CHALLENGES IN DEVELOPING AN EDUCATIONAL VIDEO ON HIV CURE RESEARCH

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Abstract

Background

South Africa’s journey with HIV has seen significant progress, but with 400,000 new infections annually and 3.4 million people living with HIV on treatment, our treatment and prevention campaigns are not enough. And so the HIV epidemic is a cure is needed. Globally a search for a cure has begun and with its strong legacy in HIV research and high prevalence rates, South Africa is likely to be involved in this developing network of cure research. Formative research with 15 stakeholders at an HIV clinic in the Western Cape revealed general awareness and knowledge of HIV cure research to be suboptimal. As the scientific approaches to a cure advance, there is a need for early and sustained engagement with the community to address any misconceptions as well as introducing “cure speak” into the community.

Description

To introduce the HIV cure discourse to people living with HIV in South Africa, the Centre for Medical Ethics and Law developed a 14 minute educational video to be shown to patients in waiting rooms at HIV clinics throughout South Africa. It reiterates the well-known messages of treatment and prevention, and introduces HIV cure research. The actors are healthcare workers in an HIV clinic, comedian and doctor Riaad Moosa as well as Archbishop Emeritus Desmond Tutu and Zackie Achmat.

Lessons learned

Developing such a video is fraught with many challenges, particularly when the science to HIV cure are uncertain. Decisions on how to message the idea will inevitably result in the exclusion of key information, thus careful consideration of the implications of the text is imperative. In particular, the script must not mislead, raise undue or false hope, but inform the community with balanced information. Of importance in this process is the inclusion of the community in the preproduction and postproduction stages. Not only the video itself, but the process must also be seen as an important part of community engagement.

Conclusions

Educating the community about HIV cure research is challenging. However through wide engagement with stakeholders and community members, it is possible to develop an educational intervention. It is hoped that this video will encourage others involved with HIV cure research to begin developing their community engagement strategies.

Abstract

Rationale

• Increase public awareness on HIV cure research
• "This is all too confusing for me to understand"
• Reinforce prevention and treatment messages
• "For now it's important that everyone on ARVs should keep on taking them and everyone should practice safe sex.”
• Start a discussion on community engagement for cure research in South Africa

Content

• Create awareness without promoting participation in HIV cure research
• "We don’t know what kind of treatment it will be; maybe it will be a vaccine, or some other kind of treatment. It’s too early to tell.”
• Acknowledge the role of culture
• "Traditional healers are an important part of our culture. Sangomas can give us spiritual support, but you must inform your doctor if you are taking any other medicines whilst on ARVs.”
• Translation of new terms (sterilising cure, remission) into African languages

Possible inadvertent consequences

• Discussing stopping ARVs may undermine progress in treatment campaign
• "Yes it’s true it’s dangerous to stop your ARVs, even for a day…if your ARVs are stopped in a research study the doctors will check your blood tests very, very carefully.”
• Realistic expectations v therapeutic misconception
• "Well he is cured, but when doctors tried it in other patients it didn’t work.”

Community empowerment

• Empower people to challenge medical professionals
• "If my ARVs are helping to keep me healthy i won’t take part in a study that would stop me from taking them. I’m scared of getting sick.”
• Reaffirm the voluntariness of the decision
• "So then I can decide if I want to take part?”
• Involvement of community members in development changed the script
• "If she’s raped she should see the doctor or go to the nearest clinic as soon as possible. If she starts ARVs within the first three days of being raped the ARVs could prevent her from getting infected with HIV. You could also give her these pamphlets and these condoms.”

Conclusions

• Educational interventions should be used in conjunction with other sources of information
• Community engaged process is as important as output
• This video is not intended to replace informed consent but can be used as a consent tool

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