



Designing mobile phone support groups for HIV positive adolescents in South Africa

Background

Despite the overall decline in HIV-related deaths globally, HIV incidence among adolescents remains high. Adolescents are the only group in which HIV-related deaths are increasing¹. To ensure that HIV positive adolescents go on to live healthy lives, high levels of treatment adherence are necessary, however it is widely acknowledged to be problematic amongst adolescents.

It is critical therefore that we develop systematic approaches to understanding and addressing the HIV/AIDS epidemic amongst adolescents both biomedical and psychosocial. Project Khuluma was set up to address the psychosocial impact of HIV on adolescents as in many instances it has been neglected. There is increasing evidence to show that it is intricately linked to health behaviour and outcomes and that social support is a key factor in disease management².

Typical mechanisms for delivering psychosocial support include individual counselling, therapy, group therapy and support groups. In South Africa it has proved to be very challenging to provide such services due to the high numbers of adolescents living with HIV, the lack of trained staff, physical space in clinics and stigma and discrimination. This has meant that for many HIV positive adolescents they receive no counselling or support at all.

Approach

Project Khuluma provides social support to HIV positive adolescents adjunct to the clinical care that they receive. Khuluma provides mobile phone peer led support groups for HIV positive adolescents aged 13-18 years old, using a group SMS technology. Adolescents are divided into closed groups where participants are able to interact with one another, and a facilitator. The adolescents can interact anonymously overcoming concerns that they might have about stigma, communicate from their chosen location. Since October 2013, ninety adolescents attending HIV clinics in Pretoria and Cape Town have taken part.



Results

Khuluma is live and on-going. Pre-and-post interviews are conducted underpinned by the IMB model (information-motivation-behaviour model of health behaviour). Over 50,000 SMSs have been sent amongst the participants, pre-post analysis has indicated a significant increase in social support and a decrease in levels of internalised and attributed stigma. Both of which have shown in other studies^{3,4} to have a positive impact on adherence to treatment protocols and health outcomes. The text message conversations have provided important insights into the issues affecting HIV-positive adolescents in South Africa. Themes include: disclosure, adherence to medication, sexual and reproductive health, relationships, careers and future aspirations.

Disclosure

Disclosure of HIV remains a highly charged issue in many South African communities. It can play an important role to facilitate access to psychosocial and peer support however there is still reluctance to disclose. Participants expressed strong fears that disclosure would lead to rejection, abandonment and discrimination.

Is it wrong to date some one with out tell them ur status?

She must nt tell him crz myb that guy will tell evry guy that she has HIV and no 1 ill date her

Adherence

Acceptance and disclosure of HIV status have been found to be linked to adherence to treatment. Conversations in Khuluma regarding medication are indicative of some of the complexities associated with treatment adherence. When presented with a checklist regarding missed medication, most of the participants indicate that they rarely, if ever, miss a dose of medication. However in the group communication they admit that they don't always take their medication.

Sometimes find it difficult to drink my medicine when I am angry... sometime when I am angry I feel like I dnt deserv to live

Participants would respond by encouraging one another to take their medication:

U have 2try them even when u r angry coz they help u

Information

A large proportion of the messages exchanged amongst the participants are to do with offering and asking for information support, primarily regarding HIV and sexual reproductive health. The groups also served as a space for busting the many myths and misconceptions about HIV/AIDS.

Social Support

Another large proportion of the messages were those in relation to checking-in, offering and requesting general social support, such as when experiencing illness.

I am sick guy sorry 4 bad news bye

Sorry get well soon.

U KNW WAT ITS GREAT TO MKE NEW FRNDZ LIKE U GUY

Guys I am going to bed goodnight and sweet dreams love you all

Conclusion

There has been a very positive uptake from HIV positive adolescents who want to take part along with clinics who want to take part. Evaluation is on-going as we increase the numbers of adolescents that we are working with.

Khuluma provides a feasible model of providing needed social support to HIV positive adolescents from anywhere at any time and understanding the complexities of living with the condition. Additionally it has the advantages of utilising a medium that adolescents are comfortable to discuss sensitive issues in, where they don't have to be concerned with challenges of stigma and discrimination.

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¹ Kasedde, S., Kapogiannis, B. G., McClure, C., & Luo, C. (2014). Executive Summary: Opportunities for Action and Impact to Address HIV and AIDS in Adolescents. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 66, S139-S143.

² Petersen, I., Bhana, A., Myeza, N., Allicoe, S., John, S., Holst, H. & Mellins, C. (2010). Psychosocial challenges and protective influences for socio-emotional coping of HIV+adolescents in South Africa: a qualitative investigation. *AIDS Care*, 22(8), 970-978.

³ Reiser, M. S. L., Mimiaga, M. J., Skeer, M. M., Perkovich, M. B., Johnson, M. C. V., & Safren, S. A. (2009). A review of HIV antiretroviral adherence and intervention studies among HIV-infected youth. *Topics in HIV medicine: a publication of International AIDS Society, USA*, 17(1), 14.

⁴ McDowell, T., & Serovich, J. (2007). The effect of perceived and actual social support on the mental health of HIV-positive persons. *AIDS Care*, 19 (10), 1223-1229.