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The ‘over-researched community’: An ethics analysis of stakeholder views at two South African HIV prevention research sites

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ABSTRACT

Health research in resource-limited, multi-cultural contexts raises complex ethical concerns. The term ‘over-researched community’ (ORC) has been raised as an ethical concern and potential barrier to community participation in research. However, the term lacks conceptual clarity and is absent from established ethics guidelines and academic literature. In light of the concern being raised in relation to research in low- and middle-income countries (LMICs), a critical and empirical exploration of the meaning of ORC was undertaken.

Guided by Emanuel et al.’s (2004) eight principles for ethically sound research in LMICs, this study examines the relevance and meaning of the terms ‘over-research’ and ‘over-researched community’ through an analysis of key stakeholder perspectives at two South African research sites. Data were collected between August 2007 and October 2008.

‘Over-research’ was found to represent a conglomeration of ethical concerns often used as a proxy for standard research ethics concepts. ‘Over-research’ seemed fundamentally linked to disparate positions and perspectives between different stakeholders in the research interaction, arising from challenges in inter-stakeholder relationships. ‘Over-research’ might be interpreted to mean exploitation. However, exploitation itself could mean different things. Using the term may lead to obscured understanding of real or perceived ethical concerns, making it difficult to identify and address the underlying concerns. It is recommended that the term be carefully and critically interrogated for clarity when used in research ethics discourse. Because it represents other legitimate concerns, it should not be dismissed without careful exploration.

1. Introduction

Approximately eighty-three percent of the world's population lives in low- and middle-income contexts (LMICs), where access to healthcare and other social benefits is severely constrained by limited resources (Emanuel, 2008; Population Research Bureau, 2016). The global HIV/AIDS pandemic has generated an imperative for the ongoing development of options for HIV treatment and prevention (MacQueen and Warren, 2016). Since sub-Saharan Africa in particular bears 50% of the global burden of the epidemic, (de Oliveira et al., 2016), there is a critical need for ongoing research to develop prevention methods suited to these contexts. Health research, conducted in LMICs by external sponsors, has contributed significantly to the understanding, prevention and treatment of ill-health, through medical, social and behavioural interventions (NCOB, 2002).

However, research in developing countries and resource-limited settings is a complex undertaking, particularly, when sponsored by developed country organisations. It raises many complicated and contentious ethical concerns, including those related to exploitation and research with vulnerable populations (cf. Emanuel et al., 2004; Hawkins and Emanuel, 2008).

The ‘over-researched community’ (ORC) is increasingly raised as an ethical concern regarding research with groups of people, especially in developing and resource-limited contexts. Two of the present authors [Wassenaar & Mamotte] are members of research ethics committees (RECs) in the region and, anecdotally, the term has come up increasingly frequently in debates about research protocols and has been used by some research gatekeepers (Singh and Wassenaar, 2016) as a reason for denying researchers access to communities (cf. Nattrass, 2006). The term is often used informally in popular discourse (cf. Mellville, 20 March 2007). Concerns about communities being ‘over-researched’ have also been raised about health and HIV-related research in

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developing countries (cf. Clark, 2008; Essack et al., 2009; Heise et al., 2008; Nattrass, 2006).

Although the term 'over-research', seems a self-explanatory concept, interrogation of the notion reveals this simplicity to be deceptive. The notion, as a gatekeeping criterion, seems primarily to be used pejoratively, implying that too much research has been conducted. However, what constitutes 'too much' research? And, what is it about 'over-research' that is ethically worrisome? In most cases of its use, the term is not interrogated, but used with its meaning taken for granted (cf. Matheson et al., 2005; Mavhunga and Dressler, 2007).

There is little published literature critically exploring 'over-research'. Clark (2008) links 'over-research' to so-called 'research fatigue' and reasons for refusal to participate in qualitative research. A critical examination of 'over-research' is provided by Sukarieh and Tannock (2012) but their discussion is limited to social science research. While Cleary et al. (2016) highlight the many possible meanings of 'over-research', they do not articulate them in an ethically systematic way. There is also little (if any) mention of the term in major international guidelines for ethical research. The notion does not appear to be explicitly defined in the existing literature nor ethical guidance.

It remains unclear what the term 'over-research' actually means - whether it refers to existing challenges regarding research in developing or resource-limited settings, which are already dealt with in existing normative frameworks, or whether it represents an emergent concern which is absent from these frameworks.

2. Study aim

The principal objective of this study was to investigate the relevance and meaning of the term "over-researched community" (ORC) as an ethical construct. At the heart of this objective were two questions: (1) Is 'ORC' a discrete ethical concern or does it reflect other existing concerns in research ethics? and (2) How do stakeholders involved in the research enterprise make sense of this term?

3. Methods

3.1. Study setting

The study took place at several anonymised HIV prevention research sites in KwaZulu-Natal and Western Cape, South Africa and affiliated South African RECs. These regions, each with urban and rural components, are proximal to several of the most research-active universities on the African continent, are host to many HIV and TB prevention trials and demographic surveillance sites and projects.

3.2. Respondents

In order to obtain a holistic perspective on the notion of the 'ORC', respondents were selected to include representatives of three major stakeholder groups involved in health-related research in community-settings, namely: researchers, community representatives (CABs) and REC members.

Letters containing information about the study and requesting permission to approach researchers and community representatives at sites, were sent to the principal investigators of seven research organisations involved in HIV prevention research in South Africa. Similar letters were sent to chairs of four South African RECs involved in the review of large-scale clinical trials, to request permission to approach members. Information sheets and cover-letters were emailed to all potential researcher-respondents at those organisations which had agreed to participate, and to REC members inviting them to indicate, via email, whether or not they would be willing to participate in a face-to-face interview exploring the concept of the 'ORC'. Once individuals indicated their willingness to participate, arrangements for a face-to-face interview were made.

The final 24 respondents consisted of seven researchers involved in HIV prevention research (both in rural and urban areas) in South Africa; eight members of two South African biomedical RECs; seven members of community representative groups (CABs) at three HIV prevention trial sites; and two community liaison officers (CLOs) at two sites. As is the practice in qualitative research, the number of respondents involved aimed to provide a diversity of views and reach a point of saturation, where no new themes emerged during the interviews.

3.3. Interview schedule

An interview schedule, containing minor variations for each stakeholder group, was developed. Topics discussed in the interviews included research experience, community engagement, participant selection, study benefits, multiple research projects/ongoing research presence in a community and the over-researched community.

3.4. Research ethics approval

Prior to data collection this study was ethically reviewed and approved by the Humanities and Social Sciences Research Ethics Committee of the University of KwaZulu-Natal (Approval No: HSS/0283/07M).

3.5. Data collection

Data was collected via face-to-face interviews. The study was broadly informed by the interpretive paradigm, through which researchers attempt to understand respondents' subjective experiences (Cresswell, 1998). A participatory approach was also adopted during the interviews. Respondents were considered active participants and were engaged in a process of critical reflection, whereby both interviewer and interviewee, through the process of exploring an unknown idea or concept, like 'over-research', create a shared understanding of the idea, and parties are prompted to reflect critically on their own views (Kelly and van der Riet, 2001).

Data were collected between August 2007 and October 2008. Informed consent and permission for audio recording were obtained before each interview. Informed consent and interviews were conducted in English and isiZulu. All interviews were transcribed verbatim and transcripts were checked for accuracy.

Based on the varied and often anecdotal use of the term 'ORC', and its rare appearance in the literature, we asked interviewees whether they had ever encountered the term 'ORC' before followed by an open question about how they understood the term. Various open-ended prompts, like: "How would you identify an 'ORC'?" and, "Do you know of any 'ORC's?", were used to encourage discussion and critical reflection on the term.

3.6. Data coding and analysis

The initial phase of data analysis involved immersion in the data. Audio-recordings of each interview were replayed while the researcher simultaneously followed the transcript of the interview. Marginal remarks containing initial observations about, and descriptions of, the data, were made on hard copies of the transcripts. Once two researchers had read five of the interview transcripts and made initial observations, a more detailed coding framework was developed.

Although interpretive approaches often primarily use inductive coding and analysis methods, because this study sought to examine whether 'ORC' concerns reflected new or existing ethical issues, coding and analysis were necessarily approached using a flexible deductive approach. As such, the Emanuel et al. (2004, 2008) framework (Table 1) for ethical research in developing countries, as a comprehensive model of ethical requirements, was used to guide coding and analysis, and formed the basic structure of the analytic framework. The