

# Culture, Actors, and Resources Surrounding Undergraduate Bioethics Education in Sub-Saharan Africa

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## **Abstract**

Scientisation is a growing trend as individuals worldwide harness scientific tools and knowledge to solve problems. This phenomenon is evident in biomedical research, which has increased across sub-Saharan Africa, and when encountering bioethical issues arising during the course of such research. This research synthesis considers how the constructs of culture, actors, and resources in the region shape undergraduate bioethics education. Using a lens of sociological neo-institutionalism, taken-for-granted bioethical scripts, like informed consent and medical confidentiality, are evident in this education; however, actual implementation demonstrates the way they are often adapted and contextualised, with implications for students and instructors, and ultimately patients and research participants. The education considered is that for undergraduates in health sciences and medicine because they are prominent actors in research and clinical practice across the region. In considering insights from this literature, the aim is to positively impact health across sub-Saharan Africa.

**Key words:** biomedicine, scientific research, ethics, African Studies, higher education, Acquired Immunodeficiency Syndrome

Le phénomène de scientification est de plus en plus répandu : partout dans le monde, les individus s'emparent des outils et connaissances scientifiques pour résoudre des problèmes. C'est particulièrement visible dans le domaine de la recherche biomédicale, qui se développe dans toute l'Afrique subsaharienne, et lorsqu'on considère les questions bioéthiques qui se posent au cours des dites recherches. La présente recherche explore la façon dont les concepts de culture, d'acteurs et de ressources dans la

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région influencent l'enseignement de la bioéthique durant le premier cycle universitaire. A travers le prisme d'un néo-institutionnalisme sociologique, on constate que les écrits fondateurs de la bioéthique, tels que le consentement éclairé et le secret médical, sont des composantes évidentes de cet enseignement. Cependant, leur mise en œuvre sur le terrain révèle que ces principes sont souvent adaptés et contextualisés, ce qui a des conséquences pour les étudiants, les formateurs et à terme les patients et les personnes qui participent aux recherches. Cet article se concentre sur l'enseignement du premier cycle universitaire dans les domaines des sciences de la santé et de la médecine, qui sont des acteurs incontournables de la recherche et de la pratique clinique dans la région. En prenant en compte les apports de la littérature, l'objet de cette recherche est d'avoir un impact positif sur le secteur de la santé en Afrique subsaharienne.

Mots clé : biomédecine, recherche scientifique, éthique, études africaines, enseignement supérieur, syndrome d'immunodéficience acquise

### **Introduction**

Science, including biomedical research, is increasingly regarded as a way to improve the life circumstances of people worldwide, especially since World War II (Schofer, 1999). Marked by increased confidence in human abilities to comprehend the natural world and subsequently solve problems, this phenomenon is known as scientisation (Drori and Meyer, 2006; Schofer, 1999).

Sub-Saharan Africa has seen an increase in biomedical research, due in part to the prevalence of HIV/AIDS (Griggins, Simon, Nakwagala, and Pentz, 2011) but also because of the continent's tremendous resources. For example, the region's inhabitants are knowledgeable in traditional and complementary/alternative medicines (World Health Organization, 2003), while cutting edge research is conducted in laboratories at its universities and research centres. Genetics researchers are also drawn to sub-Saharan Africa due to their interest in investigating the human genome and building a database of genomic material to study population history and genetic links to disease (Adebamowo, 2007).

Unfortunately, however, research involving sub-Saharan Africa is often cited as demonstrating the "10/90 gap", referring to figures indicating that less than 10 percent of health research spending across the globe pertains to 90 percent of the world's diseases (Global Forum for Health Research, 2000). In many African countries, Acquired Immunodeficiency Syndrome (AIDS), malaria, and sleeping sickness are of much more imminent concern than the diseases researched, often by Western researchers (Mbũgua, 2009; World Bank and Elsevier, 2014). This calls for African

researchers to become more involved in setting the continent's biomedical research agenda.

Bioethical issues arise in the course of biomedical research. Originating in the early 1970s (Engelhardt, 1999; Reich, 1995), the term *bioethics* has given rise to a field which includes policies, organisations, and curriculum, instructing and informing on the topic to exemplify scientisation. Examples of policy include international documents such as the *Declaration of Helsinki* and the United Nations Educational, Scientific and Cultural Organization's (UNESCO) *Universal Declaration of Bioethics and Human Rights* as well as national policies such as Nigeria's *National Code for Health Research Ethics*. Organisational examples include national bioethics committees (NBCs), institutional review boards (IRBs), and research ethics committees (RECs) that are found worldwide, including in sub-Saharan Africa, and guide the formulation and regulation of health and science policy as well as provide a forum for discussion of bioethical topics (Bogner and Menz, 2010; Herrmann, 2010). Curriculum related to bioethics is available at international, national, and university levels and is presented to both graduate students and undergraduates.

A wide body of literature focuses on fellowships and degrees offered at the graduate level. This article focuses on the bioethics curriculum presented at the undergraduate level. Such a focus is especially important in sub-Saharan Africa as many health sciences students do not go on to pursue graduate degrees (Kirigia, Wambebe, and Baba-Moussa, 2005). Furthermore, they often work in more remote areas where they are seen as authorities by those around them (Kirigia et al., 2005).

### **Theoretical Framework**

In the field of bioethics, bioethics structures in the form of NBCs, IRBs, and RECs, represent institutionalised action to address issues arising in the course of research and are currently found at national and institutional levels worldwide. The United States convened its first NBC in 1974 (US Department of Health and Human Services, n.d.), and most Organization for Economic Cooperation and Development (OECD) countries followed throughout the 1990s with at least 26 of its 30 members having national committees in place by 2002 (Syväterä and Alasuutari, 2013). Rwabihama, Girre, and Duguet's (2010) study noted that most of the committees formed in sub-Saharan Africa emerged between 1974 and 2003. However, the authors recorded different years of "continuous establishment" for many of these committees (p. 244). These dates, mostly after the year 2000, marked when study participants perceived the committees as closer to "full functioning," demonstrating more consistent activity (Rwabihama et al., 2010, p. 244).

A number of theoretical frameworks are used in the literature to explain the global spread of these committees. Two of these, functionalism and realism, are considered for sub-Saharan Africa in the sections which follow before turning to sociological neo-institutionalism, the lens applied in this research synthesis.

### **Functionalism**

Functionalists frame these committees' creation as a lever established to address scandals arising in the course of biomedical research and to, therefore, protect citizens (Sylväterä and Alasuutari, 2013). The committees are granted legitimate powers to work proactively to circumvent public harm by examining, debating, and influencing policy surrounding biomedical research (Salter and Salter, 2007). In the case of sub-Saharan Africa, a number of bioethical scandals occurred or have been uncovered since 2000 (see Barnett, 2004; Chang, 2003; IRIN, 2005; Stephens, 2006; Tangwa and Munung, 2011), coinciding with full functioning since then. However, a functionalist lens ignores the longer organisational history of these committees well before 2000.

### **Realism**

Realists focus on nation-states as primary actors, with outside influences pressuring them to enact certain policies (Arnove, 2009; Langlois, 2013; Sylväterä and Alasuutari, 2013). Most funds for clinical research in Africa come from government or charitable sources outside the continent (Horn, 2014). Furthermore, global pharmaceutical companies have been top research collaborators for sub-Saharan Africa in recent years (World Bank and Elsevier, 2014). External funding is generally contingent on regulatory compliance (Horn, 2014). An example of a compliance mechanism is the International Conference on Harmonisation (ICH)'s Good Clinical Practice (GCP) E6 Guideline, published in 1996 (Karlberg, 2010), which explains the operations, structure, and function of NBCs. An ethical and scientific quality standard, GCP has been recognised internationally as a sign that participants in experimental trials are properly treated in terms of their rights and overall well-being (Karlberg, 2010).

Nation-states experience the international pressure of regulations such as the GCP to guide the formation and work of NBCs/IRBs/RECs. While such committee approval was required by the *Declaration of Helsinki* as early as 1975, the ICH GCP E6 Guideline was particularly influential in its specification that clinical trial data obtained in one location, in compliance with the E6 Guideline, could support new drug applications elsewhere (Karlberg, 2010). This specification represents significant pressure on sub-Saharan African countries to comply both from the perspective of

long-term national gains and a sense of outside coercion.

Realists might view the reinvigoration of bioethics committees in sub-Saharan Africa as a response to the adoption of the E6 Guideline. By agreeing to this step, the region could benefit from research that benefits citizens from both a health and financial standpoint; it could also agree to the entry of outside researchers anxious for the opportunity to conduct research and, subsequently, profit. However, as in the case of functionalists, it is difficult for these theorists to explain the initial founding dates beginning in the 1970s, well before the ICH's GCP E6 Guideline was in place.

### **Sociological Neo-institutionalism**

As noted earlier, the field of bioethics exemplifies the phenomenon of scientisation. NBCs/IRBs/RECs are one of the institutional mechanisms through which scientisation occurs. Committee members and healthcare workers exemplify this phenomenon at an individual level.

Sociological neo-institutionalism provides a lens to consider a phenomenon like scientisation (see Jepperson, 2001; Krücken, 2002; Meyer, Boli, Thomas, and Ramirez, 1997). This is a more appropriate lens to frame the structural isomorphism seen in committee organisation globally as well as in sub-Saharan Africa and subsequent inactivity by the region's committees early in their establishment. Sociological neo-institutionalism expects actors to approach societal problems following similar scripts (Boli and Thomas, 1999), including examination of bioethical issues through committee deliberations and preparation to weigh these challenges through education. Legitimacy-seeking through the employment of such globally recognised scripts is also expected in sociological neo-institutionalism (Boli and Thomas, 1999); hence the efforts to convene bioethics committees globally from the 1970s to 2000 and the availability of bioethics curriculum from international, national, and local entities to educate individuals in this area. At the same time, sociological neo-institutionalism can account for situations of de- or loose coupling, seen in broad adoption across contexts worldwide that is quite often observed to be incomplete or variable when a closer look is taken at local implementation (Meyer et al., 1997; Suarez and Bromley, 2014).

Among sub-Saharan Africa's bioethics committees, this is evident in their lack of funding and a lack of capacity-building for their members following formation. Participants in Rwabihama et al.'s 2008-2009 study (2010) noted a lack of consistency in committee activity after initial creation. Even after respondents perceived the local IRBs/RECs as more fully functioning, the data demonstrated continued inaction to protect national interests (Rwabihama et al., 2010). The study found that members had

not rejected a single research protocol, met regularly, followed up during the course of clinical trials, or issued reports (Rwabihama et al., 2010). Another study of 31 RECs across sub-Saharan Africa found that 38 percent of committee members had no training (Nyika et al., 2009). As of 2013, inattention to material transfer agreements by these committees remained a challenge despite the growing need for the region to address this issue (Chima, Mduluzza, and Kipkemboi, 2013). The need to protect citizens did not seem to be reflected in effective implementation, capacity-building, or funding for committee-level actors. Yet, legitimacy was and continues to be granted to nations by the mere existence of these committees, despite a specific local impetus or, in some cases adequate resources to prepare members for action (see also Salter and Salter, 2007; Syväterä and Alasuutari, 2013).

If the situation regarding NBCs/IRBs/RECs described by Chima et al. (2013), Nyika et al. (2009), and Rwabihama et al. (2010) is to be improved, it is helpful to capture the way undergraduate education pertaining to bioethics prepares those working as healthcare providers, researchers, and committee members. A research synthesis is useful to gain insight into these areas.

### **Research Purpose**

To capture this information, this research synthesis applies a sociological neo-institutional lens to ask: *How do the culture, actors, and resources in and around sub-Saharan Africa's higher education institutions shape bioethics education?* For the purposes of this synthesis, the culture of bioethics in sub-Saharan Africa reflects the philosophy of *Ubuntu* to a large extent, due to the large Bantu population across the region. The context is that of sub-Saharan Africa's higher education institutions and the actors include undergraduate medical and health sciences students and the university faculty who teach them. These constructs are impacted by global and national scripts that promote certain bioethical approaches and ideas and offer legitimacy through their acceptance. The literature also suggests, however, that the culture, context, and actors themselves challenge the absolute legitimacy of these scripts for bioethics education in sub-Saharan Africa's higher education, thereby leading to de- and loose coupling at the level of implementation.

### **Limitations**

While the literature search on bioethics covered the entire region, the specific examples that were found mainly focused on Malawi, Uganda, and Nigeria. Future research should elicit information directly from individual university bioethics programmes, especially in other areas of sub-Saharan

Africa, in order to more fully elucidate the situation of bioethics education across the region.

### **Methodology**

Literature searches were undertaken between December 2014 and March 2015 using PubMed and Google Scholar and combinations of the key words, *Africa*, *bioethics*, *research ethics*, *education*, and *undergraduate*. The researcher focused on articles published between 2011 and 2015 in order to reference more recent literature on bioethics education and to better understand the education of recent graduates. Article bibliographies augmented the research synthesised here.

While the definition of bioethics has historically included both biomedical and environmental foci, “biomedically-oriented bioethics” is considered here (Reich, 1995, pp. 20, 22). *Research ethics* was used as a search term because these issues often arise during biomedical research. In less industrialised countries in particular, both research ethics and clinical ethics are important as biomedical research is often carried out by individuals that also conduct clinical care (Griggins et al., 2011).

Each article was scanned to ensure relevance to the constructs of culture, actors, and resources. For example, medical education in sub-Saharan Africa commences at the undergraduate level and these students are referred to as *medical students* rather than *undergraduates*. The keyword *Africa* yielded results pertaining to both sub-Saharan Africa and South Africa. Sub-Saharan Africa was selected, excluding South Africa and Northern Africa, for the research synthesis for two reasons. Firstly, according to a 2014 World Bank and Elsevier report, South African research indicators tend to deviate from those of the rest of Southern Africa in terms of infrastructure, output, and quality performance. Secondly, the “African ethics” considered here is mainly shared by the Bantu people of sub-Saharan Africa, rather than groups like the Islamic Arabic population found in Northern Africa and white Afrikaners in South Africa (Metz, 2007).

### **Constructs Emerging from the Research Synthesis**

The culture, actors, and resources present in and surrounding sub-Saharan Africa’s higher education institutions impact bioethics education in terms of subject matter and delivery. To determine the influence of these constructs, each is examined in turn.

### **The Cultural Environment of sub-Saharan Africa’s Higher Education Institutions**

Bioethics and existing bioethics training is impacted by the environment in which it is situated. Many of the characteristics of African culture

stem from the large population of Bantu people in the region and their philosophy of *Ubuntu* (Ndebele, Mfutso-Bengo, and Masiye, 2008). Characteristics marking the Bantu philosophy, including hierarchy and obedience, communalism, diversity within the Bantu community, and a preference for consensus over democratic deliberation, were referenced in the literature.

*Hierarchy and CUSTOMARY obedience:* A tradition of hierarchy and customary obedience is common in sub-Saharan Africa, with elders protecting those that are younger who, in return, show loyalty, respect, admiration and deference to them (Irabor and Omonzejele, 2009). Elders in the family or community have influence even in healthcare decision-making, at times contradicting patients' wishes (Matheson, 2009). Doctors are seen in the same light as elders, often rendering the consent process more ritualistic than practical (Irabor and Omonzejele, 2009). Such attitudes were noted in studies at Makerere University College of Health Sciences (MakUCHS) in Uganda and the University College Hospital in Nigeria and led doctors to adopt an air of superiority (Baingana et al., 2010; Irabor and Omonzejele, 2009). The result is often acceptance of the doctor's advice without questions or a second opinion (Baingana et al., 2010).

*COMMUNALISM:* The autonomous aspect of the consent process and medical confidentiality encounters a number of difficulties in sub-Saharan Africa (Irabor and Omonzejele, 2009). Family, including those of an individual's community and religion, educate themselves about an illness as they are a part of healthcare decision-making and, potentially, payment (Ndebele et al., 2008). Consequently, in an African setting, informed consent and confidentiality may involve community approval, followed by individual consent (Mfutso-Bengo and Masiye, 2011). Approval from chiefs or heads of villages is not meant to replace individual informed consent but to adapt to the context (Mfutso-Bengo and Masiye, 2011).

*Diversity:* Despite an overarching philosophy of *Ubuntu*, the setting for this research and care is a continent of great diversity in terms of language, ethnicities, and religions (Adebamowo, 2007; Griggins et al., 2011; Irabor and Omonzejele, 2009; Ndebele et al., 2008). Different colonial histories also resulted in a variety of cultural, administrative, philosophical, and social influences (Adebamowo, 2007). Values and beliefs on bioethical topics such as sexuality, birth control, substance abuse, and death vary among patients and healthcare workers (Griggins et al., 2011).

Comprehension of the informed consent process, including patients' understanding of what they are consenting to, is another consideration. At the most basic level, this means that interactions with a patient must be conducted in language s/he understands and s/he should be able to grasp the meaning of explanations, even though her/his culture may be unfam-

miliar with certain medical ideas or biological views of the human body (Matheson, 2009).

*Preference for consensus:* In classrooms and workplaces, effective discussion of ethical issues occurs when individuals discuss issues, confident that their voice counts, regardless of age, expertise, gender, or socio-economic status (Griggins et al., 2011). Given the cultural characteristics discussed above, this type of interaction may be challenging or unfamiliar (Griggins et al., 2011; Mfutso-Bengo and Masiye, 2011).

A positive example in the literature of such interaction in sub-Saharan Africa is a discussion on homosexuality in a Ugandan bioethics training workshop conducted with United States (US) and Ugandan faculty collaboration (Griggins et al., 2011). In Uganda, homosexuality is widely condemned, including by faculty and healthcare providers, while in the US it is often seen as a human rights issue (Griggins et al., 2011). The opportunity to discuss this issue with others of varying, and often polar opposite views, was found to be of tremendous value (Griggins et al., 2011).

### **Undergraduates, Faculty, and Curriculum Providers at sub-Saharan Africa's Higher Education Institutions**

Given that most health sciences undergraduates in Africa do not pursue higher level degrees (Kirigia et al., 2005), it is crucial to include bioethics and research ethics in their curriculum. Most will work in rural regions and be regarded as authorities based on their degrees, and they will bear much responsibility for the welfare of research participants (Kirigia et al., 2005). According to the *Scopus* abstract and citation database, health sciences research accounts for 45 percent of sub-Saharan Africa's total research output, with global pharmaceutical companies the top collaborators between 2003 and 2012 (World Bank and Elsevier, 2014).

Bioethics education for health sciences undergraduates thus has the potential for frequent application. It is imperative that this education includes both research ethics and clinical ethics as, in less industrialised countries, biomedical research is often carried out by those that are also involved in clinical care (Griggins et al., 2011). The following sections discuss the literature on how bioethics curriculum is presented through both formal and informal means, live in the classroom or online.

*FORMAL CURRICULUM:* The formal curriculum is considered and planned to impart knowledge in very intentional ways (Hafferty, 1998). In bioethics, formal curriculum may originate from the international level as in UNESCO's bioethics education campaign. UNESCO has approached capacity-building at the university level using four means: a Core Curriculum designed as a starting point for universities' own curriculum planning, appointed university chairs in bioethics, an Ethics Teacher Training Pro-

gramme, and the *Global Ethics Observatory (GEObs)* database, covering multiple areas of applied ethics and designed to facilitate networking (Lan-glois, 2013; Mathooko, 2013; ten Have and Ang, 2007).

At university level, the literature referenced the formal bioethics curriculum of two higher education institutions, MakUCHS in Uganda (Baingana et al., 2010) and the University of Malawi College of Medicine (Mfutso-Bengo and Masiye, 2011). Case studies, lectures, role playing, and clinical experiences are used to teach topics including confidentiality, informed consent, and doctor-patient interactions (Baingana et al., 2010). At the University of Malawi College of Medicine, formal compulsory biomedical ethics curriculum extends for the entire five years of training (Mfutso-Bengo and Masiye, 2011; Muula and Mfutso-Bengo, 2007).

Online training is also used to educate students on bioethics, offering many advantages, including flexibility, adaptability, interactive options, and real world problem-solving (Fordis et al., 2005; Horton, 2000). Training on Nigeria's *National Code for Health Research Ethics (NCHRE)* includes online modules that are uploaded to the Collaborative Institutional Training Initiative (CITI) website and are accessible through the West African Bioethics Training Program institutional portal (Ogunrin, Ogundiran, and Adebamowo, 2013). These modules were designed to work alongside those already developed by CITI (Ogunrin et al., 2013), which is based out of the University of Miami, US (Collaborative Institutional Training Initiative, n.d.).

These modules are examples of the many programmes originating in North America, Africa, and Europe which are active in online bioethics training (Williams et al., 2014). The involvement of groups outside the setting where the education and training will be applied highlights a consideration in the choice of any bioethics curriculum: *Does the curriculum accurately address the context in which graduates will work?*

The literature warns of two pitfalls of importing curriculum from outside the continent. The first is the imposition of often Western ethical views that do not represent or apply to Africa (Anderson and Giordano, 2013; Matheson, 2009). A second issue is inaccurate representation of contexts that are very different from those in North America and Europe (Griggins et al., 2011).

The literature highlights the way in which developers of online training have addressed this issue. Working with African faculty already involved in research ethics training, the African Malaria Network Trust (AMANET) developed modules contextualised for Africa, including Africa-specific, real world cases (Chilengi et al., 2013). A Ugandan training workshop included faculty from both Uganda and the US. However, only US faculty knowledgeable in African culture and Ugandan healthcare was recruited

and those chosen visited facilities in the country prior to the workshop. Furthermore, only Ugandan case examples were presented. Despite the inclusion of US leaders, the workshop participants indicated that the materials were highly applicable to their working environments, and the inclusion of US experts was ultimately determined to be a strength (Griggins et al., 2011).

Professionalisation of bioethics is further indicated in the testing that accompanies coursework, implying possible mastery of a subject that is often highly emotional and subject to compromise (Salter and Salter, 2007). While multiple-choice questions are found in online methods, essays and open-ended questions characterise assessment within university classrooms (Taylor et al., 2012). With adequate scores, university requirements are fulfilled, certificates are granted, and a bioethics degree may even be earned.

*INFORMAL CURRICULUM:* The informal curriculum of higher education, including bioethics, incorporates interactions between faculty and students (Hafferty, 1998). The literature points to weaknesses in informal bioethics curriculum for sub-Saharan Africa, resulting from past and current gaps in faculty members' own training and healthcare delivery resources. In developing countries in particular, the setting greatly impacts the behaviour modeled to students (Baingana et al., 2010).

The literature notes that, in sub-Saharan Africa, faculty who mentor often lack research experience themselves (Derbew, Animut, Talib, Mehtsun, and Hamburger, 2014; Nakanjako et al., 2011). Faculty is often overextended and burdened with clinical, teaching, and administrative tasks (Nakanjako et al., 2011). Simultaneous training of faculty and students in research methods is one of the ways identified to address this, as well as enhanced research support infrastructure, including IRBs (Derbew et al., 2014).

Training specifically dedicated to mentoring has also been documented (Nakanjako et al., 2011). A study at MakUCHS noted a lack of mentoring institutionalisation at university level, reflected in time constraints, poor logistical support, and insufficient funding (Nakanjako et al., 2011). Furthermore, it was noted that the mentor-mentee relationship often focuses on academic support, without coverage of bioethics, research, and professionalism (Nakanjako et al., 2011).

The literature also highlights the importance of role models to enhance students' understanding of the informed consent process in healthcare. In medicine, a chain of teaching occurs, with residents, who work under the guidance of consultants, teaching medical students (Irabor and Omonzejele, 2009). However, the literature notes that consultants rarely obtain informed consent themselves, rendering it unlikely the process is modelled to residents (Irabor and Omonzejele, 2009). In turn, residents are

often ill-equipped to explain medical complications and alternative treatments during the informed consent process (Angelos, DaRosa, Bentram, and Sherman, 2002). Given that medical students learn from these role models, an ineffective informed consent process is perpetuated (Irabor and Omonzejele, 2009).

### **Resource Availability around Sub-Saharan Africa's Higher Education Institutions**

Another theme in the literature is how resource availability, including for healthcare and information and communication technology (ICT) used in training, impacts bioethics education.

*Healthcare delivery resources:* The literature recognises the effect of healthcare delivery resources on the choices available to faculty, undergraduates, and providers. Health insurance is generally not a feature of sub-Saharan Africa's healthcare delivery infrastructure, and treatments such as antiretrovirals are expensive for patients (Ndebele et al., 2008). The definition of family in this region often extends to those in the community and of the same religion, and these family members often assist in paying for care (Ndebele et al., 2008). This presents dilemmas for the bioethical notions of informed consent and medical confidentiality, affecting the way that health science workers in sub-Saharan Africa should frame their approach.

Physical resource gaps also affect student understanding of bioethical approaches. Students at MakUCHS felt that bioethical exceptions were necessary in light of their situation at MakUCHS/Mulago National Referral Hospital where high patient volumes and supply shortages have been issues (Baingana et al., 2010). For example, screens were used to allow more private patient-doctor interaction, but these were not always available. Glove shortages occurred at times, requiring doctors to use the same gloves on multiple patients (Baingana et al., 2010). Preparation for working within such constraints is an important aspect of undergraduate training and may be overlooked in curriculum adopted from more resource-rich settings.

*ICT availability:* While bioethics policies and training materials may be available online, they are only useful if they are accessible. Computer and internet access remains prohibitively expensive and unreliable for many, marked by inability to support high volumes of users, address security concerns, and provide technical assistance (Kennedy et al., 2006). While appreciating its potential, users of the online NCHRE module encountered technical difficulties that in some cases hindered training (Ogunrin et al., 2013). Studies of MakUCHS undergraduate students (Baingana et al., 2010), participants that took part in the online NCHRE training (Ogunrin et al., 2013), and participants in capacity-building to protect human subjects at the University of Liberia (Kennedy et al., 2006) pointed to the difficulty

of accessing bioethics codes and documents, whether hard copies or electronic versions.

### **Discussion**

This research synthesis began by employing a sociological neo-institutional lens to consider scripts pertaining to bioethics, an area exemplifying the phenomenon of scientisation, and NBCs/IRBs/RECs in sub-Saharan Africa. The global spread of such committees from the 1970s to the year 2000 reflects national and institutional legitimacy-seeking in the area of bioethics. However, their operation in sub-Saharan Africa also exhibits decoupling. The synthesis of the literature on bioethics education using a lens of sociological neo-institutionalism, presented below, brings to light the scripts, legitimacy-seeking, and de-/loose coupling during preparation of undergraduates in their roles as providers, researchers, and members of these committees.

### **Scripts**

As elsewhere, across the constructs of culture, actors, and resources, informed consent and medical confidentiality are found to be taken-for-granted bioethical scripts throughout sub-Saharan Africa. Sexuality, birth control, substance abuse, and death arise in the realm of bioethics for the region as they do worldwide.

### **Legitimacy-seeking**

Legitimacy-seeking is evident in universities' adoption of capacity-building measures, including curriculum development tools and faculty training, offered by, for example, UNESCO, with its widely recognised reputation in education and science. Alternatively, universities are also found to adopt curriculum directly, such as that provided by CITI. Student learning through interactions with faculty, as occurs in mentoring, is a widely utilised means of training for healthcare careers during university, including in sub-Saharan Africa (Hafferty, 1998). Furthermore, legitimacy may be granted at the individual level when students earn certification and degrees in the area of bioethics or faculty are recognised, as through UNESCO appointments of university chairs in bioethics or completion of the Ethics Teacher Training Programme (Langlois, 2013; Mathooko, 2013; ten Have and Ang, 2007).

### **De- or Loose Coupling**

The literature shows that these scripts and legitimacy-seeking actions demonstrate changes and contextualisation as they are implemented and encountered across sub-Saharan Africa. Cultural characteristics, particu-

larly the Bantu philosophy of *Ubuntu*, and healthcare resources, like the absence of widely available health insurance, result in informed consent often being ritualistic, with little patient questioning of doctors, and medical confidentiality is challenging to maintain (Baingana et al., 2010; Irabor and Omonzejele, 2009). Patient characteristics, including their home language, emerge as important considerations (Adebamowo, 2007; Griggins et al., 2011; Irabor and Omonzejele, 2009; Ndebele et al., 2008). A wide spectrum of perspectives on sexuality, birth control, substance abuse, and death is frequently encountered due to cultural, administrative, philosophical, and social influences (Adebamowo, 2007), meaning that different decisions might have to be made and options offered depending on the individuals involved.

Rather than adopting curriculum in its entirety, the development of training, such as the online module developed and contextualised for Africa by AMANET as well as the criteria for US participants in workshops in Uganda, demonstrates adjustments which make it an applicable and effective resource for sub-Saharan Africa. In contrast, mentoring during clinical experience presents several challenges to bioethics education in this region. These are related to the actors themselves, as faculty face gaps in their own training and their job requirements are expanded (Derbew et al., 2014; Nakanjako et al., 2011). They are also related to the healthcare resources available, for example, to maintain doctor-patient confidentiality (Baingana et al., 2010). Universities across the region have identified obstacles in implementing online instruction due to ICT constraints. As a result, online curriculum may be expensive, cumbersome, and even impossible to utilise.

## Conclusions

Sub-Saharan Africa is an important actor in and site for biomedical research and consideration of the bioethical issues that arise. Bioethics exemplifies the phenomenon of scientisation. Understanding the scripts adopted, the legitimacy-seeking actions taken up, and incidents of decoupling is important and can be accomplished by applying a lens of sociological neo-institutionalism. This lens is helpful in elucidating the bioethics education of those in the field of healthcare and biomedical research, who are integral to patient outcomes, and curriculum developers, regardless of their location, who are contributing to future instruction in the region.

As noted previously, increased biomedical research in sub-Saharan Africa, and consequently attention to bioethics, has been attributed in part to the HIV/AIDS epidemic. The way in which sub-Saharan Africa has come to combat this epidemic demonstrates that understanding what is actually implemented and the obstacles faced can lead to contextualisation, includ-

ing for bioethics education, and, ultimately, better outcomes for patients. Healthcare initiatives for those affected by HIV/AIDS have been tested over time, with healthcare providers in sub-Saharan Africa adapting certain bioethical principles like informed consent and medical confidentiality based on what works for the region. For example, research shows that levels of adherence to treatment are higher in sub-Saharan Africa when communal approaches are considered and the family is kept informed about the patient (Ndebele et al., 2008). Patient alienation occurs when doctors impose tight restrictions on sharing information with families (Ndebele et al., 2008). Doctors are now more willing to include patients' families, even if the patient opposes this (Baingana et al., 2010; Ndebele et al., 2008). Home visits, especially for patients in rural areas with less access to transportation, are found to be viable treatment alternatives, despite privacy concerns (Matovu, Kigozi, Nalugoda, Wabwire-Mangen, and Gray, 2012).

By pointing to the ways certain changes in HIV/AIDS treatment, including taken-for-granted scripts like informed consent and medical confidentiality, positively influence healthcare outcomes, the literature exhibits the adaptations made in light of the sub-Saharan African context. The aim of this research synthesis is to similarly affect health in a positive way through undergraduate education in bioethics.

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