PROJECT KOPANO

mHealth support networks for those living with HIV/AIDS in the fight towards combating the HIV/AIDS epidemic

THE SHM FOUNDATION

THE NEED FOR SUPPORT NETWORKS

There is a critical need to find new methods and approaches to providing support and counselling to the 33.3 million people living with HIV/AIDS worldwide[1]. Those living or affected by HIV/AIDS can experience numerous day–to-day challenges that can have a detrimental effect on their quality of life, such as stigma and discrimination, fear of illness, depression and fear of disclosure. In 2007 the World Health Organization (WHO)[2] recognised that the involvement of peer support groups can play an important role in helping people to live a healthy and positive life in particular helping to increase the uptake of services. However, despite the recognition of the importance of support groups, there are numerous challenges to providing such a service to the large number of people living and affected by HIV/AIDS worldwide.

Over the past few years the SHM Foundation[3] has been working on these challenges to provide an accessible and a cost effective model for providing support networks for those living with HIV/AIDS. This work has lead to the design and the development of a model where support networks can be set up via mobile phone through the means of group SMS (mHealth Support Networks). The Foundation put forward some seed funding to support the running of three pilots. The first was in Mexico with people living with HIV/AIDS in the state of Jalisco[4] who were particularly affected by high levels of social isolation in relation to stigma and discrimination. The second pilot was in South Africa[5] with pregnant women living with a recent diagnosis of HIV who were enrolled in a prevention of mother to child transmission programme. The final pilot, which completed recently, was with HIV positive parents in the UK who are particularly affected by day-to-day challenges in relation to parenting an HIV positive child or children[6]. The SHM Foundation has worked extensively in this area, gathering evidence on the impact that these pilots have had on improving the quality of life of those living with HIV/AIDS with the vision to now implement the model on a much larger scale, starting with providing support networks for pregnant women living with HIV/AIDS in Pretoria, South Africa.

HOW THE MODEL WORKS

In all of the pilots the foundation has worked with prospective participants to co-design a support model that meets their needs. Each group has ranged between 7-11 members, with the majority of the members living with HIV, but also with group members who are indirectly affected by HIV, as well as a health professional or mentor. The groups have been run in a variety of ways, from taking a free form approach to a more structured approach with 'guest' SMS speakers (health professionals that are invited into a group to run a specific session on a specific topic).

All of the participants were given one single number that they could use on their mobile phone to communicate by SMS with their group. Every time a member of the group would send an SMS, everyone would receive it. All messages were logged and saved in order to moderate conversations and to also be used for evaluation purposes.

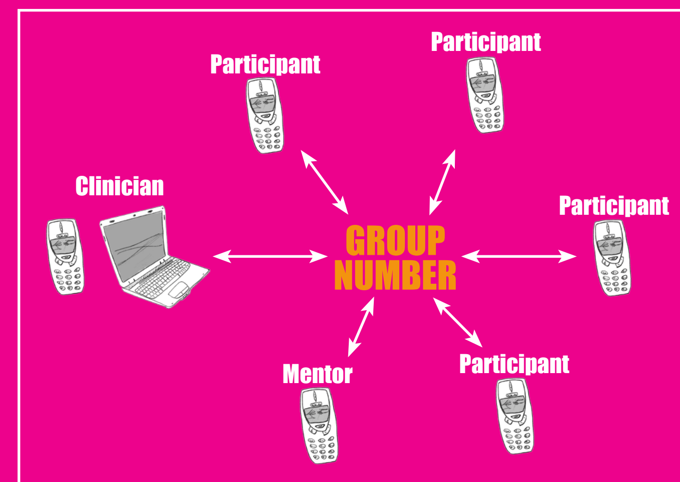

Figure 1. Diagram showing how the group technology works

WHAT THE IMPACT HAS BEEN

All three pilots have provided encouraging results in a number of critical areas:

- In many cases the emotional state of the participants improved. In Project Zumbido in Mexico levels of anxiety, depression and feelings of social isolation decreased significantly.

I felt free. I had the freedom to express myself in the way I wanted to. I had not realised how important that was for me.

- There was an increase in levels of knowledge and information in respect to HIV. In Project Kopano the participants used their groups to ask specific medical questions and concerns that they had. A large number of these messages were in relation to myths. Very quickly a health professional or mentor had the ability to respond to a particular group or member to provide them with accurate information and help dispel myths and misconceptions about living with HIV.
- There was an increase in knowledge in relation to medical treatment such as how to deal with secondary effects of the medication. In Project Zumbido there were two cases of participants who decided to re-take their medication after taking part in the project when they had previously not been taking them. Participants would send encouraging messages to each other.

Hi guys I have a long day ahead of me, so much to do! Have you had your breakfast and taken your pills? Wishing you all a great day.

- There was an increase in levels of knowledge and information in regards to access to services. An example of this can be seen in Project Zumbido where a participant had been suffering from an abscess for eight months on his tooth and had found it difficult to get a dentist that would attend him. He sent out a message to his group to explain the problem and quickly received a response from his group with contact details of dentists that would see him.
- The participants took to the group SMS technology. In Project Zumbido 250,000 SMS messages were sent amongst 40 participants in three months demonstrating the need that this group had to communicate. In both Project Kopano and Parents Aloud a large number of the participants expressed how group SMS was effective for those who did not like or found it difficult to attend face-to-face support groups. All participants in Project Kopano admitted that they would have declined to enrol in a face-to-face support group if it had been made available to them, demonstrating the power that this model can have in reaching out to vulnerable groups.

WHAT HAPPENS NEXT

The SHM Foundation is now at the stage where we feel confident to scale up this model. Specifically we are looking to roll out Project Kopano that came to an end in 2010 to see if this project has the potential to provide large scale support for pregnant women living with HIV/AIDS in South Africa. We want to address whether this model can have a significant impact on adherence rates to Prevention to Mother-to-Child HIV Transmission rates (PMTCT), decrease the rate of HIV transmission to infants and have a significant impact on improving the emotional wellbeing of the participants.

Worldwide perinatal transmission of HIV has become an important part of international efforts to halt the spread of the epidemic in resource-poor settings. This has led to increasing numbers of pregnant women worldwide being tested for HIV as a part of their prenatal care.

IN SOUTH AFRICA, 29 % OF PREGNANT WOMEN ARE INFECTED WITH HIV[7] LEAVING MANY SERVICES OVERBURDENED IN TERMS OF ENSURING THAT THEY GET THE RIGHT SUPPORT THAT THEY NEED[8].

In high income countries mother to child transmission (MTCT) has been virtually eliminated due to access to antiretroviral therapy, safe delivery practices and access to testing and counselling services but there is a critical challenge as to how to improve PMTCT rates in Africa where 90% of the MTCT infections occur[9].

The difficulties that many HIV positive pregnant women can face are often in relation to psychological impact of a diagnosis such as high levels of anxiety, depression, lack of social support and non disclosure to partners and family. As health professionals and policy makers increasingly recognise the psychological impact that an HIV diagnosis can have, the provision of support groups are becoming vital part of comprehensive care particularly in improving adherence rates[10].

Despite these recommendations there are often significant barriers to providing support services in resource poor setting. Many clinics do not have the staff to run support services and there is often the problem that many of the clinics lack the physical space to run them[11]. In addition those who show interest in attending a support group are regularly faced with challenges such as childcare requirements or travel limitations, this can be particularly challenging for those living in isolated and rural areas. Finally the psychological impact of an HIV diagnosis such as social isolation and stigma can lead to concerns about attending a face-to-face support group.

The mobile phone has proved to be an effective tool for creating support groups in the pilots that we have run. There are a number of benefits; firstly the communication is immediate helping to respond to questions and concerns when they arise. It is an intimate form of communication; the majority of the participants who have taken part in the pilots have felt comfortable to use SMS to communicate about a range of psychological and medical questions and concerns. The mobile phone is also accessible to many in rural and urban areas in South Africa[12].

There are also some additional benefits to using the mobile through helping to bridge physical distance and informal hierarchies. Using the mobile has enabled groups to have members that are diverse in respect to their experiences and backgrounds of living with HIV. In Project Zumbido the group members came from a range of experiences, backgrounds and geographical locations which led to interesting debates and discussions on human rights or discussions on the relationship that the church has to the HIV epidemic.

The mobile technology in addition has the benefit of keeping a log of the messages sent amongst the groups. The content of these messages have the potential to be valuable in helping health professionals see where the key gaps are in terms of the participants' knowledge to living with HIV or what types of health messages could work in the areas of prevention or treatment compliance.

The next stage of this pilot will look to work with 1000 pregnant women who have been recently diagnosed HIV positive in Pretoria, South Africa. We will work closely with the University of Pretoria and the Yale School of Medicine who previously partnered with us on Project Kopano to recruit the participants and evaluate the model with a focus on understanding how the operational model will work if expanded to thousands of participants. There will be a particular focus on understanding how the model can become financially sustainable, exploring whether running such a model could generate cost savings for government agencies if it can be proved that adherence rates increase amongst the participants.

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[1] www.avert.org/world-aids-day.html

[2] http://www.who.int/hiv/pub/prev_care/OMS_EPP_AFF_en.pdf

[3] The SHM Foundation (www.shmfoundation.org works globally to bring about positive social change through projects in the areas of Learning and Citizenship, Health and the Arts. The Foundation aims to provide communities and individuals with the practical tools they need to develop innovative solutions.

[4] Project Zumbido (http://www.shmfoundation.org/zumbido.php). This pilot was selected as one of the finalists for the Stockholm Challenge Awards 2008, an award scheme that looks to promote innovative use in ICT.

[5] Project Kopano (http://www.shmfoundation.org/kopano.php)

[6] Parents Aloud (http://www.shmfoundation.org/body_and_soul.php)

[7] South African Department of Health (2009). The 2009 National antenatal sentinel HIV and syphilis prevalence survey. http://www.doh.gov.za/docs/index.html

[8] Comprehensive HIV/AIDS care must include clinical care for everyone, psychological support, socioeconomic support, involvement of people living with HIV/AIDS and their families and respect for human rights and legal needs (A guide to monitoring and evaluation HIV/AIDS care and support, National AIDS Programmes, 2004

[9] http://www.avert.org/motherchild.html

[10] Baek C, Rutenburg N. Implementing Programs for the Prevention of Mother-to-Child HIV Transmission in Resource-Constrained Settings: Horizons Report. PublicHealth Reports. Washington DC: Population Council 2010; 125: 293-304

[11] Kalichman SC, Sikkema KJ. People Living with HIV infection who attend and not attend support groups: a pilot study of needs, characteristics and experiences. AIDS Care 1996; 8 (5): 589-99.

[12] Over 82.9% of the population in South Africa own a mobile phone with widespread mobile phone ownership in both rural and urban areas, making the mobile phone a tool that is accessible to many. http://en.wikipedia.org/wiki/List_of_countries_by_number_of_mobile_phones_in_use