

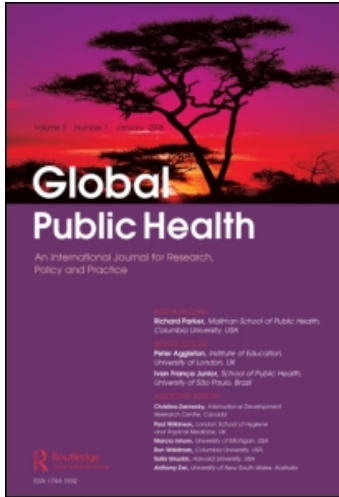
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Okukkerá Ng'omuzungu (lost in translation): Understanding the social value of global health research for HIV/AIDS research participants in Uganda

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As major global governance entities begin to re-assess the structure and goals of health research in resource-poor settings, social science can make a vital contribution by expanding the traditional field of research ethics to include new concepts such as the *social value* of global health research. This essay recasts the definition of social value in health research by shifting away from the official spaces where research occurs and towards the meaning of research as it is produced in the everyday spaces inhabited by the local community. We present three cases that reveal the local view of the social value of health research for Ugandans: autonomy and consent; the concept of risk; and what appears to be a classic case of therapeutic misconception between researcher and informant. Ultimately what we see, we argue, is the fundamental collision of the logic of biomedical research with the logic of local social relationships, that is, researchers perform their role as a transaction, while participants anticipate their involvement in research to be transformative. When we expand the analysis of the impact of research from the research/participant dyad to shifting community networks, we conclude that didactic models, such as the therapeutic misconception, are of limited utility for understanding the social value of global health research in resource-poor settings.

Keywords: Uganda; HIV/AIDS; global health research ethics; social value; risk and consent; therapeutic misconception

Introduction

As major global governance entities begin to re-assess the structure and goals of health research in resource-poor settings (Bamako 2008), social science can make a vital contribution by expanding the traditional field of research ethics to include new concepts such as the *social value* of global health research. In a widely cited paper, Emanuel *et al.* (2004) suggest eight benchmarks for assessing the values and ethics of externally funded clinical research in the developing world. While most of these benchmarks focus on technical issues related to clinical research, one surprising benchmark, social value, is introduced among such familiar research principles as informed consent, risk–benefit ratio and selection of study participants. According to the paper, the social value of clinical research is enhanced when researchers are

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attentive to beneficiaries of research findings, develop collaborative partnerships to disseminate research findings in the community, and attempt to integrate research results into the local health-care delivery system. Similarly, Lairumbi *et al.* (2008) argue that improving collaborative partnerships in health research can maximise social value, and Lavery *et al.* (2007) recommend a critical examination of the norms of multinational health research and call for a new ‘mutual aid principle of clinical research’.

This is good news for communities where the deployment of medical research often sets in motion significant and unexpected economic and social changes. However, these authors are vague in their definitions of social value. They restrict the concept of social value to the functional aspects of the partnership between researcher and community, or to the potential health outcomes of the research study itself. This is well within the current practices of biomedical research, where social interactions between researcher and participant are narrowly defined and the possibilities for creating value are restricted by standardised, pre-determined benefits, such as equipment, training and medication. Finally, there is little recognition that research itself is a cultural activity embedded in a broad set of social relationships, some explicit, some less so. Anthropologist Marilyn Strathern (2006) writes that research is neither defined nor controlled by either the scientist or the community, and she suggests that the problems of equity in research run deeper than merely improving the terms of collaboration. It is simply good science, she argues, to want to define how the culture of research unfolds beyond regulations in the everyday world.

Defining social value in the context of global health research

This paper will attempt to define and understand the social value and ethics of global health research beyond rule-bound practices and calculations of material benefits. For example, the source and scope of funding for global health research has a significant impact on how people experience health research in their everyday lives. Health-related aid to Uganda as a percentage of gross domestic product (GDP) increased from 8.2 to 13.3% over the past decade (Okidi and Guloba 2007). For the period 1990–1997, health research in Uganda totalling 12 million USD was approved, virtually all of it funded by external sources (Uganda National Health Research Organisation 2000, p. 19). Uganda is a signatory to the Africa Public Health Rights Alliance 15% Now Campaign which binds the country to allocate at least 15% of its national budget to health; Uganda has increased the percentage of its national budget allocated to health from 11.6% in 2003 to a target of 13.2% in 2009 (Uganda Ministry of Health 2005, p. 101, see also Burke and Matlin 2008). Therefore, rural Ugandans are as likely to encounter ‘global health’ through research and externally funded health interventions than through ‘normal’ government-sponsored health care.

We can expand the definition of social value by shifting away from the official spaces where research occurs and towards the meaning of research as it is produced in the everyday spaces inhabited by the local community. A few social scientists, most working in Africa, are examining these questions (Molyneux *et al.* 2005, Fairhead *et al.* 2006). Ours is a collaboration between an American medical anthropologist and a Ugandan physician/HIV/AIDS researcher (Sewankambo *et al.* 2000; see also Kapp 2008). When considering social interactions between people, for example, the

dyadic relationship between researcher and informant or researcher and larger networks of kin relations, both are changed by the presence of a significant research project in the community and the participation of a family member in research. New questions crop up for researchers: What do informants talk about as valuable in their participation in research? How does informant understanding of research and motivations for participation change with long-term participation in clinical trials? How are local social networks disrupted when significant external resources change the balance between local social roles and community responsibilities? On this last question, we observed that members of community advisory boards (CABs) had difficulty reconciling their ambiguous status as mediators triangulating between the community, research participants and scientists with their pre-research role as trusted community leader. In this context, then, the creation of social value associated with health research was a complicated iteration of the CAB member balancing existing community expectations of trust and reciprocity with new professional responsibilities related to research protocols and project rules. In three extended examples below, we discuss the Ugandan view of autonomy and consent, the local concept of risk and what appears to be a classic case of therapeutic misconception between researcher and informant. Ultimately what we see, we argue, is the fundamental collision of the logic of biomedical research with the logic of local social relationships; researchers perform their role as a transaction, while participants anticipate their involvement in research to be transformative.

Study description

The study ($N=102$) described here offers one of the first rigorously designed and sampled, in-depth qualitative studies on the ethics of health research in Africa from the perspective of the individual research participant. Uganda is an especially rich place to explore this issue because HIV/AIDS in Africa was first identified there (Serwadda *et al.* 1985), and the country has the longest on-going national HIV/AIDS sero-prevalence and community-based intervention studies of any country in Africa (Uganda AIDS Commission 2001). AIDS vaccine trials began in Uganda in 2000, and the evidence for one of the most widely adopted behavioural interventions, the contested A–B–C approach, originated there. Our project explores many themes related to the experience of participation in intensive health research, for example: opinions of the value of research; motivation and preparation for participating in research; actual experiences of participating in research; comprehension of the consent process; local definitions and concepts of consent, risk, individual autonomy and benefits; and perspectives on the ethics of research. However, this paper will present only a small subset of the results concerning local definitions of autonomy, consent and risk, and the impact of participation in long-term intensive medical research in a resource-poor setting on notions of the benefits of health research.

Methods

Study design and sample

The study was conducted in three locations in Uganda using an observational case-comparison study design. The case group is located in Rakai District, Comparison

Group 1 is located in Kalangala District (Ssesse Islands) and Comparison Group 2 is located in a Rakai District community which borders the case group (see map, Figure 1). The key inclusion criterion for the case group was at least 3 years of concurrent participation in intensive health research, while the key inclusion criterion for the comparison groups was never participating in any research that required completion of an informed consent form. In fact, no one in either of the comparison groups ever had participated in any research. Cases were randomly selected from a list of current research participants living in one of the 56 communities involved since 1988 in a population-based cohort and intervention research initiative to study and reduce transmission of HIV/AIDS in rural south-western Uganda (Wawer *et al.* 1994, 1999).

Comparison Group 1 was comprised of residents in an interior farming community on a remote island in Lake Victoria where no formal health research has ever been conducted. Comparison Group 2 was randomly drawn from a community which neighbored the case group but which did not participate in the HIV/AIDS intervention study. Because neither census data nor neighbourhood lists were available to us, we could not randomly sample Comparison Group 1. Instead, the study communities were informed of our project by local leaders and villagers freely decided to participate. In an attempt to minimise the bias that was likely introduced into this self-selected group, we purposively sampled the self-selected participants to create a balance of gender and age. In any case, there was little to no significant difference between the three study groups according to type of residence, economic activity, education or other basic demographic variables. We randomly chose a subset of 62 interviews for the analysis here, which allowed for robust non-parametric (chi-square) analysis of significant associations between multiple variables.

Instruments and interviewing

All study instruments were translated from English into Luganda with considerable attention to accuracy, meaning and local idiom common in the rural interview sites. A language specialist at Makerere University back-translated the materials and we pre-tested and piloted all instruments. The survey included basic demographic information, closed- and open-ended questions about research and semi-structured discussions of several short stories, or scenarios, regarding local concepts of risk and autonomy. Case and Comparison Group 2 interviews were conducted in a private spot in or near the participant's home, while Comparison Group 1 interviews were conducted in private locations in or near the local health clinic during non-business daylight hours. The tape-recorded interviews ran for 60–90 minutes and were transcribed and translated from Luganda into English by local research staff trained in both survey and ethnographic research methods. Stewart personally observed a short segment of each interview. Neither Stewart, nor any research assistant, observed any of the clinical interviews associated with the case group, nor did our study have access to any personal health information of any participant in any of the study groups.

Ethical considerations

This study was approved after full review by the Ethics Review Committees of the Uganda National Council for Science and Technology (Kampala, Uganda) and



Figure 1. Political map of Uganda with research sites (Rakai and Ssesse-Kalangala Districts).

Northwestern University (Chicago, IL, USA). The time it took to complete the consent process varied between 10 and 25 minutes. All survey participants received a bar of soap (US\$0.25), which is the standard compensation for the Rakai Health Sciences Programme. Refusal rate for the case group was less than 2%. All participants who began the interview completed it.

Autonomy and consent

Autonomy (respect for persons) is a central concept in health research, particularly in the context of the process of informed consent. As described in the Belmont Report, an autonomous person is ‘an individual capable of deliberation about

personal goals and of acting under the direction of such deliberation'. The report continues very simply by stating 'that individuals should be treated as autonomous agents' and notes that researchers are bound by the 'moral requirement to acknowledge autonomy' through the process of obtaining informed consent for health-care or medical research.¹ Two conditions are essential to establish an individual's autonomy: liberty or 'independence from controlling influences' and agency or 'capacity for intentional action' (Beauchamp and Childress 1994, p. 121). The three core features of informed consent are: providing necessary and sufficient information about the treatment or research to enable the patient or potential participant to accept or decline; sufficient comprehension by the patient or research participant of that information to assess his or her own risks and benefits; and voluntariness in the individual's consent to treatment or to be a study participant. The Nuremberg Code is the first modern legal doctrine to mandate the central roles of autonomy and consent in medical treatment and research. However, much has been made in the bioethics literature of the deep and uniquely western roots of the concept of autonomy reaching back to Enlightenment thought about individualism and reason. This historical legacy is the precursor to the current rights-based or patient-centred approach to health care in the USA. In this framework, then, the autonomous person is 'conceptualised as possessing a sphere of protected activity or privacy free from unwanted interference ... able to exercise his or her liberty ... which express[es] the patient's right of self-determination of his or her body' (Kuczewski 1996, p. 8).

What are the implications of these core 'cultural traditions' and, in some cases, legal formulations, for the American regulation of informed consent overseas? First is a tenacious belief that only westerners make medical or research-related decisions independent of consultations with individuals other than their physician. This is often held in stark contrast to non-westerners, in particular sub-Saharan Africans, who are stereotyped to have an underdeveloped sense of individuality that is subordinated to their communal identity. If Africans could, the thinking goes, they would prefer to make medical or research-related decisions communally; that is, a chief would make the decision to participate in research on behalf of his community, and a husband would make the decision to participate on behalf of his wife. We argue that this unexamined myth has misdirected researchers for decades, causing them to focus their efforts to improve informed consent on establishing the voluntariness and autonomous decision to participate by the fact of collecting a single signature at the end of a complicated and contradictory legal form.

Data cited below are analysed in light of Beauchamp and Childress' (1994, p. 121) two essential conditions for establishing an individual's autonomy: liberty or 'independence from controlling influences' and agency or 'capacity for intentional action'. We clearly see strong evidence of an indigenous sense of the necessity for the autonomy of the individual in decision-making, and a conviction that one can refuse to make a decision even when others attempt to persuade or force a decision. Therefore, the conditions for liberty are met.

Informant 7: I have left my home and come here. I have decided to come myself. Nobody has forced me and I have put down my signature that I have agreed to participate in the research you have told us about.

Informant 1: A female decides and gets married to the man she feels like marrying and then refuses one that she is being forced to marry.

Informant 8: Someone can decide to stand for the post of chairman without being forced by anyone or without anyone deciding for him or her. He or she consents for self.

Female opinion leaders from non-research community

FGD/02/12–13

Informant 4: Consenting is when you are ready to decide. For example, your parent may be doing some problems for you at the early stage. Time comes when you can decide alone and weigh what shall benefit you and what shall not. At that point you decide to do something you shall benefit in and leave what you may not benefit.

Informant 5: When there is no force and you eternalize the issue within your heart and nobody is forcing you. Okay you may be forced to accept, that can happen, but after none has forced you it has been your own will.

Male youths from non-research community

FGD/03/8–9

Agency is also clearly understood and valued in decision-making.

Moderator: What do you understand by consenting in daily life?

Informant 1: It refers to making a decision from the bottom of my heart about anything I may be doing at that time and I have done it.

Informant 3: I would say consenting is all about pronouncing your decision and opinion because consenting come from the heart. [He beats his chest in emphasis] You then make your mind known to other people . . . at first we had our own mind/opinion about this very research when you asked us to sign the consent. I got some concerns internally in fact you twice gave me the pen and I twice refused because I had some ideas internally which I wanted clarification about before I could sign the consent. I asked the question and other people heard it. Then you clarified it and I made a consent and this is an example of consenting. So after making a decision within your heart, you show it to the rest by signing to indicate that we have consented.

Male opinion leaders from non-research community

FGD/01/8–10

As with Informant 3 above, the quality of information determines a person's ability and willingness to comfortably give consent.

Informant 8: A person consents based on an idea that is well explained to him. Once he is satisfied, he consents accordingly.

Male opinion leader from non-research community

FGD/01/8–10

Informant 7: To me consenting means that you have been read every single thing in a document, which everything you have understood very well and following your proper understanding of everything do take a decision after even consulting your heart 'okwebuza

ku mutiam gwo' on whether to accept something or to refuse it but that only follows your proper understanding of everything.

Male opinion leader from research community

FGD/05/7

It is clear that the concept of individual autonomous consent is a strong one in Uganda both for daily life and in research, and it appears to conform closely to Euro-American ideals of autonomous consent. The broad process of informed consent is also generally well understood. In fact, the evidence from both the case and control communities is equally strong and consistent across gender, age, education and residence. This suggests that ideas of the autonomy of the individual in decision-making are deeply embedded in a Ugandan worldview and is independent of exposure to research. Then why does the literature generally present the process of informed consent as a problematic one in resource-poor countries? We would argue that the problem is not a conceptual or philosophical issue of the autonomy of the individual or the role of the community, but a problem with the mode of communicating content or information from researcher to participant. What is missing is sufficient time to convey the details of the study in a variety of different modes – verbal, pictorial, interactive (role playing) and written. Lindegger *et al.* (2006) recently explored this issue in the context of HIV-vaccine trial participation in South Africa and concluded that a variety of formats are essential to improving comprehension of clinical trial participation. Fitzgerald *et al.* (2002) come to similar conclusions based on research conducted by the Haitian Study Group on Kaposi's Sarcoma and Immunodeficiency Disorders, but, more important, they argue, is the need to assess measures of the 'autonomy of study participants to give consent freely in the context of severe poverty, sex inequality, and little access to basic health care' (Fitzgerald *et al.* 2002, p. 1302). Another approach is to explore local definitions of the concept of risk and understandings of local options to mediate exposure to and consequences of risk.

Okukkera Ng'omuzungu² (lost in translation): risk

The Belmont Report advises that a 'systematic, nonarbitrary analysis of risks and benefits', which could result from participation in research, should be clearly explained to the participant during the informed consent process. The general requirements for the informed consent document are outlined in 45 CFR 46.116, and it specifies that it must include a 'description of any reasonable foreseeable risks' and an explanation of compensation for research 'involving more than minimal risk'. Risk is a central, but largely unproblematised, concept in public health. In an editorial in the *Journal of the American Medical Association*, the former Director-General of the World Health Organisation asserted that the world is 'living dangerously' due to increased risks to health, and called on governments to implement 'risk-reducing' interventions to improve health outcomes globally (Brundtland 2002). In this public health context, risk is expressed primarily as a numeric assessment of the probability of a certain health outcome; for example, a one in six risk of cancer.

However, as the Belmont Report acknowledges, not all risk is equal. For example, the term 'small risk' indicates a low probability that harm will come to the research

subject as a result of participating in the research. The term 'high risk' more often refers to the severity or magnitude of the probable harm, not simply an increased probability that harm will come to the participant. In other words, the single term, risk, in English carries multiple meanings: probability or chance of an adverse outcome and the severity of that adverse outcome. The imprecision of the language term, whose meanings are embedded in a probabilistic framework, complicates the legal regulations of 45 CFR 46, which mandate a very precise, but also very peculiarly American, treatment of the concept of risk in the informed consent document. Van Ness (2001, p. 360) suggests that the persistence of pairing the terms 'risk and benefits', in English, is a reflection of the ambivalence people feel about chance and uncertainty in their lives. Certainly this tendency is also culturally bound and demands careful analysis when translating the text and the multiple meanings of risk into a local language. Risk reduction is generally presented as a matter of changing individual behaviour or introducing new government regulations, for example, lowering salt intake or increasing taxation on tobacco products. But is the concept of risk and the process of risk reduction similarly understood by individuals outside this public health context? Do sub-Saharan Africans, for example, and Ugandans in particular, discuss the likelihood of certain health outcomes in numeric, probabilistic terms? Do they believe that they can change their individual health by virtue of changing their own behaviours? And in the context of global health research, what are the implications of multiple interpretations of risk?

Determining the most meaningful translation of 'risk' presents significant challenges. The process of translating terms such as risk, autonomy and beneficence between Luganda and English is difficult and imprecise. Of the seven major published Luganda dictionaries, the most recent Luganda–English/English–Luganda dictionary is the 1925 publication by Kitching and Blackledge (1925, revised primarily for orthography in 1952 by Mulira and Ndwula; see Table 1).

There is no up-to-date, single source for moving back and forth between English and Luganda. Therefore, the most common approach to preparing informed consent forms is to compose them first in English, translate them into Luganda and then back into English, relying on research field assistants or professional linguists at Makerere University. This introduces tremendous variability into the process and leads to unstable and unreliable translations.

However, even if we were to rely only on Luganda dictionaries, other problems emerge. For example, 'risk' in the English section of Mulira and Ndwula (1952, p. 203) is translated as *-egabula*, *-etunda*, *-evuubiika* and *-tunda omwoyo*. When we back translate these terms using the same dictionary, we immediately recognise the variety of meanings that the English word 'risk' gives us in Luganda, for example, to voluntarily bring risk or danger to your body or life by ignorance or by compulsive behaviour. By 1993, our only contemporary option for translating 'risk' from English is to consult Nsereko's (1993) Law Dictionary. Nsereko translates 'risk' as '*akabi akayinza akugwawo*'. However, to completely understand Nsereko's translation, we must then refer to the Snoxall (1967) Luganda–English dictionary to back translate. Snoxall gives a separate translation of each of Nsereko's terms '*akabi akayinza akugwawo*': (1) '*akabi*' is harm, danger; (2) '*-bi*' is bad, evil, dirty, dangerous; (3) '*-yinza*' is to be able, to have power and authority, to make possible; and (4) '*-gawo*' is to give to, to distribute. The literal translation of 'risk' or '*akabi akayinza akugwawo*' is 'it gave to you the power to do evil or harm'. Therefore, if we use Nsereko's legalistic

Table 1. List of all known published dictionaries of Luganda or Luganda/English.

Dictionary language Luganda/English	Publication date	Type of dictionary	Author
L-E/E-L	1892	General	O'Flaherty
L-E/E-L	1911	General	Blackledge
L-E/E-L	1925	General	Kitching and Blackledge (revised for orthography in 1952 by Mulira and Ndawula)
L-E	1921	Medical phrases	Cook
L-E	1967	General	Snoxall
L-E	1972	General	Murphy
E-L	1993	Law	Nsereko

term for 'risk' we convey a negative and dangerous meaning that carries the additional gloss of power and authority and is further complicated by the reflexive verb.

If we choose the standard, more conversational usage of 'risk', which is also the most common translation of risk on consent forms – *buzibu* – we find the same sense of negativity, but not danger, and certainly not power and authority. *Buzibu* means 'difficulty' or 'big problem'. It correlates only to a negative outcome, but most importantly, it does not carry any sense of probability of outcomes, whether they are good or bad, as the English use of the word 'risk' does in consent forms. An alternative approach would be to analyse a set of conceptually related words to establish a continuum of meaning that forms the cultural universe of 'risk' for Luganda speakers; for example, consider the following:

<i>-kатыabaga</i>	risk, trouble, difficulty, endangering situation
<i>Omukisa</i>	good luck, high chance, probability, unexpected good fortune
<i>Omukisa omuni</i>	bad luck
<i>Ekisirani</i>	bad luck, fate due to God's will, loss of life
<i>Ekizibu</i>	problem
<i>Buzibu</i>	risk, difficulty, bad situation
<i>Nteekateeka ya katonda</i>	God's will

We see that *buzibu* is the result of human action, but it always results in bad outcomes and therefore is an inappropriate term for the informed consent document. *Mukisa* is often translated as 'chance' or 'probability' or 'luck' and is used to convey that sense, but as we see from the discussions below, *mukisa* carries a sense of divine intervention. *Omukisa*, however, is a means for accounting for seemingly random outcomes – why one person died in a bus accident, while another did not. Women offered a similar analogy related to pregnancy outcomes. *Omukisa* also has a sense of unexpectedness, an inability to predict the possibilities of, or even prepare for outcomes.

Informant 7: Risk [buzibu] is what puts [you] into problems but chance [mukisa] is what uplifts you from danger.

Male opinion leader from research community

FGD/05/15

Informant 1: 'Omukisa gujjira mulamu.' Chance is for the living. Provided you are still alive, chance can always come your way.

Moderator: Where does chance come from?

Informant 5: 'Mu bajjaja' From the traditional gods, I give them offertory and then open up my way for chances.

Informant 6: I can also wake up in the morning, get ahold of my 'sapuli' (rosary), pray to God and he deals me with chances and luck.

Moderator: Where does risk come from?

Informant 5: In most cases, it is we who fetch danger or risk to ourselves.

Male opinion leaders from research community

FGD/05/15-16

Moderator: What other words do you use which mean 'omukisa'?

Informant 6: Also at times we can all be 'bazitto' [literally: heavy, colloquial for pregnant], we can all go to hospital to deliver, they may deliver my friend with a Caesarian section, and for me I deliver normally. That is 'mukisa'.

Female youth from non-research community

FGD/04/13

Moderator: What is the other example of 'omukisa'?

Informant 1: When one gets something good which he never expected. Like if I have been walking and I came across a million shillings.

Informant 6: I could have failed to conceive for a long time until I even separated, but on getting another man, then I get a baby. Wouldn't that be a 'mukisa'?

Female opinion leaders from non-research community

FGD/02/22

Early in the project, when our research assistants began to realise the difficulty of translating 'risk', they summed up the problem as *Katogo!* Literally translated, *katogo* means the leftovers you eat for breakfast, but metaphorically it indicates a mess, or a situation that is all mixed up. It is clear that there is no single word, in either English or Luganda, that conveys all the meanings of 'risk' according to the criteria of the Belmont Report. A more effective strategy would be to translate bundles of concepts, rather than single words.

Revisiting the therapeutic misconception

First described by Appelbaum and colleagues (1982), the therapeutic misconception occurs when research participants transfer their understanding of the therapeutic

role of the physician in the clinical setting to that of the health-care investigator in a trial or research setting. Whereas the physician is obligated to act in the best interests of their patients, the physician-investigator is obligated to uphold the research protocol, which may or may not be in the best interests of the research participant. Over two decades later, this classic interpretation of the therapeutic misconception continues to be reported in research settings in both resource-rich and resource-poor settings (Dresser 2002, Marshall *et al.* 2006, Onvomaha-Tindana *et al.* 2006).

However, the therapeutic misconception is neither static, nor do all examples follow this classic description. Belkin (2006) argues that the therapeutic misconception developed as a distinct phenomenon not because the practice of medicine or medical research suddenly became more moral, whereby practitioners finally recognised the ethical challenges of the therapeutic misconception, but because the practice of research and medicine became more distinct, 'more capitalised, industrialised, standardised, and thus more easily and necessarily organised in predictable and generalisable routines'. As the relationship between research and treatment continues to change, we can expect the contours of the therapeutic misconception to also change. For example, increased access to knowledge about clinical HIV/AIDS trials changed the relationship between trial participants, particularly in the USA, and their physicians and physician-investigators. By the early-1990s participation in clinical HIV/AIDS trials was seen as superior to the therapy offered by a physician, and HIV-positive patients actively sought participation in clinical trials to supplement or even supplant their physician's care. Dresser (2001) identifies a new therapeutic misconception, one in which cancer and AIDS patients seek out participation in phase one trials of experimental therapies, hoping for a therapeutic effect, even when the research design specifically indicates a low chance of such an effect.

Why does the therapeutic misconception persist in time and across space? Is it simply a matter of ineffective communication between researcher and research participant, a miscommunication which can be addressed in the same vein as the process of improving informed consent? Or do we see evidence that goes beyond miscommunication to indicate different worldviews and moral imaginations about the value of health research, especially in resource-poor settings? Do African research participants, who describe research in the classic formulation of the therapeutic misconception, engage with research as treatment not in a misunderstanding of these two separate activities, but because their lived experience of health research is that it is their only option for treatment in a resource-poor setting? Or perhaps because African research participants observe that research subjects receive more efficacious and consistent care than those who seek treatment at public clinics? And what of the apparent conflation of health research with community development or education; miscommunication or a reflection of fundamentally different expectations for health research?

Reconciling these divergent viewpoints and expectations requires more than better communication or collaboration. It demands revisiting the therapeutic misconception in light of a classic debate in the anthropological literature on African health systems: the false dichotomies of science and folk systems; empirical observation and magic; biomedicine and traditional herbal healing; and open (dynamic and testable) and closed (static and non-empirical) knowledge systems. The explanatory power of the therapeutic misconception is increasingly limited by its

commitment to the false dichotomy of research and treatment. In his article on therapeutic choices among the Ghaambo of Tanzania, Feierman (2000) re-examines this debate and argues that failing to move beyond such dichotomous frameworks means we ultimately fail in our ability to understand and interpret local judgements in a resource-poor setting. Feierman describes the search for diagnosis and treatment by a woman whose biomedical diagnosis was hookworm, yet her description of her symptoms focused on her social marginality. In fact, she did not separate the two domains and 'she expected a course of therapeutic action to address the whole of her condition'. Diagnosis reflected the 'logic of social relations' and treatment was expected to address the moral economy of local resources (Feierman 2000, pp. 332–334). In this context, where existing treatment options are limited and often unsuccessful, the therapeutic misconception needs to be recast from research and treatment to a process of research and development (R&D; either personal or community).

Feierman's framework helps us to understand what at first glance appears to be a classic case of therapeutic misconception (participation in health research is personalised treatment), but is instead a reflection of the logic of local expectations of new social relationships based on the presence of a research project in the community. In our qualitative study we discussed health research with experienced research participants from the Rakai Health Sciences Project (RHSP) and research-naïve residents from the Ssesse Islands where no systematic health research had ever been conducted. Our discussions ranged over a wide variety of topics related to health research, but here we only present evidence about the *social value* of research.

For the Rakai group, the most commonly reported benefits of participation were material: learning HIV status; access to ARVs; and health check ups.³ Their focus is clearly on the researcher/participant dyad and expectations that participation in research will lead to personal improvements in health status. In contrast, the Ssesse Islands group did not cite treatment or diagnostic benefits as a motivation for participation in research; they prioritised individual health education in the service of community development as the most valuable aspect of research. This indicates a more complicated moral calculus whereby one should strive to transform personal benefit into community benefit. The researcher/patient dyad was merely the starting point for distributing and amplifying the scarce resources that come into the community from research. Attending school is rare in this island community and education is a valuable social resource: '*Ndimugezi nga mubuulire* (I am a clever person, but only after I am informed)' and 'An educated person does not suffer much with this world'. The residents of the Ssesse Islands strongly believed that the chance to gain new knowledge should not be squandered: 'The community only ... recommends for research ... the person they think will get knowledge and share it with others'. Research participants were believed to gain personal authority and a new visibility in the community by virtue of their exposure to a research project: 'To be invited as an individual to participate in ... research ... it becomes a prestige to you ... You certainly have the credibility and can be consulted by other people'. With that new prestige comes a new social responsibility: 'When a research participant learns something from research, she informs others in the community ... and they benefit', and 'We should also go and teach others the way you [researchers] help others, that is the same way we should help others'.

Do we interpret the statement, 'We shall go and get knowledge, more so for us who never went to school', as confusion between research and education; or is it a statement about the larger social value of research? When someone says, 'I expect research to improve people's living standards by availing us health units and seminars on health to help us learn more about good health', do they mistake research for NGOs, or is this a moral statement that research is, first and foremost, development? These statements suggest there is merit in shifting our attention from research ethics and material benefits to recognising social changes in communities that host clinical trials. For the same reason that Ugandan youths gained unprecedented authority over their elders when they mastered the scientific language of HIV/AIDS from NGOs (Stewart 2001), people are willing to participate in health research because they can create meaningful roles for themselves in the community and fulfil a moral obligation to share the benefits of their knowledge with others. Expanding our analysis of the impact of research from the research/participant dyad to shifting community networks underscores the limited utility of didactic models, such as the therapeutic misconception, for understanding the social value of global health research.

Conclusion

The year 2008 was remarkable for global action on health research in the developing world, particularly in Africa. The World Health Assembly adopted the resolution, Global Strategy and Plan of Action on Public Health, Innovation and Intellectual Property.⁴ The United Nations Economic Commission for Africa convened the conference, Science with Africa, concluding with a panel on Developing Guidelines for Health Research in Africa.⁵ Ministers of Health, Science and Technology and Higher Education, at the second Ministerial Forum on Research for Health, held in Mali, called for a paradigm shift from health research to research for health.⁶ A recent editorial in *The Lancet* noted the central importance of social science research to determine why certain health policies or programmes succeed or fail (Anon 2008). By identifying new R&D priorities, promoting innovative research methods, supporting stronger review of the ethics of R&D research, and advocating for increased funding, there is a clear recognition that the structure of global health research must change.

Benatar (2005) recently suggested that a lack of moral imagination is the greatest challenge to improving global health. If we define moral imagination as the ability to see contextual factors, to reframe problems from a variety of perspectives and interests and to envision, act on and justify the solution to the problem (Johnson 1993, p. 202), then we have defined the essence of anthropology. It is at the intersection of ethical principles and moral experience, or the 'close-up world', as Kleinman (2006, p. 233) writes, where anthropology makes its most unique and significant contributions. Rules and regulations can guide a research protocol, but a moral imagination and experience of the local context are essential to understanding the social value of health research. It is the responsibility of social and behavioural scientists to promote this concept and advocate for a prominent role for local research participants and their communities in this global initiative to re-prioritise health research.

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Notes

1. This paper does not discuss informed consent or assent for vulnerable populations, such as children or prisoners, or diminished autonomy of mentally incompetent persons.
2. For an alternative translation of this phrase, see Rowe (1991).
3. A much larger survey ($N = 811$), conducted at the same time as our qualitative study, found similar results (Thiessen *et al.* 2007, p. 2495).
4. Available at http://apps.who.int/gb/ebwha/pdf_files/A61/A61_R21-en.pdf
5. Available at <http://www.uneca.org/sciencewithafrica/>
6. Available at <http://www.bamako2008.org/>; this was followed up in January 2009 with the WHO Executive Board's EB124.R12 *WHO's role and responsibilities in health research*, available at http://apps.who.int/gb/ebwha/pdf_files/EB124-REC1/2B124_REC1-en.pdf

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