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HIV Cure Research in South Africa: A preliminary exploration of stakeholder perspectives

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Abstract

Progress in HIV research has led to the development of innovative strategies for HIV cure so that patients can be disease free in the absence of antiretroviral therapy. Consequently research studies are being designed and planned globally. South Africa is no exception. However little is known about stakeholders' knowledge, understanding and expectations of future cure research. This study aimed to obtain in depth qualitative insights into stakeholder perspectives at this formative stage of HIV cure research in South Africa. We interviewed 15 stakeholders in a busy HIV research clinic in the Western Cape, South Africa. This purposive sample comprised patients, community advisory board (CAB) members, research nurses, doctors, counsellors and a project manager. All participants provided informed consent. Interviews were transcribed verbatim and analysed using thematic content analysis. The study was approved by the Health Research Ethics Committee at Stellenbosch University. Broad themes that emerged included the meaning of cure, awareness of HIV cure research, risks and benefits of such research. General awareness and understanding of HIV cure research was lower than expected. Healthcare workers interpreted "cure" to mean complete eradication of virus from the body including from reservoirs while patients' perceived cure to be a return to normality with no need for future medication. Some participants expressed a fatalistic attitude to the disease and described HIV as an "end-time illness" with no prospect of cure. In general, HIV cure research was regarded as risky - biologically psychologically and socially. If study designs were to include treatment interruption, participants would comply only if there was a guarantee of success. Given these perceptions of HIV cure research, significant challenges to consent processes and participant recruitment can be anticipated for proposed trials

in South Africa. Authentic community engagement and intensive educational interventions will be necessary prior to future cure research in the country.

Keywords

HIV cure research; ethics; community engagement

INTRODUCTION

South African health researchers have been actively involved in HIV research for more than three decades (A Violari et al., 2008; Auvert et al., 2005; Mayer et al., 2006). Despite challenges in HIV prevention research and treatment trials (Wadman, 2011), the research community in Africa is committed to future research in search of a “cure” for this formidable disease as prevalence remains high and it is clear that prevention and treatment alone will not bring this epidemic under control (Rehle et al., 2010). However, given the controversial history of cure on the continent, false hopes have been created, and misperceptions are rife, posing a challenge to future recruitment of participants into cure trials.

To date anecdotal reports of possible “cure” have been reported in adults in Germany and France (Hütter et al., 2009) (Saez-Cirion et al., 2013), and a child in Mississippi (Persaud et al., 2013). Basic science research in the global North is exploring various cure strategies such as very early treatment of neonates, neutralizing antibodies, gene therapy and therapeutic vaccines (Anaworanich & Fauci, 2015) with the aim of rendering patients disease free in the absence of antiretrovirals (ARVs).

News that the “Mississippi Baby” and the “Berlin Patient” could be “cured” of HIV has created expectation in people living with HIV in South Africa (Hütter et al., 2009; Persaud et al., 2013). However as the scientific community grapples with new developments with the Mississippi Baby, tensions have emerged over attributing the word “cure” to these breakthroughs too early as caution needs to be exercised before adopting the term “cure” prematurely.

Attention is now focussing on the ethics of HIV cure clinical trials, with early discussions focusing on therapeutic misconception, risk-benefit ratio and study design (Lo & Grady, 2013; Persaud et al., 2013; Shah et al., 2014). However, to truly inform these discussions, an understanding of HIV infected patients’ knowledge of cure research, their expectations from participating in such research and any factors which may impact their ability to give informed consent is essential. It is against this backdrop of controversy and complexity that we sought to elicit views of stakeholders. To date there has been no published empirical enquiry into participant perspectives on HIV cure research. This study was conducted to gain preliminary data to guide future phases of this project in South Africa and to contribute to the larger multisite HIV cure project on ethical and social issues related to HIV cure research in North Carolina, USA and Guangzhou, China where extensive stakeholder interviews are underway.

METHODS

In this qualitative research project fifteen semi-structured interviews were conducted in an HIV research clinic in a public hospital in the Western Cape to obtain in-depth data on stakeholder perspectives on future HIV cure research. Three doctors, three nurses, one project manager, one counsellor, one social worker, three community advisory board (CAB) members and three patients were interviewed in March 2014. The interviews included questions about demographics, experiences with HIV treatment and participant knowledge and perspectives on HIV cure research.

Interviews were conducted with informed consent primarily in English by the same interviewer and lasted approximately 60 minutes. Where necessary, some interviews were conducted in isiXhosa and translated prior to data recording. The study was approved by the Stellenbosch University Health Research Ethics Committee (N13/05/063).

Recorded interviews were transcribed verbatim by the interviewer and data analysis was conducted concurrently. Transcripts were read and re-read by the authors to elicit major deductive and inductive themes. Due to the small number of interviews, conducted as a preliminary exploration, content analysis was conducted manually. The principal investigator (KM) and project manager (MdR) conducted data interpretation. This was validated by an independent qualitative researcher (analyst triangulation).

RESULTS

The main topics explored in the qualitative interviews are reported here. Deductively coding the qualitative data lead to a better understanding of the meaning of cure, awareness of HIV cure research, cures offered to patients, participation in future trials and perceived risks and benefits of participation in future cure research.

Meaning of cure

Healthcare workers understood HIV cure to mean the complete eradication of disease with no virus in the body, not even in reservoirs. Antiretroviral treatment (ART) was perceived as an unstable or insecure landscape and life on ART was perceived as a vulnerable place for HIV positive patients. Patients indicated that living with the challenges and stigma of having HIV meant being “unable to live freely” and they viewed cure as a “return to normality” with no need to take medication again. A notion of purity and cleanliness was expressed with references to “clean blood” associated with cure as opposed to having “dirty blood” when infected. A few participants mentioned that in the near future a vaccine could prevent HIV but believed that it would not be a cure.

Awareness of HIV/AIDS cure research

While some healthcare workers had heard stories of cure, others had not heard about cure research at all. Cure was generally anticipated as something that would occur in the future however a sentiment was also expressed that perhaps HIV is an “end-time illness” and would not be cured:

“I don’t think there’s ever going to be a cure, that’s my opinion of it. It seems to me it’s an end time sickness. The Bible did not say it’s going to be cured...end time means the last day we have on earth.”

Cures offered to patients

Some patients have been offered “miracle water” as a cure while others were promised cures by religious leaders in the church. Some patients had used traditional medicines as “cures” and had consulted with sangomas (traditional healers) in addition to Western doctors in public health clinics. This was mainly because it is easier to access a traditional healer than a Western doctor. Although some patients discussed their visits to traditional healers (sangomas) with their regular doctors in the clinic, most did not. Many patients visited traditional doctors due to family or community pressure.

Trial participation in future hypothetical cure trials

There was a general belief that patients would not be motivated to take part in future trials as a result of a fear of becoming sick again. This fear was significant and one healthcare worker commented: “You would really have to convince them that stopping treatment would not make them sick again”.

Perceived risks of participating in HIV cure trials

Biological risks: Treatment interruption was regarded as a major risk.

Psychological risks: Many participants expressed the fear that patients would be devastated if the “cure” did not work. The psychological impact of becoming ill again in the event of failure of the proposed “cure” would be enormous.

Social risks: Participants expressed concerns about competition to participate in trials, especially if more than one family member was HIV positive. Others indicated that family members would judge them and chastise them for participating. They expressed a fear of loss of support from families and communities.

Perceived benefits of participating in HIV cure trials

The greatest benefit expressed was the freedom to be able to live without medication after taking part in a cure trial.

DISCUSSION

While healthcare workers and patients were familiar with HIV prevention research and treatment trials, there was generally a low level of awareness about HIV cure research. In particular, there was no differentiation between the concepts of functional cure and sterilising cure (Tucker, Volberding, Margolis, Rennie, & Barre-Sinoussi, 2014).

When research participants and community members did engage in discussions around cure, their knowledge of cure was mainly in the context of non-biomedical cures and the concept of cure was clouded by competing offers of cure in the past and distrust in offers of cure generally. The belief that holy water can cure people of HIV has been noted elsewhere

(Berhanu, 2010). Religious beliefs intermingled with individual perspectives on HIV has been demonstrated in a study from rural Mali, where 47% of participants believed that HIV is a punishment from God (Hess & Mckinney, 2007). Similarly, in a Tanzanian study, 53.2% believed that HIV is a punishment from God and 34.9% believed that those infected had not followed the word of God (J Zou et al., 2009). This parallels the reference to HIV as an “end time sickness” in our study. Such fatalistic attitudes, if widely present, may have a negative impact on future HIV cure research and willingness to participate as potential participants may not be keen to enrol in cure clinical trials. If they do enrol and perceive lack of benefit or experience adverse events with new interventions, attrition and loss to follow-up is likely.

The expectation of benefit from future cure studies creates a clear picture of therapeutic misconception (TM) and therefore will be a challenge to address during consent processes in future cure research. In particular, efforts must be made to ensure that participants understand that they are unlikely to benefit in early phase cure research.

Although participants did want certainty that the trial would make them better, it is interesting to note that risks were perceived in the context of a biopsychosocial framework with social and psychological risks given significant weight. Discussing a hypothetical cure with patients provoked an unexpected adverse event in the form of an emotional reaction amongst the three patients. Discussions of cure during the interviews appeared to conjure up fantasies of a life without HIV and almost created false hope. Participants became tearful and distressed when reminded that a cure was only a possible event in the distant future. Likewise interviewers felt anxious and upset that they may have inadvertently raised the hopes of participants simply by discussing the possibility of cure in the context of the interviews. In this study, debriefing was arranged after the interviews and provision for debriefing has been built into future phases of this study (Crawford, Bowser, Brown, & Maycock, 2013; Kim et al., 2009; Swaminathan et al., 2007)

This formative research has served to sensitize the research team to the use of the term “cure”. The general understanding of the term “remission” from oncology must be revisited. “Remission” may be a more concise term to use at this stage of scientific exploration into HIV “cure” strategies given the case of the Mississippi baby where what initially appeared to be a cure later turned out to be closer to a remission. In future consent discussions and documents related to HIV cure trials, use of the word cure could be problematic and careful consideration must be given to appropriate explanations of risks and benefits to avoid therapeutic misconception especially in early phase studies.

Although a limited sample size was qualitatively surveyed, our findings contribute to the scientific literature and will inform future phases of empirical work being planned with key informants and a much larger sample of stakeholders in South Africa. It is clear that HIV cure research raises some unique ethical considerations requiring further investigation. Shifting the emphasis from “cure” to “remission” in consent conversations and documents may enhance understanding of the limitations of HIV cure efforts. It is evident that all HIV cure research must be preceded by authentic community engagement and widespread educational interventions to enhance and legitimise consent processes.

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