Ethical issues in clinical trials and treatment strategies

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Proposed HIV cure research in South Africa: perspectives of HIV researchers, clinicians and advocates on the anticipated ethical challenges

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Background: South African health researchers and clinicians have been actively involved in HIV research for more than three decades. Despite challenges in HIV prevention research and treatment trials, the research community in South Africa is committed to future research in search of a “cure”. To date HIV research has focussed on prevention and treatment and associated ethical challenges. More recently the ethics of proposed HIV cure research has received attention: therapeutic misconception, risk-benefit ratio and study design. To date there has been no published empirical enquiry into key informant perspectives on HIV cure research in South Africa. This study was conducted to gain preliminary data to guide future phases of a larger multisite HIV cure project on ethical and social issues related to HIV cure.

Methods: A purposive sample of twelve key informants in academic institutions, HIV clinics and HIV research units in South Africa, was interviewed after obtaining informed consent. Recorded interviews were transcribed verbatim with concurrent thematic analysis. To establish data credibility we triangulated the perspectives of three groups of participants: researchers working in treatment and prevention, HIV clinicians, HIV activists (triangulation of sources). In addition, analyst triangulation occurred.

Results: Common themes emerged from in-depth interviews: HIV cure research has enhanced understanding of the pathogenesis of HIV, especially viral reservoirs. Insights about sterilizing and functional cures have parallels in oncology especially remission. Cure research should not replace or overshadow treatment and prevention research. Cure science is complex and must be translated for communities. Cure research should not be limited to the developed world. We should not create undue expectations/therapeutic misconception. The risks of cure research and treatment interruption must be acknowledged.

Conclusions: A holistic approach integrating biomedical treatment, prevention and cure research is critical with cognisance of social and ethical dimensions. Resource allocation to all domains is imperative. Community engagement to translate complex HIV cure science into lay conversations about cure to enhance consent processes is essential. We need research in Africa with capacity development and technology transfer. Knowledge sharing and collaboration with research scientists in treatment and prevention will accelerate progress towards cure.