COLLEGE OF HUMANITIES (HUMAN AND SOCIAL SCIENCES)

SYSTEMATIC REVIEW OF AN AFRICAN BIOETHICS FRAMEWORK: CONCEPTION OF PERSON-HOOD AND ITS INFLUENCE IN IMPROVING THE PROCESS OF INFORMED CONSENT IN HEALTH RESEARCH

By

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ABSTRACT

Cultural pluralism is vital to the understanding of bioethics in different societies. The principles that guide research ethics decision-making have a cultural basis derived from the west. These principles are drawn from just one worldview out of the many existing worldviews and they are often presented as universal. When these principles are implemented internationally, they are not sufficient to address rising concerns around informed consent. The challenges of implementing these principles in Africa are not an exception. It has been very challenging to obtain genuine informed consent for research, as the procedures of decision-making, in addition to the implementation of community engagement, are always accompanied by the importation of a western ethical philosophy, some of which differs from that of the African people. The western conception of the process of informed consent is premised on the idea of individuality and an abstract self that is not encumbered by culture and society. Culturally embedded semiotic aspects of ethical decision-making are often neglected.

A systematic review was conducted on how the African understandings of personhood and community have influenced decision-making in the process of informed consent and community engagement, using keywords to recruit research papers published in English via the HINARI and Google Scholar electronic databases. Among the 322 papers identified, 46 were eligible to be recruited for the study.

The results from this study indicate the community plays a critical role in the successful implementation of a truly informed consent. The findings indicate the process of informed consent and decision-making varies with the level of risk and complexity associated with the research, as well as the category of the participants who will be involved in the study. The study recommends that research ethics committees should take into consideration the level of community engagement and the process of informed consent when making a decision on a particular protocol.

CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

Mainstream modern bioethics principles have cultural underpinnings rooted from the western culture, making it difficult for their adaptation into non-western culture (Christakis, 1992; Chukwuneke et al., 2012). Like all bioethical or ethical traditions, principlism is based on taken-for-granted assumptions, values, philosophies, etc., all of which are rooted in historically particular ontologies with little diversity in terms of the reality of other cultures. Africa has different issues and challenges in the area of ethics and this requires a framework that is in line with African cultural reality (Brodwin, 2001; Frimpong-Mansoh, 2008; Karenga, 2004). A culture, which is defined as all aspect of a person's life and how he/she understands and interprets reality, is very significant to the understanding, articulation and justification of bioethics in a given society (Onuoha, 2007).

The African indigenous metaphysical reality gives less emphasis to the individuality of a person, in the abstract sense, since this isolates the individual from history, culture, community, and family (L. Chuwa, 2014). The emphasis on the individuality of a person in the abstract sense is the basis for the development of the western principles of bioethics which according to Beauchamp and Childress (2012), advance four principles namely: respect for the person, non-maleficence, beneficence, and justice. According to Onuoha (2007), in his perspective, three principles have been advanced in Afrocentric bioethics; these include: respect for life, solidarity, and justice in healthcare. Like the African philosophy, the knowledge and beliefs of the African societies that definethe ethical behavior of people living in true African community with little influence from western thought and approach to what is termed ethical behavior, have not been given detailed research and interpretation. Thus, there is a need for extensive philosophical analysis and interpretation of some of the processes and procedures in research involving human beings in Africa.

Many studies have criticized the western individualistic conception of informed consent; some of these have proposed a communal or semiotic approach to informed consent which is informed by the African philosophical perspective (Bhutta, 2004; Mkhize, 2008). According to Doumbo (2005), informed consent is recognized as a flexible process that requires taking

into consideration the context in which the project is being implemented. He also asserts that the nature of a project can also inform the processes of informed consent and decision-making for a potential participant to participate in a research project.

1.2 STATEMENT OF THE PROBLEM

In post-colonial Africa, the proposed principles based on the individuality of a person have significantly influenced the process of research involving human beings, especially in terms of the process of informed consent and decision-making (Christakis, 1992). The African indigenous perspective towards ethics is holistic, in that it is not only interested in the idea of an abstract individual, and their thoughts, but goes beyond to holistically incorporate spirituality, corporeality, and the relationship between the individual and their community/society. The individual will consult widely in order to base their decision-making to participate in a research study or medical intervention on a discourse which is emphasized rather than basing their decision-making process on the style that favors abstraction, as proposed by western principles (Mkhize, 2008).

A new set of questions has been arising in Africa concerning the ethics of health research and healthcare; this is due to the advancements in technology and science which often come to Africa with the importation of the western ethical philosophy, which focuses more on the object of intervention rather than the subject carrying out the intervention (Tangwa, 2000). This has made it difficult to deal with dilemmas related to western principle of respect for person as applied in the process of informed consent, which arise from international collaborative research and intervention, healthcare and genetic research (Kegley, 2004). These complications have influenced African scholars to propose an Afrocentric bioethics framework; this framework deals with those aspects of bioethics which are ignored in the typical western framework and seeks to develop a holistic as opposed to a partial perspective towards bioethics.

1.3 PURPOSE OF THE STUDY

The purpose of this study was to use a systematic review of critical literature to narrate emerging trends on African approaches to the ethics of informed consent. It also intended to establish how published studies in ethics, particularly health-related studies, have incorporated indigenous African worldviews/philosophies in the way they conceptualized and implemented informed consent, decision-making in healthcare and health research, while

promoting community engagement. The study will also look at how the African indigenous conception of personhood has contributed significantly to the creation of an Afrocentric bioethics that is informing the process of informed consent and decision-making.

1.4 OBJECTIVES OF THE STUDY

This study sought to understand how the relational, communal view of the African indigenous conception of personhood (self) influences:

1. The process of informed consent in a community setting in Africa.
2. The understanding of the process of decision-making in Africa.
3. The understanding of community engagement and participation in health research.

1.5 RESEARCH QUESTIONS

➢ How does the understanding of personhood influence the process of informed consent in African community settings?

➢ What is the contribution of the communal view of personhood to the process of ethical decision-making in Africa?

➢ In what ways does the relational, communal view of personhood as manifested in African communities influence community engagement and participation in health-related research?

1.6 SIGNIFICANCE OF THE STUDY

There is a paucity of information that informs bioethicists and researchers on how research and publication from researchers and bioethicists have incorporated other worldviews and epistemologies in the conduct of research and ethics. This study will clarify how the communitarian perspective towards personhood permeates published studies in health research, especially those on informed consent, decision-making and community engagement. In addition, the study will guide researchers and healthcare workers in handling the increasing dilemma that is arising in healthcare and health research due to the importation of western medicine, as this is often accompanied by western philosophy especially issues around informed consent, community engagement and decision-making to participate in health research or healthcare.

1.7 HYPOTHESIS OF THE STUDY

This study hypothesized that the understanding of African indigenous conceptions of personhood has informed the current trend seen in the widely promoted community engagement in health research and healthcare. This trend is to improve the process and procedure of obtaining and achieving consent that is truly informed, as this will enable participants to make a decision that is well-founded with regard to their participation in health research or healthcare.

1.8 SCOPE AND DELIMITATION OF THE STUDY

This study is only valid to the extent to which the systematic review was conducted. This was determined by the identified databases where the search and the keywords that were used, in addition to the list of important citations that were used, ensured there was the thorough coverage of important literature that was necessary for the study.

1.9 OPERATIONAL DEFINITION OF TERMS

Personhood: A person is defined here as a status an individual will achieve after fulfilling certain morally correct duties in his/her community.

Person: A living beings of human parentage who, by being exposed to moral persuasion and correction through the biological, psychological, cognitive, and moral apprenticeship from childhood, has come to develop moral sensibilities and rational habits conducive to a productive and edifying life in society

Human beings: This refers to living beings of human origins.

Community: A community here is defined as the set of relationships that makes a human being become a person.

Africa: Africa in this document is defined by the continent, without any distinction into North and sub-Saharan Africa.

Informed consent: permission granted by research participants or patients to researcher or medical doctors with knowledge of possible consequences.

Culture: Culture is defined here as the totality of the life of a person and how he/she understands and interprets reality.

Afro-centric bioethics: This is an approach to bioethics that brings in the African indigenous perspective.

Spirituality: This is defined as life forces which are interacting with all matter.

1.10 SUMMARY AND OVERVIEW OF THE STUDY

The current method of implementing informed consent, and the approach used by research participants in decision-making that will enable them to participate in health research in Africa, depend on the western principle of abstraction of the individual person, with very little consideration of the relational person, as demonstrated in the African world view. This abstract principle often encounters challenges which, if not appropriately handled with respect for the norms and cultural values of the people, can lead to more harm than good. This study is intended to provide healthcare workers and health researchers with an understanding of the concept of personhood from the indigenous African perspective, as well as how it has influenced the evolution of the concept of informed consent, decision-making, and community engagement. This research will prepare the ground for the growing ethics committees, research, and healthcare intervention in Africa and will act as a platform for informed ethical decision-making, while protecting the community physically, socially, and culturally.

CHAPTER TWO
LITERATURE REVIEW

2.1 INTRODUCTION

Informed consent has become one of the highest principles promoted in health-related research and healthcare. Because of its great importance in research, it has also been transferred to the social sciences, especially for those research studies that use humans as their participants, and this has given it a status as the gateway to any research that involves the participation of humans. The process of informed consent has been based solely on the western principle of respect for persons (individual autonomy), which has faced many criticisms from researchers and ethicists around the world. Critics of this principle in Africa believe that collective decision-making is the ideal approach to have an informed consent that is truly informed. This criticism has given rise to the widely promoted community engagement in research; however, their understanding of what a person is and what a community is, as referred to in the African context, has put to question the principle of respect for personal autonomy and the meaning of community engagement. This literature review summarizes the different philosophical paths to the process of consent that is truly informed, through various debates among philosophical interlocutors in the west and in Africa around personhood, in addition to empirical research backing the various claims.

2.2 HISTORY OF INFORMED CONSENT

The process of obtaining informed consent before recruiting research participants to participate in research has long been an essential process in research conducted with the involvement of humans, especially in medical research and intervention. Informed consent is among the main principles of the Nuremberg code generated in the trials following horrifying research that was conducted on humans by the Nazi government during World War II. These trials were held in Nuremberg in 1946 and they led to the establishment of many principles to guide research conducted with human participants. Among these principles was the principle of informed consent, which became the main principle often emphasized in research because of its role as a gateway for participants to participate in a research study. This principle was later adopted in the Declaration of Helsinki by the World Medical Association in 1964; this declaration has undergone a series of amendments, with the most recent update being in 2013.

The process of informed consent has been adopted in the legislation of many countries, guiding the implementation of research both in the so-called developed and the developing countries (Boulton & Parker, 2007). The importance attached to the process of obtaining informed consent in research has spread beyond medical research into other fields of study which implement research of various kinds involving humans or their information. This is evident in the vast majority of literature published in different areas of study for which informed consent is seen as a critical step and it plays a pivotal role in a research process involving human participation. The process of informed consent is believed by many contributors in research ethics to be constructed on a social foundation and to be implemented in a social relationship which changes with time, values, expectations, and understanding between parties involved. This leaves many to believe the process is supposed to be a flexible one which can be adapted according to the society in which it is implemented (Creed-Kanashiro, Oré, Scurrah, Gil, & Penny, 2005; Lidz et al., 1983).

2.3 THE PRINCIPLE OF INFORMED CONSENT

The foundation of the modern ethics of informed consent depends on the principle of individual autonomy based on human rights which are generated from human dignity. According to Eyal (2012), everyone has the right to the integrity of his/her body and mind and this gives them the right to not participate in research without a proper informed consent. Informed consent is defined as the decision made by a competent research participant, who has been properly given all the necessary information about the research to his/her adequate understanding, who after considering the understood information decides freely to give his/her consent, either orally or by providing a signature, in the absence of coercion or an undue inducement (Emanuel, Currie, & Herman, 2005; Nelson et al., 2011a).

According to Worthington (2002), the validity of an informed consent process does not in any way depend on the signed written words, but on the interaction that exists between the researcher and the potential participant; he further put it very clearly that the documentation of the informed consent is just part of the process. According to Sin (2005), the process of informed consent does not end with the signing of the document, but is a continuous process that occurs before, during, and after the research. Sin (2005) went further to clarify that it is the duty of the researcher to go back and inform the research participants if new information or other factors emerge that might affect their already given informed consent.

The development and evolution of the process of informed consent, based on the western principles of respect for individual autonomy, has identified four basic elements for the process of informed consent. These are: capacity of the individual participant to consent; disclosure of information relevant to the research; ability of the participant to adequately comprehend the information; and lastly, voluntary decision-making to participate and to withdraw from the research study without any consequences (Lindegger & Richter, 2000; Nijhawan et al., 2013).

There are two type of capacities to be considered in the process of acquiring informed consent in a research study, namely **factual capacity**, which is the ability of an individual to consent by virtue of their sound mental state, and **legal capacity,** which is the ability of an individual research participant to consent for research by virtue of law. This could be in relation to age or status as set by the law of the country in which the research is being conducted (Andanda, 2005; Appelbaum & Roth, 1982; Meisel & Kuczewski, 1996).

At the level of information disclosure, researchers are obliged to disclose to the participants the necessary information, with the reiteration that they are involved in research and not treatment, and that they can disengage from participating in the research at any time. In the case of therapeutic research, the following information must be revealed to those participating in a research: the purpose of the research; the expected duration of the research and the planned follow-up process that accompanies the research; foreseeable risk and benefit associated with the research; and alternative procedure or course of treatment available, if any. These must be disclosed to the participants in a language that is understood by them. This stage is further modified by the Declaration of Helsinki which states that some additional information should be disclosed to the participants. This information includes: aims and method of the study; the source of funding and possible conflict of interest; risk and benefit anticipated from the study; discomfort and right to participate or withdraw from the study without any consequences (World Medical Association, 2013)

Capacity to comprehend is another requirement for potential participants to give informed consent in a research study. This is often assessed according to the capacity of the participants, not limited by virtue of being classified as a minor, unconscious, intoxicated, being psychotic or senile. Many scholars have identified that the most appropriate way to determine if research participants have comprehended the information provided is to give

them adequate time to ask questions, as well as using a case scenario that will help the participants to understand the process involved and the risks associated with the research. Many assert that the questions asked by research participants in the process of informed consent should be answered honestly, promptly and completely (Bhatt, 2015; Hall et al., 2012; Narumi et al., 1998; Nijhawan et al., 2013; Nunes et al., 2015; Takeda, 1998). This clarifies issues like therapeutic misconception which mostly occurs among patients participating in a clinical trial that is testing a new therapy, thinking it will help improve their health situation. According to Cherry and Fan (2015), Chiapponi et al. (2015), Morrow, Argent, and Kling (2015), Ssali, Poland, and Seeley (2015), and Uusitalo and Broers (2015), comprehension can also be enhanced by encouraging interaction between research participants so as to enable them ask questions concerning the research among themselves, as this breaks the barrier that exists between the researcher and the participants (Nelson et al., 2011b)

Voluntariness is recognized as one of the important stages in the conduct of informed consent and can be compromised by undue influence and coercion. Andanda (2005) asserts that the issue of financial benefit and compensation should be discussed after the informed consent has already been procured, as this will reduce the capacity of the financial benefit or compensation causing undue influence. For voluntariness to also be enhanced, it is important for a third party to play the role of obtaining informed consent from participants if the recruiting scientist has a therapeutic relationship with the research participants.

2.4 CULTURAL INFLUENCE ON BIOETHICS

To conceptualize the influence of culture on bioethics, there is a need to first of all understand the meaning of culture as used in the African approach to bioethics. Onuoha (2007) construes culture as "the totality of the life of people and how they understand reality" (p. 212), while Wikipedia (2017, November 12) regards culture as the social behaviors and norms found in human society. Research ethics are inseparably married to culture and, in order to arrive at a meaningful conception of ethics in research, the assumed framework for ethical references for the Afrocentric standpoint and the cultural realities of the people must always be taken into consideration when resolving ethical dilemmas in health research and health care (Gbadegesin, 1993).

Theories in research ethics such as utilitarianism and deontology, among others, from which the dominant discourses on research ethics are developed to inform most health-related research have cultural bases of individuality of personhood (Gyekye, 2011). Hence, culture is considered a meaningful component in the comprehension of any societal ethical principles.

There are four research ethics principles, which comprise respect for persons (autonomy), beneficence, justice, and non-maleficence, by which the Euro-American view of bioethics operates and which guide ethical decision-making in health research (Beauchamp & Childress, 2012). These principles are drawn from just one worldview, which is based on the individuality of a person, out of the many existing worldviews and they are often touted as universal; however, when implemented internationally, these become insufficient (Benatar, 2004). The challenges of implementing these principles in Africa are demonstrated in the process of obtaining genuine informed consent for research, the procedure of decision-making, and the implementation of advanced imported technology in health and research. This is because these are always accompanied by the importation of western ethical philosophy, some of which varies from that of the African people (Andoh, 2011). This variation in culture is the stimulus that informed the notion that culture intertwines with the current principles of bioethics and the need for the understanding of other worldviews in making ethics-related decisions.

The western conception of the process and procedure of informed consent emphasizes the individuality of informed consent with little concern for semiotic decision-making in the informed consent process. It does this by requesting that information related to the informed consent should be disclosed to the understanding of a competent individual who voluntarily gives his/her consent to participate in research or treatment (Beauchamp & Childress, 1977; Nelson et al, 2011), with the absence of undue inducement and coercion (Emanuel et al., 2005). Different models of decision-making have been identified, with their own strengths and weaknesses. According to the work of Cottone and Claus (2000):

> [T]here are many practice-relevant models (many building on foundational works) that can be chosen as guides for ethical decisions in particular practice settings, within specialties, with specific types of clients, or according to a published standard of practice and as to whether one model is better than another is yet to be determined.

Because of the absence of the communitarianism which dominates African society as a philosophical ideal in the conception of bioethics and codes of ethics, writers in the African philosophical approach to the process of informed consent have critiqued the western emphasis on individuality in the process of informed consent. By so doing, these writers encourage community engagement and assent which intrinsically incorporates the individual aspect of informed consent as one of its main elements (Frimpong-Mansoh, 2008). Frimpong-Mansoh also asserts that the difference between the individuality of informed consent as promoted by western philosophy and that of the communitarian philosophy of the African people is at the point of emphasis. This brings us to the need to understand why the African indigenous metaphysical reality emphasizes communal decision-making rather than the individual, as in the west.

According to Gbadegesin (1993), this complication is visible because there are cultural variations in understanding of concepts such as personhood and decision-making, which influence health research and medical practices, theories, and policy development in general. Cultural sensitivity is important in research implementation and the stand-alone individual consent is not sufficient for certain research in some cultures (Kegley, 2004)

Due to the limitations of the borrowed foreign models of bioethics in resolving ethical dilemmas in Africa, and with the exclusion of local conceptual frameworks and worldviews, an Afrocentric bioethics framework has been under development. According to the definition of a conceptual framework in (Miles et al., 1994), an African bioethics framework will be referred to as an ethical system which is used to construct bioethics practices and choice for ethical decision-making that will enable participants to participate in research conducted in Africa. The development of this framework is ongoing, and the present version considered the values of humanity, community, and morality as the most important for its development (Onuoha 2007). Onuoha asserts that an African ethical approach should be internally aligned with the way the African people understand and interpret ethics. Thus it should be in line with a basic moral sense and reflection which uses African values and norms to produce principles that will guide the practice of the people when faced with concrete cases; such principles should also be pluralistic.

The motive for an Afrocentric ethical framework is to model the ethical evaluation of actions, policies, and decision-making of individuals, groups, and communities in Africa. This has

influenced the development of three core principles in Afrocentric bioethics as proposed by Onuoha (2007); these are respect for life, solidarity and justice in healthcare. However, since the development of African bioethics is ongoing, others might propose a different perspective and to an extent advance different principles or modify the already mentioned principles.

To understand the development of these principles, there is a need for detail on the values from which they were developed. In an African ethical philosophical approach, humanity is considered as the first object of respect, based on identity and dignity. This is followed by the aspect of community value, which is seen to enforce the social and communal value of human life, and lastly, morality, which is made up of those interests and values that are to be defended by a society at all times. These values are developed with special attention to the theory of communitarianism and egalitarianism that dominates the African society.

The principle of respect for life declares in very clear terms that all life is important and should be respected, with little consideration to personality or the autonomy of a person per se (Tangwa, 1999). This principle further lays emphasis on the fact that every human being has a certain degree of inborn dignity that must be protected and respected at all times, irrespective of their psychological, physical, or mental condition or state (Mkhize, as cited in (Rogoff, 2003). This principle emphasizes the obligation for all humans to respect life and not to intentionally harm another in a form that is not welcome by the community. Therefore, all life is important and deserves equal treatment, even when it is still developing as an embryo. The fact that all life is sacred, and comes as a gift from God, places an embargo on all humans not to take life or risk life because all are equal in the face of the giver and nature. Life, in a general understanding, is not only focused on human beings; it involves the plants as well as animals, birds, insects, and the cosmos.

The principle of solidarity promotes the concept of community or common good, which is an important ingredient derived from the theory of communitarianism and egalitarianism of justice in healthcare (Chuwa, 2014. The emphasis of this principle is on action beneficial to every member of the community rather than that beneficial only to an individual, as promoted by the Euro-American approach to ethical decision-making. This consideration is one of the common characteristics of life in African culture, as this is considered important in enabling individuals and communities to take the interests of others into consideration when making decisions or life choices. This is because this has the potential to affect another member in the

community, either directly or indirectly. Thus, any action taken must be that which either promotes or protects the common good of all, including the cosmos or the environment.

Lastly, the principle of justice in healthcare imposes a just and fair distribution of healthcare to everyone in need, without any consideration of the economic and political status of the person involved. In the indigenous African setting, treatment was provided to all those in need, irrespective of their status or their ability to pay for healthcare. An example is demonstrated in the fact that the traditional healers in the indigenous settings used to be given a token of payment only once the sick person had been healed. Treatment was never withheld on the basis that payment could not be provided by the person or his/her family. The moral theory of egalitarianism in justice is an important factor for the successful implementation of justice in healthcare for all in a community. Going back to the traditional indigenous African setting, there was a high attachment to human life, leading to a free healthcare system for all, guarded by the traditional and cultural philosophy of Ubuntu (Romeiras et al., 2012). However, this is no longer the case, due to the marginalization of the African indigenous knowledge system in the present post-colonial Africa and the world at large.

From the above development, it is very clear that Africans undoubtedly have their own ethical system that is somehow different from that of the west, underscoring the fact that there are different approaches to ethics, based on an indigenous worldview and philosophies. This disparity is demonstrated in the concept of what constitutes a person where, according to western thought, a person is an individual entity worthy of moral thought, as defined by Engelhardt in his book *The Foundations of Bioethics* (Engelhardt, 2000). This definition separates what is considered a person from fetal material, fetuses, children, defective people, brain-dead patients, plants, and animals at risk (Tangwa 2000). Tangwa also asserted that a person is a source of values that extend beyond an individual and that every human being is connected to their ancestors and even to non-humans ranging from plants to animals.

According to Gyekye (2010), there are two concepts in the African philosophy of ethics that warrant consideration. These concepts are personhood and human beings; these are distinguished, according to Gyekye (2010) by the notion of character, which is gaining strong ground in today's research ethics. However, the relational and communal view of the self as manifested in the African worldview in relation to the informed consent procedure and decision-making in health research is yet to be well established. Although communal assent

and community engagement are gaining ground in research implementation, there is a need to understand why the African people hold strong to this value and existing common norms.

2.5 WESTERN CONCEPTION OF PERSONHOOD

Understanding the concept of personhood as demonstrated in western philosophy requires the understanding of personal identity which plays a pivotal role in the definition of personhood. According to Rene Descartes, just like Plato and Aristotle, reason is the most reliable source of knowledge and therefore personal identity resides in the immaterial object which is the mind (Internet Encyclopedia of Philosophy, n.d.). Rene Descartes expounded his radical scepticism, which is the basis for the western values, and concluded in his book *Meditation on first philosophy* that reality resides in the immaterial world. He further concluded that he could only believe in the existence of his mind by advancing his idea of *cogito ergo sum* (I think, therefore I am), which has influenced the current principles underlying the process of informed consent based on the individuality of a person.

Transcendentalism is a philosophical phenomenon that is predominant in western tradition. This philosophical view holds that individual personhood transcends any boundaries; this means that an individual person has an infinite moral value which cannot be limited by any means. This philosophy holds that a person is recognized by its capacity for self-consciousness, rationality, and autonomy. This perspective holds that a person is an all-or-nothing entity with the belief that it can never be reduced by the absence of inter-relationship with other human beings or diminished rationality. There have been a number of debates among western philosophers regarding personhood, with those of the performance theory stating that a human being is recognised as a person only if he/she demonstrates an intrinsic capacity for self-consciousness, rationality, autonomous volition, and ability to communicate using language (Tooley, Warren, Rachels, & Ramey Mollenkott, as cited in Beckwith, 2009).

Other contrasting views to western philosophy hold that a human being is essentially a living animal of the species Homo sapiens. Among those holding this view is a divided opinion with some stating that all living human animals count as persons because of their intrinsic potential for self-consciousness, rational thought and autonomous volition, even in situations where one cannot yet, or can no longer, demonstrate the above-mentioned potential (Escoffery, 2004; Sweetman, 2003). Other opinions under this view argue that personhood must be considered as a phase in the life of a living human animal's existence.

The above-mentioned views can be summarized based on different criteria often advanced and elaborated by different western philosophers. These are discussed in the following sections.

2.5.1 Genetic criteria of personhood

John Noonan, in his work on the basic right to life for a fetus, rejected the various historical criteria of considering human beings as persons based on: 1) ensoulment, 2) viability, 3) impact on adult sentiments, 4) sight, 5) touch, and 6) social visibility. According to May, Wong, and Delston (2011), Noonan agreed to the genetic make-up of the fetus as the major criterion for personhood and humanity. He further developed his argument based on probability in which he considered the probability of sperm and egg cells becoming a person to this probability for a fertilized egg. He concluded that there is a sharp dividing line in the continuum of the development of life which justifies designating the conceptus as human and thus endowed with rights, with no such designation allocated to egg or sperm (*Noonan and Catholic perspectives*, n.d.).

2.5.2 Cognitive criteria of personhood

Mary Anne Warren, in her approach to defining what can be referred to as a person, identified five different characteristics that must be present for an object to be called a person. Among these criteria are consciousness, reasoning, self-motivated activities, capacity to communicate, and self-awareness (Wikipedia, 2017, July 4). According to Warren, the above-mentioned conditions are sufficient for a human being to be called a person and an object like a fetus does not meet these criteria, and therefore cannot be referred to a person.

2.5.3 Social criteria of personhood

This view holds that one is referred to as a person only if one matters to others. According to Chappell (2011), the view of personhood arguing that the properties of consciousness, reasoning, self-motivated activities, capacity to communicate, and self-awareness are necessary or sufficient conditions for personhood confuses criteria for personhood with parts of an idea of personhood. He argued that, in normal situations, identification of a creature as a person precedes the act of looking for it to manifest the personal properties of personhood and it is this pre-identification which plays an important role as part of what makes it possible for people to see and interpret the creature as a person in the first place.

2.5.4 Sentience criteria of personhood

According to Peter Singer, the key to personhood is sentience which is the ability to feel pain and pleasure. His view made it clear that it is wrong to cause unnecessary pain to anything that can feel, but if it can feel, we do not harm it by excluding it from the group of beings that matter. The most obvious criterion of personhood for those disinclined to allow that bacteria or trees are persons, but eager to grant personhood to human babies, is sentience, which is, of course, the favored criterion of moral standing (Cushing, 2003).

2.5.5 Gradient theory of personhood

The gradient theory of personhood holds that personhood comes in degrees and an individual can have more or less of it. This view is also expressed by African philosophers with a focus on protection. By this view, the fetus has less personhood than children who in turn have less personhood than their parents; in a situation where the personhood of a fetus conflicts with that of their parents, the personhood of the parents will always dominate that of the fetus. This view places children's interest and those of the fetus in a lesser position than those of adults and might not be a good theoretical platform to protect children or to base principles of ethics.

Based on the flawed nature of the theoretical understanding of personhood as demonstrated in western philosophy, the ethical principle of respect for persons will be meaningless unless we explore another ethical worldview through the establishment of how Africans conceive and understand the concept of personhood.

2.6 AFRICAN INDIGENOUS CONCEPTION OF PERSONHOOD

2.6.1 Character as the central point to personhood in African ethics

African ethics is recognized by many as an ethics based on character and it states clearly that the quality of character demonstrated by an individual is the most fundamental ingredient in the moral life of that individual person. A society has the responsibility of imparting moral knowledge to all members of that society. In the case of Africa, this is done through morally-freighted proverbs and folktales which are told to young members of the community with the hope that, when the time comes, they will pass this moral knowledge to the next generation (Gyekye, 2010; Praeg, 2014; Wiredu, 2009). The reason why proverbs and folktales have dominated African ethics is to help juveniles to gain, incorporate, and internalize the various

moral values offered by the society in addition to specific virtues ingrained in the various narratives of ethical principles. The response of young people to the moral instruction is expected to be appropriate and to eventually lead to the addition of appropriate habits which will eventually translate to their characters (Afisi, 2009).

Gyekye (2010) asserts that having a moral grasp or being alerted to the moral principles and values is one requirement, while being able to live a life that is a reflection of those moral principles and values is another. Thus, to carry out the transition of ethical knowledge into action is the most important accomplishment in African ethics. The failure of an individual to carry out the transition of ethical knowledge into action is considered to lack good character. In other words, for the ownership of good character, it is a requirement for the person to act in line with the moral principles and rules set by that society. The performance of good or bad relies solely on the nature of a person's character (Gbadegesin, 1991). For this reason, one's character is considered very important in African ethics.

The African indigenous system states very clearly that character is acquired and for this reason, a person is therefore in charge of the type of character that they portray to their society and they should be responsible for it. With that said, it will be fair to say that character results from the habitual actions of a person. It is commonly held in Africa that an individual is never born with a bad head; but because he or she is on earth, it is the earth that instills in him/her a character that is bad (Gyekye, 2010).

Because character is gained through people's actions and habits, responses to moral instruction can change or reform an individual. Therefore, the character of an individual is delineated by the African philosophers in relation to habitual action which results from an individual deed or action. Carrying out a particular action is likely to result in a habit which might eventually become an individual's character. It is on this ground that African ethicists capitalized on restorative justice rather than retributive justice, especially when the doer admits and recognized their wrongs.

To achieve virtue, an individual must be able to perform actions that are good and morally acceptable all the time, as this will enable them to become addicted to such habits. Any action or deed that will lead to the gaining of a new good habit must be encouraged and vigorously

performed so that such a beneficial habit can be enhanced and will lead to virtue (or good character), which will be the end result gained by that individual.

The original nature of human beings at birth is believed to be morally neutral (neither good nor bad) and this is the logic behind the development of an individual's character or habits. This original neutral nature of a human being will at a point be affected toward one direction (good or bad) by his/her actions or responses to the diverse moral instruction, advice, and persuasion they encounter in their daily life. The neutrality of the original nature of a human being constitutes the foundation of a moral person. What a person does or does not do is central to the creation or improvement of his/her character, which either qualifies him/her as moral or immoral.

2.6.2 African communitarian concept of personhood

The African indigenous conception of personhood is communitarian in nature; because of this, the word person has normative layers of meaning. The first layer of a person is regarded as a status achieved only after fulfilling certain conditions set by the society in which one is growing. The second layer carries with it a descriptive component to the concept of personhood. In most African communities, the prerequisite of personhood is marriage and procreation, with less concern given to the role of age and time in the development and status of all human beings (Flack et al., 1992). In African culture, infants are not recognized as persons; this does not provide a cultural license for the abuse of children. On the contrary, infants are recognized as a precious entity among humans and worthy of protection because their potential is yet to be developed and they might be of high benefit to the community and the world at large (Tangwa, 2007). In the case of an adult, there is less protection as compared to infants because, in adulthood, there is less worry about the magnitude and direction of their potential as almost all of their potential has already been dissipated. However, indigenous Africans accorded more respect to the elders because of their assumed full development of personhood and their contribution in transmitting personhood to other members of society. This is the reason why even a demented elder in African society will never be looked down upon as having less personhood because his/her true personhood value is still circulating in society through those he/she impacted.

Wiredu (as cited in An-naim & Deng, 2010) asserts that there is a divine element associated with all human beings despite their developmental stage and it is because of this element that

all human beings are entitled to a certain degree of respect and dignity, whether young or old. Thus, this gives all human beings the right to fundamental human rights. In the African metaphysical reality, the theory of selective reincarnation is demonstrated with great significance in all tribes and communities in Africa. When an infant dies, funeral ceremonies are unacceptable not because the infant soul and his/her dignity as a human being are not respected, but because of the recognition that the infant did not exploit his/her full potential to become a person. The infant thus does not have the license to become an ancestor and by this, the infant soul must be crying for generic restoration. In the same line with generic restoration, when a deformed baby in most villages in the north-west region of Cameroon dies, rituals are performed to the ancestors to have that deformity corrected before the return of that same child. The wish for generic restoration which originates from the unnatural death of an infant is granted by shortening the time for grief and depression which is but natural among the parents, thus giving them time to procreate another infant, which is believed to be the reincarnation of the unnatural departed child. It should be noted here that the idea of selective reincarnation does not mean the parent is going to give birth to the same child, but the child that will come forth will be having the same life that was not fully developed in the departed child.

The African concept of personhood does not claim that there is no child abuse in Africa. Child abuse is just one wickedness among human beings which is evenly distributed among the different people of the world according to the overall statistics; it cannot be attributed to a race, tribe, state or country. However, this concept assumes the position that the manifestation of wickedness toward children is reduced among African people and that the role of poverty and poor governance, both introduced from the western philosophy of individuality directed toward African children and the people, should not be misinterpreted as the values of the people. In a true indigenous African society, worth was evenly distributed and the community was living in harmony and complemented one another.

Having established the fact that an infant is not recognized as a person but as a human being with the full potential of becoming a person, a non-achieving adult is also considered in the African indigenous system to fall short of personhood if their judgment is focused around achievement. While an infant falls short of personhood because they are still in preparation for the status, an adult falls short because they are doing little of what is expected by the community. Personhood, in the African context, is something that has to be attained, and it is

attained in direct proportion to how one participates in communal life through the discharge of the various obligations defined by one's society; these are necessary for harmonious living and the sustenance of that society (Gyekye, 2010; Jensen & Gaie, 2010). According to Gyekye (2010), it is the carrying out of these obligations that transforms one from the it-status associated with childhood, which is marked by the absence of moral function, into the person-status of later years, marked by a broader maturity of ethical sense.

In African culture, prejudice toward an adult who lacks personhood is only elicited when the adult's behavior leads to extreme waywardness and can possibly cause negative attributions to their lineage, ethnic group and, to a large extent, the species, unless this failure is because of impotence. When an adult falls short of behavior because of impotence, this elicits sympathy among the family and well-wishers, who jointly seek a solution by providing facilities for physical and psychiatric treatment, if necessary. This is unlike the western approach to personhood, whose focus is on the individuality of a person with little attention to the communal person. This supports the common saying among African philosophers which says a person becomes a person through other people and an individual cannot be isolated from the community in which she/he grows up (Chuwa, 2014).

Among the African people, a series of events which include marriage, birth, illness, and death give rise to urgent obligations which determine one's capacity as a person (Imafidon, 2012; Kanu, 2014; Masolo, 2010; Tangwa, 2000). Any individual who meets these obligations in a timely and adequate manner is often referred to as a true person. The abovementioned test, with its associated obligations, is just the common and most general one, as there are other ways and tests for determining an individual's status as a person. To bring more light to this, getting married and having children is not enough to give an individual a 'ticket' to personhood as the household must be provided for and wisely administered by both spouses. In addition to this, one is expected to make a material contribution to the survival of the community and one's lineage, in addition to one's ability to act on the basis of rational reflection (Gyekye, 2010).

If an individual falls short of rational reflection in his/her actions in the community, the individual invites upon him/herself a negative judgment of character and by so doing be subdued under rational persuasion and moral correction. During this time, it is the duty of his/her household and the community to press for character reform, as disgrace for a member

of a household or lineage is a disgrace for all. If this irrational behavior persists despite the efforts of the community for character reform through critiques, mentors, and moral persuasion, then it will be assumed moral deterioration has taken place and only at this point are medical and psychiatric treatment considered necessary. Extra-human forces are also considered to be playing a role in such a situation and this often leads a household to seek spiritual solutions too. Persistent deterioration is an indication of lack of free will or responsibility and self-control. In the African indigenous knowledge system, there is no difference between freedom and responsibility as in the west. This value is susceptible to degree, meaning some individuals are more free or responsible than others with respect to a given sphere of conduct, and it also holds that no one is free or responsible to perfection.

An individual human is considered to reach full personhood only when he/she is free and responsible. (Flack and Pellegrino 1992 p 191) assert that "[a]n individual is responsible or free to the extent that his/her conduct can be modified through rational persuasion or moral correction". This is an indication that to attain full personhood and freedom is a difficult task, underscoring the reason why decision-making among African people is a collective action, as the strength of one complements the weakness of another. This position is in line with the Kohlberg stages of moral development in relation to justice (Kohlberg, 1981). identified three stages of moral development as follows:

1) The pre-conventional stage, also known as the hedonistic stage, where the physical consequence of human action is the determinant/motivation of their moral values.

2) The conventional stage, where conformity with the authorities and society, or meeting the expectation of others, is the sole determinant of moral values.

3) The post-conventional stage which assumes the position that the determinant for moral action should be independent of physical consequences, societal and authority expectation or even personal bias.

In a nutshell, a true person can be referred to as a living being of human parentage who, through the biological, psychological, cognitive, and moral apprenticeship from childhood by being exposed to moral persuasion and correction, has come to develop moral sensibilities and rational habits conducive to a productive and edifying life in society (Flack & Pellegrino, 1992).

2.7 SYNTHESIS OF THE LITERATURE

A communal approach to personhood regards the human person as inherently in relationship with its community; the person is thus embedded in the context of social relationships and interdependence. This, however, contrasts with the isolated, atomic individual approach of the western philosopher. The analyzed facts regarding the African conception of personhood show that it identifies a community as not just a mere association of individual persons whose interests and ends are contingently congruent, but as a group of persons linked by interpersonal bonds, biological and/or non-biological, who consider themselves primarily as members of a group with common interest, goals and values.

According to David Hume in his bundle theory, a person is just an ever-changing bundle of impressions whom the mind misleads to think is constant because it is packaged in a fleshy receptacle (Pike, 1967); by this view, it will be wrong to base ethical principles on the individuality of a person as understood in western philosophy. Philosophically, the only thing that remains constant as we progress through life is the set of relationships that we establish in life, and our personality can only be defined based on these relationships. Hume concluded his thesis with a strong stand that personal identity does not persist over time. According to Obioha (2014), the conception of the human person as a partner in progress with the community, and not as a submissive servant, is better for human well-being than the individuality conception which will only lead to the violation of human rights. He demonstrated that the communal view of a person, which is often criticized, could play a pivotal role in protecting human rights and fostering progress.

Therefore, it will be difficult to obtain an informed consent based on respect of the individual person (which is ever changing) without considering his/her community as of the time of informed consent. To make matter worse, 'preachers' of individual informed consent often emphasize free well as an important ingredient in the process of informed consent. However, because we live in a deterministic world, with our actions being influenced by both external and internal factors, according to Baron D. Holbach (2015), it will just be normal for the community to have a say in the process of informed consent through the individual involved, without whom it can never be informed. Patricia Churchland demonstrated clearly that we cannot talk of freedom in decision-making but need to consider the level of control over both the external and the internal factors influencing our behavior (Churchland, 2019)

CHAPTER THREE
METHODOLOGY

3.1 INTRODUCTION

This research implemented a systematic review of critical and empirical literature to understand the concept of personhood as used by African scholars to debate ethical dilemmas arising from research in Africa and the world, through the lens of the process of informed consent. This research has been expanding due to advancements in technology, science, and commerce which have been recognised as the motivation factor for the increased level of international research in Africa.

This method capitalized on the recent method of conducting systematic review developed and presented by the Griffith University, Social and Behavioural Research College. There are 15 steps involved in this method, divided into four important sections (Ballantyne and Pickering, 2015; Barros et al., 2015; Crisp, 2015; Pickering et al., 2015). According to (Pickering & Byrne, 2014) the first section presents a systematic review of the literature which relies on the explicit and reproducible ways in which papers are selected for studies; the second brings out the quantity of research done in the study areas; the third section brings out the comprehension of the research by assessing different combinations of locations, subjects, variables, and responses; and the last section deals with working out what is important about the literature by collecting and analyzing it, and developing the project under study.

3.2 PAPER SELECTION

By using the above method, research papers on informed consent published in English-language journals were obtained by searching the Health InterNetwork Access to Research Initiative (HINARI) electronic databases for journals, so as to access and recruit papers of interest that captured the African perception of personhood and community. HINARI is a program set up by the World Health Organization, together with major journals around the world, to enable researchers from low- and middle-income countries gain access to one of the largest collections of biomedical and health literature. This study accessed Google Scholar, bookzz, and the HINARI database which harbored up to 15,000 journals in 30 different languages, as well as more than 47,000 e-books and 100 other information resources (WHO/HINARI, n.d.).

Many journals were selected from the HINARI database for search, using search engines like AJOL, PubMed, and Public Health Ethics. Keywords that captured African perceptions on informed consent were used to select papers from the chosen journal. Only literature describing the results of original research or insight about African perceptions of personhood as applied to the process of informed consent were selected. To ensure large coverage of literature, reference lists and citations were used to cross-check coverage, and through this, additional papers were added to the list of papers which were reviewed.

Figure 1 below illustrates the steps by which the systematic literature review took place and how the results of this study were generated. The flow diagram below can be grouped into three categories which constitute systematic review with the first section (steps 1-4) indicating the process of initiating the research study, the second section (steps 5-10) representing the process of creating a database for the research study, which in this case was done using Zotero (n.d.) to organise the selected literature and Epi Info form to capture the important information from the selected papers as they were reviewed. The last section (steps 11-15) indicates the process of writing the review for publication.

Turnbull, Farrow, and Winchester (2013) assert that systematic review is very important in emerging areas of studies, especially in areas where the method of generating knowledge is diverse and trans-disciplinary. These criteria fit very well in the area of the Afrocentric perspective of research ethics as applied in the process of informed consent.
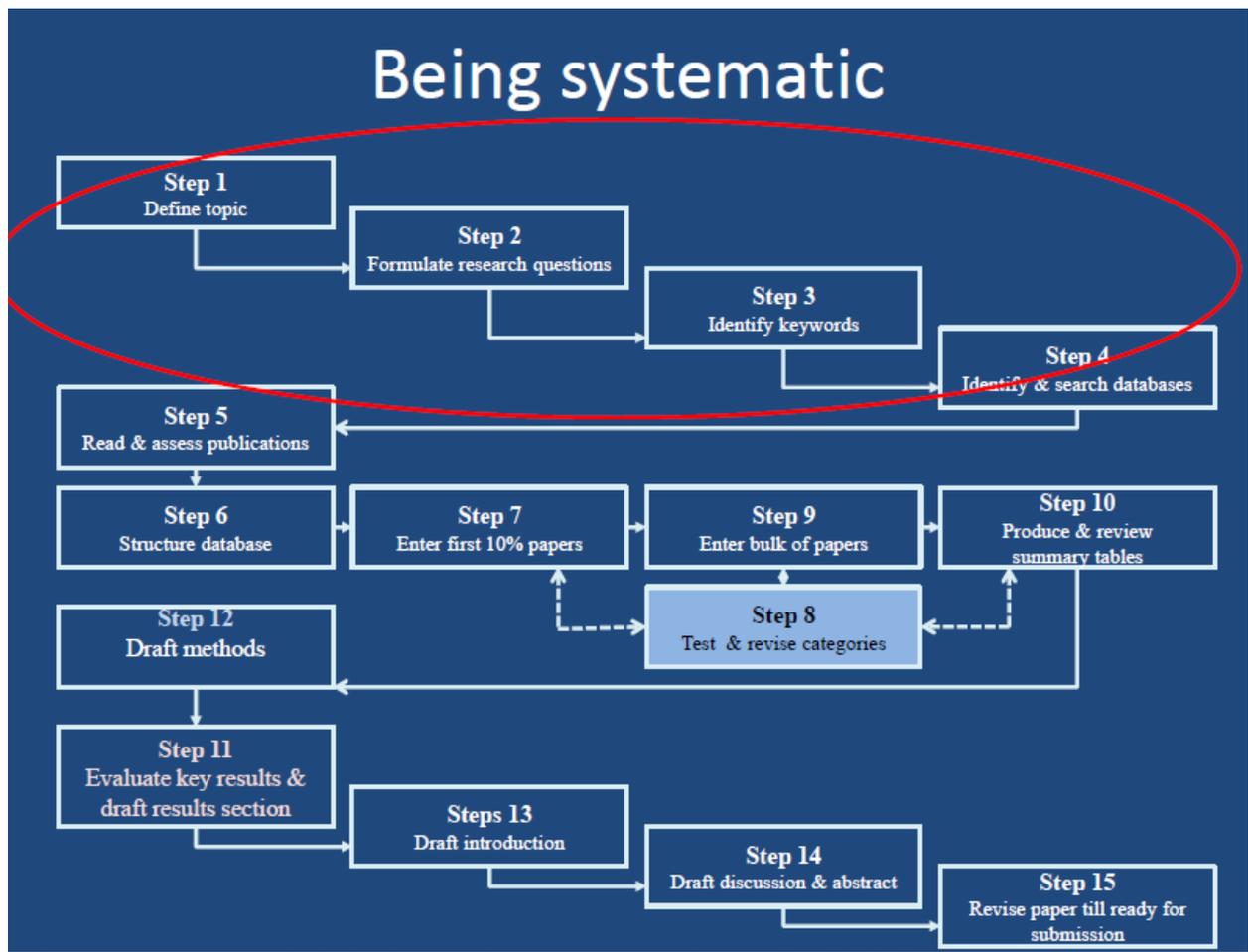
Figure 1: Steps in conducting a systematic review (Griffith University)

3.3 VALIDITY AND RELIABILITY

According to Terre Blanche, Durrheim, and Painter (2008, p. 152), the term reliability is conceptualized as the "dependability of a measurement instrument, that is, the extent to which the instrument yields the same results on repeated trials", while validity is the "degree to which a measure does what it is intended to do" (Terre Blanche et al., 2008, p. 147). Cook and Campbell (1979) developed a system of potential threats to research validity, namely: statistical conclusion validity; construct validity; external validity and internal validity. Internal validity refers to whether the inferences from the data collected are accurate (i.e. valid) and external validity refers to the ability to generalize the results of the study from one environment and population to other environments and populations.

The threat to the validity of this systematic review method is that it might not fit very well with external validity as the papers recruited for this study only reflected publishing information in English. This left out a vast amount of published literature on the concept in

other academic languages spoken in sub-Saharan Africa like French, Spanish, Arabic, etc. Most importantly, indigenous views may not be documented at all. However, the strategies of clarifying researcher bias have been considered in the design and conduct of this study from the outset. Success in responding to this problem lies in the ability of the researchers to convince both themselves and their readers that the findings of their study are genuine results, based on a critical, unbiased analysis of the information collected and not based on a few 'well-chosen examples', as this is always a potential threat to the overall validity of a study.

Other threats to both the internal and external validity of this study have been identified by the researcher during the design process. These were especially in terms of the use of systematic qualitative review and not quantitative review to analyze Afrocentric perspectives to research ethics as reflected in the process of informed consent in relation to the understanding of personhood; this has not previously been used. The researcher affirmed that because the research is based on a desk review carried out on public philosophical and empirical documents available on African approaches to research ethics, it is possible that the study will return results that are high in external validity, although a certain degree of the illusion of unanimism is recognized.

3.4 DATA ANALYSIS

The descriptive data on which the results of this study are based are from the identified papers published in the English language on African understandings of personhood and how these philosophically influence discourse around the informed consent process, decision-making, and community engagement. The identified papers to be recruited for this study were read and assessed, and important themes that capture African perceptions of personhood were extracted and coded into QDA Miner Elite for analysis. Literature right up to December 2015 was recruited and analyzed.

A thematic analysis technique was used to synthesize data from QDA Miner Elite. Themes were identified by bringing together components of ideas, experiences, and views embedded in the philosophical discourse among the African ethicists on the conceptions of personhood. Themes were constructed to form a comprehensive picture of African researchers' and philosophers' collective understanding of the concept of personhood and how it can practically influence the process of informed consent and decision-making among research participants in sub-Saharan Africa. A narrative summary technique was used to aid

interpretation of informed consent procedures and decision-making in health research which are informed by African understandings of personhood and community.

3.5 ETHICAL CONSIDERATIONS

This study was approved by the College of Humanities at UKZN and, since it was conducted on information available in the public domain, it was exempted from formal ethical clearance according to the UKZN Biomedical Research Ethics Committee criteria (UKZN Research Office, May 09, 2017).

CHAPTER FOUR
FINDINGS

4.1 INTRODUCTION

The results presented in this study are in the form of a narrative. This is for convenience, in order to clarify how the African indigenous approach of communitarianism, through the understanding of the concepts of personhood and community, is implemented or translated into practical ethical considerations in the processes of informed consent and community engagement.

4.2 DESCRIPTIVE ANALYSIS OF RECRUITED PAPERS

A total of 322 articles were reviewed for the study of which 46 were recruited; these were published between 2005 and 2015. Among the papers recruited for the review, 39% (18) were focused on the process of informed consent in sub-Saharan Africa and 11% (5) were focused on the process of informed consent decision-making procedure. The remaining 50% (23) of the papers were focused on the community engagement process in sub-Saharan Africa and its importance in the successful implementation of both international and local health research.

4.3 PRESENTATION OF RESULTS BY RESEARCH QUESTIONS

The results from this systematic review indicate that the principle of respect for persons (individual autonomy) is gradually changing and that other worldviews are now being integrated. This principle of autonomy has been claimed as a universal principle and has been guiding the implementation of the process of informed consent and decision-making in health research in the west since it had been exported to other parts of the world. Challenges encountered in Africa in using this principle have been improved by using the local understandings of the concepts of personhood and community, as demonstrated.

Themes	Percentage	Selected exemplars/samples from the papers
Engaging others in research	98%	"Participants usually talked with someone else and, in many cases, sought permission from a spouse before participating in a research" (Osamor & Kass, 2012, p. 10).
Wider consultation in decision-making to participate in health	85%	"Before making the decision, we talked about this research with our friends … and got different feedback, such as 'They are going to vaccinate you and you don't

research		know what will happen to you in ten or twenty years': 'You might grow a lot of hair like monkeys' [all laugh] or 'You will die a slow death' … It was hard, and we actually had to think hard before volunteering" (Ssali et al., 2015, p. 6).
Consultation with the immediate family to make a decision	65%	" …it is a tradition to talk to husband and relatives before making any decision that affects both husband and wife" (Masiye et al., 2008, p. 54). "People discuss their options with spouses, family members, and/or others before participating in health research" (Osomar & Kass, 2012, p. 7).
Decision-making beyond individual autonomy	80%	Respect for community autonomy and their right to self-determination; due consideration of the consequences of the research for the community as a whole; and, a complete understanding of human autonomy (Buchanan et al., 2008).
Level of consultation should depend on the complexity of the research.	46%	"Community engagement and the development of flexible and adaptive informed consent procedures are critical for facilitating the inclusion of the most vulnerable populations" (Corneli et al., 2014, p. A123).
Beginning research with community consent	10%	"The thing about [a rural] community is to take permission from the elders. Even if the villagers agree [to participate], there must be a word from the elders… maybe because of the way they live, you know, they believe there must be a word from their elders if there is going to be a stranger coming to the village" (Marshall et al., 2014, p. 7).
Community engagement as a flexible process determined by risk and the complexity of the research	55%	"There is no logical reason to insist that informed consent be identical in countries with markedly different cultures, social traditions, and literacy, as illustrated by community participation in the decision-making process and differences in literacy, access to medical care, and the understanding of complex issues such as the right of refusal and randomization. Insisting that the same strategy is used in such different environments is both illogical and inappropriate; it has the potential to severely reduce international collaboration on important health questions" (Krogstad et al., 2010, p. 746).
Community engagement tailored research to the context	36%	Substantial community engagement provides unquestionable input in health research for participation, participants recruitment and the process of informed consent (Embleton et al., 2015).

4.3.1 Personhood and the process of informed consent

This study found that 98% of the papers reporting on the process of informed consent in Africa were open to promoting the opinion which asserts that informed consent will be meaningful if research participants can engage other members of their family when participating in health research as well as medical intervention.

> *Initial decision-making for informed consent is typically vested in the community rather than the individual. Illiteracy is recognized as a common limitation to the value of written documents and signatures.* (Krogstad et al., 2010, p. 743)

This is in line with the African understanding of personhood which asserts a person is a person through other people (Comaroff & Comaroff, 2001). Personhood is achievable in direct proportion to how one participates in a community by fulfilling the various obligations set by the community, unlike the western conception which focuses on intrinsic characteristics (rationality, conscience, and communication). Thematic analysis of the results reviews the following themes regarding the process of informed consent in the African communitarian society.

4.3.1.1 Informed consent as a flexible process

This study showed that flexibility in the process of informed consent is of great importance, especially in a culturally diverse society like that of Africa. It is highly recommended that researchers adopt an informed consent process that will take into consideration the values and norms of the society in which the research is being implemented, in addition to the nature of the study being conducted:

> *There is no logical reason to insist that informed consent be identical in countries with markedly different cultures, social traditions, and literacy, as illustrated by community participation in the decision-making process and differences in literacy, access to medical care, and the understanding of complex issues such as the right of refusal and randomization. Insisting that the same strategy is used in such different environments is both illogical and inappropriate; it has the potential to severely reduce international collaboration on important health questions.* (Krogstad et al., 2010, p. 746)

Information provision at the individual level is not common in African communities; other approaches to tailoring the communication style to the local context are essential (Dawson & Kass, 2005). Although there might be differences in information-delivery preferences between urban and rural areas, the rural areas, though termed primitive by many, are more highly influenced by traditional African values and norms than the post-colonial urban areas, which are highly infiltrated with the western ideas of individual autonomy. In other studies, respondents indicated the preference to precede individual informational delivery during informed consent processes with group informational communication, as this enhances understanding as cited below.

> *Respondents advised preceding the individual level consent process with group information provision using community gatherings. Other researchers also advocate such pro-active community-based information giving in an African context.* (Tekola et al., 2009, p. e482)

4.3.1.2 Informed consent process as relationship building

Informed consent in African society is better appreciated when it is treated more like a relationship than a standard procedure to conduct research and to vindicate the researcher in case of any research-related accident. Though informed consent should meet the minimal standards set by both local and international guidelines, the process of implementation must take into consideration cultural and linguistic competency. This is especially so when implemented in diverse populations as this requires sensitivity to both the complexities of terms associated with the study *and* the social meanings, including the relative importance attached to the research and the consent process (Marshall, 2008). Cultural and linguistic competence can only be ascertained if there is a well-established relationship between the research team and the community.

> *Ensuring and gaining informed consent should be understood and treated as a relation-centered, dynamic supportive process throughout the duration of a research study.* (Ssali, Poland, & Seeley, 2016, p. 2)

While relationships might need to be established between the researcher and the research participants, there are other forms of relationship which are also important in the process of informed consent; these include those which exist between the participants and their families, as well as friends, who are often consulted by the potential research participants.

> *Participants usually talked with someone else and, in many cases, sought permission from a spouse. This is an important finding because current notions recognize the need for individual autonomy in making the decision to participate and having to seek permission from a spouse seems contrary to this expectation. It is now common for research studies to give consent forms to potential participants and allow them to discuss with family members before making a final decision.* (Osamor & Kass, 2012, p. 10)

The findings advocate that the process of informed consent in this community is known and practiced as a relational exercise that must involve others in the decision-making process; therefore, the adaptation of the informed consent process to fit into the culture and the values of a community is of critical importance.

4.3.1.3 Informed consent beyond legality and regulations

For many in the west, informed consent should be firmly rooted in legality and the regulations set by the different institutions in their concern for the process to be valid. However, this study found that, in Africa, informed consent transcends the formal requirements of legality and regulations into continuous interaction and sharing of results, challenges, and possible solutions between the research team and the research participants. In this view, the idea of a presumptive legal strike that has often characterized the current process of informed consent is neutralized by the relationship that has been created between the research team and the participants.

> *The informed consent process is not only about the formal enactment of regulations as isolated events, but also depends on the continuing interactions between the research team, the research volunteers, and their communities throughout the trial.* (Ssali et al., 2015, p. 13)

Although the signing of informed consent in research is important, this study found that it should not be the major emphasis in the process of establishing informed consent in Africa; this is because participants value the relationship and the trust that is built between the research team and the participants more than any formal document. A study by Ssali and colleagues in 2016 found that research participants in Africa will not even appreciate the presence of a third party because, according to them, what is important to indicate participation is the level of trust in the relationship created during the study.

The signing of informed consent is important to the researcher as an evidence of participation but this process for someone who can't read or write in the presence of a third party was not welcome by the participants because understanding research information doesn't correlate with reading and writing. (Ssali et al., 2016)

Though research participants usually have sophisticated knowledge about informed consent, the identification of a community permission-giving institution is very important for the success of a project in local communities in Africa. Although the permission-giving institution might vary from country to country, and community to community, its importance in Africa has been confirmed by findings in other countries (Kengne-Ouafo et al., 2014).

4.3.2 Communal ethical decision-making

Understanding the particular local factors and cultural context to the decision-making process that enables participation in research studies is of great importance to research implementation. This may result in the adoption of an informed consent process which is culturally sensitive (Osamor & Kass, 2012, p. 10). In this study, 70% of the research papers recognized the role of the community and community leaders as very important to the successful implementation of a truly informed consent. How the community contributes to the decision-making process differs depending on the type of research and its complexity, including the targeted participants. In addition to accepting the role of informed consent in biomedical research, participants in most studies acknowledge the role of the community in making a decision about participating in health-related research, especially for research involving children and youth (Vreeman et al., 2012a).

The thing about [a rural] community is to take permission from the elders. Even if the villagers agree [to participate], there must be a word from the elders… maybe because of the way they live, you know, they believe there must be a word from their elders if there is going to be a stranger coming to the village. (Marshall et al., 2014, p. 7)

Bringing other trusted people in the community to participate in research activities in a community builds the trust and relationships needed for the successful implementation of health research, since it is critical to the process of decision-making during the course of obtaining informed consent. The findings of this study raise some themes that are worth

expanding upon to give a clear picture of how African people view decision-making, especially in the process of informed consent.

4.3.2.1 Parental involvement in decision-making for children

Many ethical sources recommend that decision-making for children to participate in research that concerns them should be through the legal parents or guardian of the child, with assent from the child to participate in the research. However, the present study argues that the African community holds a slightly different view regarding the assent of the child. Since children in Africa belong to the community, which assigns value to child and not only the parents, an appropriate decision-making process will involve the community leaders in the area where the research will be implemented. These leaders are the first layer of decision-making for children to participate in a research study, before narrowing down to the parent who actually makes the final decision for their children to participate. In the African community, children's assent is not really considered as an important element to making decisions about participating in a research study, especially when the community and the parents have understood the importance of the research.

> *Research on children is important to the children's welfare but informed consent must be obtained from the parent and guardians. Sometimes little regard is given to children's assent from other caregivers like community leaders and community assemble are also involved in the consent process.* (Vreeman et al., 2012)

This approach might seem as if the children's right to assent to research has been violated as argued by many international and national guidelines; on the contrary, the African community believes that children are better protected through the chain of decision-making in the community. It is not in every situation where even the parents of the children might be in the right position to provide a valid consent, especially when it comes to research in an emergency situation, as reviewed by some studies around the decision-making process in emergency situations (Morrow et al., 2015).

> *You know, even you if you are in a state of shock [laughing] you may say yes to something if you are not mentally stable… you may say yes then later you say no when you came to that part of filling in the consent form… at that point, it will be wise for you to withdraw that child from the study and*

it's really understandable... it is very important to go back as soon as possible. (Molyneux et al., 2013, p. 5)

4.3.2.2 Parental involvement in decision-making by youth (18+ years)

Some research is designed to target young people since they are very active and better results can only be achieved when this group is involved; however, one will wonder how this group of research participants will make their decision to participate in a research study. Study participants in studies that were recruited for this review indicated a very strong relationship between the decision-making of young people to participate in research and their parents and the community at large.

> *There is a strong relationship between decisions made by a youth to participate in a trial and her/his parents' support or lack thereof. We would be lying if we said a young person can decide independently of his/her parents since our young people have not been brought up that way.* (Mbunda et al., 2016, p. 5)

This decision by young people in Africa to consult others before participating in a research study is not related to whether the person involved is dependent or independent. It is a process that has been intrinsically built among young people, especially as it brings with it packages of advantages should anything go wrong through participating in the research.

> *It does not matter whether a young person is dependent or independent because there is always a relationship between that person with a mother or a father or relatives. Therefore, if s/he decides to volunteer in a trial without their blessing and then gets a problem, even if it is not related to the vaccine, that person will not be able to get assistance from the community because s/he will be rejected.* (Mbunda et al., 2016, p. 5)

In Africa, the initial decision-making for informed consent is typically vested in the community rather than the individual, since illiteracy is a common factor among research participants and acts as a limitation to the value of written documents and signatures which characterize the current procedure in the process of informed consent (Krogstad et al., 2010).

4.3.2.3 Communal decision-making among adults

Adult decision-making in Africa is not individualistic as in the west. Although adults are allowed to make decisions to participate in research, there is still some level of understanding that consultation and consensus need to be reached with the family for the consent to be truly informed and valid. Studies have shown that women are more likely to consult their spouse before making a decision to participate in a research study than men. A study in Nigeria found that women were more than twice as likely as men (54% versus 24%, p=0.002) to report that they obtained permission from someone else before participating in research, with nearly one-half of women (42%) obtaining permission from their husbands (Osamor & Kass, 2012). This is not a sign of domination as many put it, but the value system of the people which causes no harm but strengthens the decision-making process for everyone involved; this is shown in this quote from another study:

> *It is a tradition to talk to husband and relatives before making any decision*
> *that affects both husband and wife.* (Masiye et al., 2008, p. 54)

Though an individual is given preference in terms of the ultimate decision-making, that decision comes after wide consultation with the set of relationships that give that individual its personhood (ability to make a morally relevant decision); these relationships might not actually be visible at the time of decision-making but are indirectly influencing the individual's decision to participate in the study.

> *Before making the decision, we talked about this research with our friends ...*
> *and got different feedback, such as 'They are going to vaccinate you and you*
> *don't know what will happen to you in ten or twenty years': 'You might grow*
> *a lot of hair like monkeys' [all laugh] or 'You will die a slow death' ... It was*
> *hard, and we actually had to think hard before volunteering"* (Ssali et al.,
> 2015, p. 6)

The shift from the individualistic approach to the process of informed consent to the communal approach in Africa was very visible in this study's results, with 85% of the identified publications advocating for options that would enable research participants to consult others before giving their consent to participate in research. With this result, one will wonder when the research participants actually make their decision to participate in the research, but this review indicates that the majority of the research participants must have

already made their decision to participate in research, especially if information about the study is obtained from trusted individuals. According to Paré Toe et al. (2013), for many participants the decision to participate in a research study had already been taken before undergoing the informed consent process and this is based on the information conveyed through the community (Paré Toe et al., 2013).

Overall, 45% of the papers advocated for a general informed consent from structured communities' leaders, especially when the researcher needs to gain access to the community (location or social groups). This process must be followed by individual informed consent and must not in any way represent the view of potential individual participants but is a source of respect to the community. In total, 65% of the papers emphasized the need for participants to consult with the members of their immediate family before granting their consent to participate in a research study.

> *While individual research participants are autonomous in deciding to participate in research, participants in research in Africa usually talk to someone else before participating in a research and in many cases sought permission from a spouse before participating in research.* (Osamor & Kass, 2012b)
>
> *It is clear that many people within the household, family, and community influenced women's ability to participate in research.* (Ganle et al., 2015, p. 11)

The complexity associated with decision-making among adults in Africa is partly because of the effect of colonization which has infiltrated the indigenous value system and makes it difficult for many to balance the values of the colonial master with those of Africa. This has brought some slight difference between decision-making in urban areas, where the value system is dominated by western values, compared to the rural areas where the indigenous value system might be strongly followed. A study to identify the role of the elders in decision-making reported there might be rural and urban differences regarding the importance of community elders in the implementation of research:

> *The thing about [a rural] community is to take permission from the elders. Even if the villagers agree [to participate], there must be a word from the elders...maybe because of the way they live, you know, they believe there must be a word from their elders if there is going to be a stranger coming to the village. Then the Baale or the Chief would [say] 'Okay, you can go*

ahead,' ... I don't think it is possible to go into a village and carry out a study without the approval of the community leader. (Marshall et al., 2014, p. 12)

Deducing from this thematic analysis, it will be fair to say that the majority of the recruited papers identify decision-making as a process which goes beyond an individual to the community and beyond, although it will be presented by the individual involved. The mistake we often make is that we lose sight of the contribution of the community to the information that the participants carry along and use to make the required decision. It is true that sometimes some participants will come to participate in a research study without prior knowledge of what the research is all about but these individuals are armed by the community with all it will take for them to make a good decision. The work of the research team is to guide the participant to select that which is appropriate for that participant at the time of decision-making.

According to Leach et al. (1999), 50% of parents who participate in research in the Gambia take advice from researchers, 24% take advice from health workers, 16% consult friends, and 12% consult family before participating in a research study, but in all cases, the decision is made by the participants. With this analysis, I can, therefore, conclude that effective decision-making among adults will be successful if it balances individual autonomy with the recognition of cultural values based on the respect for authority, in addition to the importance of discussion and negotiation before participating in research.

4.3.3 Community engagement and informed consent

In the African indigenous knowledge system, a community is often understood in terms of relationships which could be physical or spiritual, rather than in terms of geographical location or a group of people with shared history and origin, as recognized by western ethics. Many papers have indicated that the level of consultation in the process of decision-making in health research and medical intervention should depend on the complexity of the research and of the medical condition under consideration, but stress the importance of bringing in the contribution of the immediate family members.

4.3.3.1 Community autonomy is as important as individual autonomy

Contrary to the traditional western notion of individual autonomous persons, African societies hold a communalistic notion of person; hence, there is less regard for individual autonomy and rights and more emphasis on the communal good and maintaining the continuity of relationships and interdependence shared within a community (Ganya et al., 2016). The community has the right to self-determination which cannot be dominated by individual rights and there are certain risks in participating in research that only the community faces and which cannot be attributed to any individual.

> *Respect for community autonomy and their right to self-determination;*
> *due consideration of the consequences of the research for the community*
> *as a whole; and, a complete understanding of human autonomy.*
> (Buchanan et al., 2008)

It is important to understand that the extent to which a community's autonomy is respected needs to be determined by the research ethics committee, which is one of the only many body that are promoted to be engaged before research is being implemented. However, research engagement that is limited only to this level of community is bound to experience challenges which might eventually lead to unethical decision-making in the process of informed consent. Therefore, understanding that community goes beyond ethics committees and any individual directly participating in the research is very important, as a community is recognized as all those affected directly and indirectly by the research:

> *'Community' should be interpreted broadly as all who will be affected by*
> *the research results, including lay residents of a local area, practitioners,*
> *service agencies, and policymakers.* (Strauss et al., 2001, p. 12)

4.3.3.2 Community engagement and leaders

To many, community engagement in health research is often seen as a process that is valued in a culturally vibrant society like that of Africa because its norms and values might be different from those of the west. However, this study showed that engaging the community does not only respect the community and its authorities but also provides a strong instrument for the implementation of the process of informed consent. This is related to promoting a shared understanding of the research by the potential participants and a process to seek consensus through education. Though the community authorities are at the center of

community engagement, their understanding of the research to be implemented relies on some degree of confidence between the researcher and the understanding of the research, either by the leaders or some well-informed member of the community. This fosters better understanding of the research, especially as research is often associated with complex scientific procedures and terms which in some cases might not be easy to translate for the understanding of a common man.

The understanding that individuals within a community might harbor, with the capacity to understand the complex procedures in research, is very important to the promotion of community engagement. Although these individuals might not be direct participants in the research, they might play a critical role in the successful implementation of the research by building the trust between the researcher and the participants. The traditional leaders are the first level of authority in African society before group leaders like religious authorities, for example:

> *Researchers are expected to ask leaders for permission to invite community members to participate in their studies. Traditional chiefs are highly respected in the community and are mostly men.* (Tindana et al., 2006, p. 1)

Because of the complexity of some societies, there is a need for the researcher to better understand any community where a particular research study is intended to be implemented, as the structural arrangements of African communities vary from community to community. Therefore, it is the duty of the researcher to identify whom to engage in a research study and, in the case of group leaders and groups working to protect their interests, it is better to identify and engage them in the consent process so as to ensure risks are minimized (Molyneux et al., 2016)

4.3.3.3 Enhance comprehension of informed consent through community engagement
A study in Ethiopia reported 84.6% dissatisfaction with the current approach in informed consent, citing cultural difference as one of the causes. According to participants' responses to an interview, educating the community should be at the center of community engagement, not just getting the consent of the community authorities. The research will be a failure if the community is engaged in the appropriate engagement pathways without enough education on the pro and cons of the project in the community. This means it is the responsibility of the

researcher to educate all members of the community about the study, whether they are participating in the study or not.

> *You don't go to the field with your backpack and say I am from France, and assuming these people are subjects and they will agree, this is what was done in the old days. Now in the community, you have to try to teach them as much as possible, telling them the pros and cons of the research. … They have to negotiate their benefit.* (Addissie et al., 2014)

Community engagement enables researchers to take account of staff and community opinions in addition to the various issues that arise during a study so as to adapt messages and methods to address emerging ethical challenges in that community (Marsh et al., 2010). Appropriate communication between the research team and the participants can be the best approach to identify the appropriate authorities to engage in a study, as participants themselves carry with them this information and can only provide them when asked:

> *Respondents were able to outline the structures of authority and permission-giving in the community and clear routes by which communities might be approached. Although the structures are unique to communities, the presence of certain trusted groups is common to several other communities in Kenya and Ethiopia explored using similar techniques.* (Kengne-Ouafo et al., 2014, p. 9)

The most accepted information communication channel mostly reported and accepted by the community is through the religious leaders, health professionals, and selected community leaders. These channels are very useful for the dissemination of information to the community. Political administrative leaders are also a recognized path to engaging the community but their involvement in research is mostly related to legal issues rather than the effective implementation of research and subsequently informed consent.

> *For health studies, health professionals are better. Others, like community leaders, also have the chance to meet the community.*
> *It is eh … here there are three types: the administrators, religious leaders, and health professionals should discuss together how the information should be disseminated to the community. (Male, 45 years, priest)*
> *Religious leaders are the most accepted, more than community leaders or*

administrative members of the kebele. (Female, 37 years, housewife) (Abay
et al., 2016, pp. 6–7)

Substantial community engagement provides unquestionable input in health research in terms
of participation, participant recruitment and the process of informed consent. Collaboration
with the local community provides local context and knowledge in research that might not be
available to the project developer at the time of protocol development. This context and
knowledge should be reflected in the materials to be used in the research process (Woodsong
et al., 2014, p. 3).

CHAPTER FIVE
CONCLUSION

5.1 INTRODUCTION

African ethics holds that a person cannot be defined on the basis of some intrinsic property like self-consciousness, rationality, autonomy or communication, but only with reference to his/her community as the main instrument for the generation of such property from the status to the personal status. The African indigenous knowledge system acknowledges that those properties as identified in the western conception of personhood are vital to the attainment of personhood, but should not be the focus of moral consideration. Instead, the African indigenous knowledge system emphasizes the importance of a relational person as the best underpinning for making an ethical decision.

5.2 DISCUSSION OF FINDINGS

This study has found that, in Africa, an appropriate informed consent process and subsequently making the right decision to participate in health research are influenced by many factors. According to the findings, the complexity of the research, including the participants to be recruited for that study, should be taken into account. Informed consent is considered as a process that does not only end after the research has ended but a process which goes beyond the research. In an appropriate African setting, a researcher implementing research in any community has to do so by building lasting relationships and trust. It is these relationships that are considered to be a protective mechanism rather than a written document that participants are often forced to sign.

The informed consent process varies and takes into consideration the target population involved in the research. This study found that in research that targets children, the process of informed consent should be passed through the community leaders (elders and traditional rulers) for them to give their consent. This should be the first step in the consent process before the researchers can be granted access to the community for such research to be conducted. This is based on the belief that children belong to the community and must be protected by everyone, not only by their immediate parents or guardian. This is contrary to the western approach which limits consent to the parents or the legal guardian of the child, with little consideration for the role of the community leaders.

This complex procedure in the process of informed consent can be understood as being based on the beliefs that, although children are not persons in the reality of the African people, their lack of personhood is a motivating factor for additional protection by the community. This brings us to the statement which, according to that is captured in Tangwa's work, says a human infant or a mentally or physically handicapped human being deserves, if anything, even greater moral consideration than the paradigmatic person. In addition, the morality of an action in African ethics is determined from the standpoint of the agents (researchers, medical doctors, etc.) rather than the objects (research participants, embryos, patients, even nonhuman animal and plants) (Tangwa, 2000). Because of this level of protection in research with children, the assent of the child is not always considered to be as important as that of the community, so long as the community and the parents of the child or legal guardians have given their consent. Though children's assent is encouraged, the lack of it is not considered a violation of any ethical principle, so long as the community and the parents or legal guardians have given their consent. Therefore, the decision-making procedure for children to participate in research starts from the community leaders and moves to the parents or legal guardians; then, depending on the age of the child, an assent can be considered as an appropriate step in the decision-making process, rather than a required step.

For research that involves young adults, the informed consent process has a slightly different procedure from that of children, as reported by the findings of this study. Because young adults are mature enough to understand the process of informed consent and to some extent make a decision of their own, the pathway to the process of informed consent includes community engagement through community leaders which in this case are the authorities that are put in place to govern the people and ensure their safety. This could include government institutions as well as traditional institutions. The young adult is then given an option to consult widely with other members of the community of his/her choice before making the final decision to participate in the research. Although the final decision to participate in the research is that of the young adult, and not that of the parent (as in children), their decision-making to participate in a research study is the result of the contributions of members of that community who have helped that individual make a decision that will be good for him/her and the community at large.

Should any unforeseen consequences arise due to participating in such research, the damage that it will cause will be reduced since it will be the responsibility of the whole community to

seek possible solutions. This is the reason why for many in Africa there is no individual 'you' at a particular time. This narrows down the understanding of the concept of personhood which can only be defined in relation to others. Though young adults and the researcher are both persons, "[h]uman persons are moral agents, carrying the whole weight of moral obligations, responsibilities, and duties on their shoulders, not that human persons possess greater moral worth and deserve greater moral consideration than other human beings" (Tangwa, 2000, p. 40).

Researchers have some certain level of responsibility in order to engage the community in the research. While the researcher engages the community authorities for consent to implement research in a community, the young adult also engages the various relationships which make them 'person' for better advice to make a decision that will also benefit the entire community. This is in line with Gyekye's assertion:

> There are certain fundamental norms and ideals to which the conduct of a human being, if he/she is a person, ought to confirm, that there are moral virtues that an individual has the capacity to display in his conduct and ought to display them, if he is a person which can only be determined through the eye of another person. (Gyekye, 2010, p. 6)

Adults' informed consent process, decision-making, and subsequently community engagement are different from that of children and young adults. Although young adults and adults do have some level of individual autonomy, their autonomy is not considered more than that of the community. The community is recognized as having some degree of risk through the actions of individuals which must be prevented and protected from occurring by the community itself (Buchanan et al., 2008). It is for this reason that community engagement is very important for research, even with adults. The approach as reported by this study is to consult the community leaders, some of whom (e.g. traditional rulers) will give consent, while others (e.g. religious leaders) should provide assent before such research can be rolled out in the community.

The role of a family for an adult when participating in research is that of awareness, endorsement, and support for the participant to participate in the research. This is particularly of great importance because the burden that might arise should there be any harm from the research will involve the effort of every member of the community; likewise it will affect

members of the family. The final decision-making to participate in the research is that of the individual adults, based on the foundation of that of the community where that research is being implemented. The autonomy of the individual is never compromised with that of the society but is complementary for a better understanding of the research and informed consent which is truly informed.

5.4 CONCLUSIONS/IMPLICATIONS OF THE STUDY

The attributes that fuel the principle of informed consent of individuality should rather be the focus for moral liability, culpability, and responsibility, for it is a person who does research. Therefore, the principle of informed consent based on individual autonomy (respect for a person) rather than community autonomy or respect only helps to give room for unethical practices as it switches the focus of ethical responsibility from the object (researchers) to the subject (participants). This is a greater reason why the prima facie principle of a presumptive legal strike is inevitable in the current process of informed consent, which is developed from the western culture which focuses judgment on the participant's signature, rather than on the researcher's responsibilities.

Achieving a truly informed consent in Africa entails engaging the various relationships that enhance an individual's efforts to achieve its personhood. This is the very reason for the existence of research ethics committees which act in some form to relate the researchers and the research participants. The growing interest in ethical decision-making based on wider consultation with members of the community as demonstrated in this study is a clear indication that communitarianism has taken its rightful place in the process of informed consent and researchers in Africa are coming to terms with the reality of the African people. As reported in this study, the pathway for the process of informed consent and subsequent decision-making through community engagement is different for research with children, young adults, and adults. In addition, it is highly influenced by the type of research that is being implemented and the level and type of risk associated with the research.

The quest for an Afrocentric bioethics that will adopt principles and approaches that extend protection to human beings and their community has been recommended by many studies but this review indicates that research ethics committees in Africa should focus on determining the level to which the community will be engaged and the process of making ethical decisions that will reflect the values and norms of the community. This can be achieved if it

is guided by the level of risk involved in the research, in addition to whether the research involves children, young adults or adults. There is a need for research ethics committees in Africa to learn how to balance individual autonomy with that of the community, especially for research involving young adults and adults.

5.5 RECOMMENDATIONS FOR POLICY AND PRACTICE

This study recommends a change in the approach of validating the process of informed consent by the research ethics committees in Africa from the emphasis on individual autonomy to a more flexible position that will respect the community. Community respect should be evaluated for every research study that is conducted in Africa and the level of community engagement should be determined, based on the level of risk associated with the research and the targeted audience involved in the study before such research protocol can be approved by the ethics committee. This is basically because decision-making as determined by this study could be graduated depending on the circumstances of the research.

5.6 LIMITATIONS OF THE STUDY

This study was limited in that the researcher had limited access to some of the papers that were recruited for the study and could only extract the intended code used in the study from the abstract. Another limitation was the fact that only papers that were published in the English language were recruited for the study and, considering the diversity of language in Africa as a continent, other important publications might have been missed because the keywords could not capture and recruit them in the study. This study also limit it scope to issues around research ethics.

5.7 RECOMMENDATIONS FOR FURTHER RESEARCH

This study recommends the following:
- There is a need for similar review in other languages to bridge the existing gap in this study.
- There is also a need to study and determine the level at which potential research participants will consult others to participate in a research study, depending on the type and degree of risk.
- Studies should be conducted to determine the extent to which members of research ethics committees can recommend community engagement as a condition to approve

a study protocol and the degree at which they would prefer engagement to occur for the different types of research.

- There is a need to track global recognition of community engagement and share decision-making as an appropriate means to conduct the process of informed consent.

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APPENDIX

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18 April 2017

Mr Nchotou Ndimuangu
Applied Human and Social Sciences
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nchotoundimuangu@gmail.com

Dear Mr Ndimuangu

Title: Systematic Review of African Bioethics Framework: Conception of person-hood and its influence in improving the process of informed consent.
Degree: Masters
BREC REF NO: EXM228/17

I refer to your application to BREC received on 30 March 2017 and wish to advise that exemption of ethics review is granted for the above study.

This exemption will be noted at the Biomedical Research Ethics Committee meeting to be held on 09 May 2017.

Yours sincerely

Professor J Tsoka-Gwegweni
Chair: Biomedical Research Ethics Committee

cc: supervisor: mkhizeg@ukzn.ac.za