to participate in biobank research and donate tissue or not, is often unaware of the meaning of this kind of research and the value of one's own biological samples. Due to these limitations, s/he cannot take an informed, responsible decision regarding tissue donation. Sometimes the level of one's own agency is insufficient or is undermined by external "incentives" or even coercion. Under such conditions a potential tissue donor cannot take any valid decision.

The matter of personal willingness and consent to participate in research and donation of "bodily material" might easily raise various ethical queries. The elementary problems here are the quandary of proper interpersonal communication (between the researcher and the potential donor) and the difficulty to obtain reliable, voluntary

consents from individuals, particularly patients with mental disorders. In particular, the process of obtaining consent has to be controlled by medical representatives and should also be supervised by competent ethical councils and committees.

Only a conscious and fully voluntary decision to participate in biobank research can increase one's own sense of freedom and agency. This profit is priceless. It involves the development of personal capabilities, as postulated by Sen [6], and the enhancement of the human capacity for self-actualization, underlined by Osigwe [7]. This should also be considered as a great "human capital" which must be invested to bear fruit in the future.

A person has to develop oneself, one's capabilities and all kinds of virtues embedded in one's own potentiality. This is exactly a personal role played in the process of socio-economic development of the whole society. I believe that the exploration of inherent attributes and values instilled in an individual must bring great benefits in Nigeria. However, the process of adequate preparation of the mindset and strengthening morality of individual citizens is important. The situation of giving consent to tissue donation is a good litmus test of moral maturity and development. Biobank research has to lead to the person's flourishing, not to the sense of "commodification", exploitation or abuse.

To recapitulate the individual level, I want to clearly identify tasks which should be accomplished to effectively introduce the idea of biobanks in Nigeria based on the Holistic Approach to Life of Osigwe:

1. Provide reliable information in order to develop personal awareness and understanding of the need of biobanks in Nigeria;
2. Conduct communication in a proper way. The process of communication between the researcher and the potential tissue donor should be based on trust, mutual understanding of the aims of donation, and must be free of coercion.
3. Strengthen the sense of personal self-esteem, personal sense of dignity and value of one's own life and personal inherent attributes. Only a person who is strongly confident about their own value can consciously support the introduction of biobanks and participate in research.
4. Forge the personal moral mindset and foster it. This process must be started in childhood. Only a person well-versed in the virtues such as truth, honesty and responsibility can fully become an agent (from *agere*, a person, who has a sense of agency) of moral decisions and can consciously take part in research for biobanks. This is one of the fundamental elements of Osigwe's holistic approach to human development. No step can be taken without personal moral maturity, which is the kernel of self-mastery.

Conclusions

The last statement of this paper's author is consistent with Osiigwe's prescription that Nigerian development inevitably has to begin with developing individual "personality that is nurtured with faith in the self, faith in his antecedents, faith in the community and a competitive intellect." [8] However, the question is not only how to develop individual personality towards the success of the community and the nation. The true *cul-de-sac* is how to identify and remove the obstacles lying in the way of this development and success. Thus, my suggestions regarding the mentioned obstacles are that the following impediments should be overcome:

1. Personal and community passive attitude towards genetic (biobank) research and projects;
2. Fear of taking independent actions and responsibility for the establishment and development of biobanks;
3. The lack of knowledge about structures and models of governance in biobanks;
4. The sense of inferiority, helplessness and the lack of self-confidence in the clash with extraneous bioethical ideas, such as biobanking

In conclusion, what do I recommend, what should be done?

1. To open up in a "wise" way. Somewhere between the indigenous approach of Osiigwe (who postulated *introspectionism*, which is not tantamount to self-seclusion or isolationism [4]) and the remarks coming from the experience of other countries, there must be a way, a "unique" way for establishing biobanks in the Nigerian context. And this should not be considered as an intrusion or creating a strange hybrid, but rather as an assimilation of international ideas into the Nigerian cultural frameworks and surroundings. Then, in this respect "wise openness" on the concepts of biobanks is highly recommended. The mindset towards biobanks has to be changed into a positive one.

2. To monitor the level of a person and the community. The institutions of biobanks can bring to light and develop hidden but inherent Nigerian collective capabilities such as common trust, interpersonal reliance and solidarity within community. The introduction of biobanks can also lead to self-mastery and the sense of personal agency. Thus, the implementation of the biobank net in Nigeira should be done with simultaneous attention and scrupulous monitoring of the level of personal and community development.

3. To take the risk of initiative and refrain from idleness. Even if nothing is done, some change may actually occur. This is a change for worse, namely "entropy" of energy cumulated in the people, wasting of their capabilities, burying of their hopes. Not to do anything results in a regress, atrophy of values and chaos. The risk of initiative should be taken; this risk must be taken.

Then, let us take the risk of acting towards the development of biobanks in Nigeria, for Nigeria and by Nigerian citizens in the spirit of confidence regarding restored indigenous potentials, capabilities and in the name of strengthening the faith in Nigerian culture; faith which can re-ignite the thought that Nigerian and other African people can *have it in their own power to begin the world over again* [9].

Take Home Message

A metaphoric question: "When the seagulls cry" - in the context of aforementioned words and verses describing various cultural perspectives and different human scenarios - this question leads to a blunt sound of retort: it happens when one realizes the irreversible loss of one's own capabilities. Such a waste brings unbearable pain. Thus, try not to waste capabilities. Do not lose tradition, but enrich it. Greet undiscovered lands with bravery and self-confidence. This is the way of progress, "when the seagulls don't cry".

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