

## [A novel intervention for HIV & AIDS: Books of Hope 'give voice' to new HIV & AIDS prevention initiatives](#)



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Today, approximately 33.4 million people worldwide are living with HIV & AIDS.(2) Efforts to scale up prevention have become the focus of a considerable number of international health care agencies. The World Health Organisation (WHO) has noted a decrease in the number of new HIV infections across the globe between 2000 and 2008, and explains that this success is due, in part, to successful prevention efforts in the fight against HIV & AIDS.(3)

In low- and middle-income countries, there is not only a strong emphasis on scaling up prevention, but also access to HIV treatment and care initiatives as well as intervention programmes.(4) In addition to the heavy burden of HIV & AIDS, these countries are facing a number of psychosocial and public health issues, ranging from high fertility rates to armed conflicts.(5)

This paper discusses the nature and efficacy of a novel intervention in HIV & AIDS prevention that is gaining increasing impetus in the drive to decrease the incidence of the virus. The *Books of Hope* project, which aims to enhance basic health knowledge in low literacy contexts, has developed this innovative multi-media intervention, which they refer to as a 'speaking book'. This represents a new and potentially efficacious method of delivering critical health messages, including those surrounding HIV & AIDS, to low-level literacy communities. In order to appreciate the psychosocial climate and public health sphere within which these books operate, it is first necessary to examine the importance and effects of education and illiteracy on HIV & AIDS prevention efforts.

### **Education and literacy in the context of HIV & AIDS prevention**

Literacy is seen as a fundamental human right. Even so, The *Education for all: Literacy for life* report commissioned by UNESCO, eloquently highlights how "[t]he fact that some 770 million adults – about one-fifth of the world's adult population – do not have basic literacy skills is not only morally indefensible but is also an appalling loss of human potential and economic capacity."(6)The United Nations Educational, Scientific and Cultural Organisation (UNESCO) has consequently called attention to the illiteracy epidemic facing the globe.(7)

Literacy has been identified as a core component of drives to enhance human capabilities across the globe, with resulting benefits including critical thinking, improved health and planning capacities, HIV & AIDS prevention, poverty reduction, and active citizenship.(8) HIV & AIDS, on the other hand, has come to be seen as a significant barrier to development around the world. The influence of the epidemic affects learners and educators, as well as the institutions and forums within which they function.(9) Estimates made in 2008, suggested that by 2010, approximately 10% of primary-school age children in sub-Saharan Africa would have been orphaned by HIV & AIDS, other health crises and political conflicts. This necessitates specialised interventions to ensure their further education and literacy skills development.(10)

Additionally, it is a harsh and unforgiving reality that often, "with HIV & AIDS the consequence of pedagogic failure is terminal".(11) The educational setting provides an invaluable forum for the transmission of knowledge as well as information acquisition skills. In instances where literacy skills are not

available, a vital opportunity is denied to acquire knowledge in both immediate and future contexts. The combination of these factors, in conjunction with the socio-political climate, has produced the overwhelming number of youths who grow to become the adults who today lack basic literacy skills. The urgency of appropriate knowledge dissemination must, in light of this, become apparent.

## **Books of Hope**

In light of the impact of low-level literacy as a barrier to knowledge health issues, including HIV, it becomes critical to account for this in health interventions if the interventions are to be effective in reaching their target markets. As a significant portion of mass media campaigns and health technology information systems are reliant on reading skills as a critical form of communication, high illiteracy rates represent a significant barrier to improved health among HIV risk populations. This issue permeates a number of interventions in low- and middle-income contexts. For example, managing director of the Books of Hope programme and founder and director of the South African Depression and Anxiety Group (SADAG)'s Zane Wilson, has noted that despite the best-practice interventions being implemented by the organisation in South Africa, "It doesn't matter how good [of a publication] I did in Zulu or Sotho or Xhosa, if people can't read and write, they can't read the best brochure in the world".(12) This highlights the acute need for accessible, *functional* education and health literacy tools.

Essentially, the concept of a speaking book is a simple one - a book that 'speaks'. In a 16 page, brightly-coloured and simply-worded format, each book deals with a particular health issue.(13) Topics range over a number of public and personal health concerns, including malaria, HIV & AIDS, hypertension, and tuberculosis, as well as more socially-focussed aspects like the application process for a social grant.(14) These books differ from other awareness texts in that for each page, a corresponding button - annotated on the page with a corresponding image - will play a soundtrack of the text. This means that no matter the reader's level of literacy, the information contained within the book can be read, heard, or both. The books are available in a number of languages, including English, Zulu, Spanish, Mandarin and Hindi.(15) In addition to the text and audio, these messages are accompanied by simple and culturally relevant illustrations.(16)

Evidence is beginning to emerge which suggests that speaking books are an efficacious intervention in low-level literacy populations. For example, a speaking book which deals with the nature of participation in a clinical trial, as well as the ethics and basic rights associated therewith was evaluated in a recent Ugandan study.(17) The results of this study showed a statistically significant increase in the level of knowledge of participants who made use of the speaking book. Further, the results lend considerable support to the assertion that within low-level literacy contexts, such novel techniques for information dissemination have the potential to be critically effective in enhancing levels of knowledge.

## **Speaking books and HIV & AIDS**

HIV & AIDS has been recognised by the Books of Hope programme as an important focus area. To date, six speaking books have been dedicated to the topic, the titles and topics of which are listed in Table 1 below.

### ***Table 1: Speaking book titles and topics***

**Book title**

Living with HIV and AIDS Doesn't Mean Living with Depression

My Body, My Choice

Caring For You, The Caregiver

Safe Disclosure to Children with HIV and AIDS

What You need to know about HIV and AIDS

Coping in a World with HIV and AIDS

Knowledge and Hope About Your Health

**Topic**

Coping with Depression

Teen Sexual and AIDS Awareness

Psycho Social Help for Home Based Care Workers

Parents Guide for Children with HIV & AIDS

Essential information about HIV & AIDS

Important coping skills in dealing with HIV & AIDS

HIV and the use of ARV's

The programme is strongly supported and partnered by SADAG, one of the leading mental health advocacy groups in South Africa.(18) The organisation seeks to redress service delivery, education and social development concerns, with a particular focus on HIV & AIDS and mental illness in under-resourced communities.(19) SADAG representatives have been instrumental in initiating the development of this technology and have contributed expertise regarding mental health needs of low-income communities to enhance the applicability and relevance of the content of these books.(20)

UNESCO has identified the Books of Hope and SADAG speaking books as a useful training and learning support tool, and when highlighting useful resources in HIV & AIDS education, noted how these books are being made freely available to rural communities, funded by the South African Department of Health, the World Bank, and a number of corporations, foundations and NGOs.(21)

**Speaking books users speak**

Interestingly, having cited the partnering of mental health advocacy groups with health and educationally focussed organisations, it is of use to note that the link between HIV & AIDS and mental health is a commonly neglected one. This is despite the fact that research has, in fact, demonstrated an association between HIV & AIDS and the prevalence of mental disorders.(22) In light of this, one of the most promising speaking books currently in circulation is called '*Living with HIV and AIDS Doesn't Mean Living with Depression*' (see Table 1 above). This book is focussed on increasing knowledge surrounding mental health and HIV & AIDS.

SADAG and Books of Hope have begun distributing these books amongst home-based care workers (HBCWs) working in urban communities in South Africa. The responses from some of these carers lend considerable support to the efficacy of these books as intervention. For example, when asked what their patients/clients who had been diagnosed with HIV liked best about the book they noted how the books' format was particularly engaging and how patients wanted to "listen again to other different messages which can help to understand that having depression and HIV & AIDS does not mean to die isolated from the community."(23) They further emphasised that people were now more easily able to identify their symptoms, and seek appropriate

treatment. The accessibility of culturally relevant language and expression enhanced the ease with which patients were able to comprehend the content of the book.(24)

When asked to reflect on new information acquired through the use of speaking books, the participants noted important points such as "symptoms of headaches, stomach aches and more pain than usual may be not only be due to AIDS diagnosis, you may also have depression" and "that depression is a real illness, I thought it is just a feeling and it comes and goes without any treatment".(25) An improved knowledge of symptom aetiology in the context of mental health and HIV & AIDS is reciprocally beneficial in both contexts and may have significant implications.

Of note is the fact that under normal intervention circumstances, a significant aspect of the process of information dissemination and health education occurs through the active involvement of knowledgeable 'trainers', who are not permanently accessible to the communities in which they are involved. Speaking books, however, have the advantage of remaining behind after the intervention or dissemination occurs. For example, in the study cited above, it was estimated that while each book was directly accessed by 59 individuals each, the speaking books reached approximately 11 000 people in the community.(26) This statistic effectively highlights the considerable diffusion of knowledge throughout the community as a result of its members' interaction with the speaking books.

### **Concluding remarks**

The discussion presented here has sought to shed light on a new form of intervention that endeavours to increase levels of knowledge amongst those at risk for HIV and AIDS. The joint product of the Books of Hope programme and the South African Depression and Anxiety Group, speaking books, represent an exciting new avenue for developing effective tools for health promotion.

It is clear that while this is a relatively novel form of intervention, speaking books have the potential to become effective tools in critical health information dissemination in lower- and middle-income community contexts. Particularly within the context of the public health crisis posed by the HIV & AIDS epidemic, such simple and effective tools for improving health knowledge and psychosocial coping skills in HIV risk populations are becoming invaluable.

### **NOTES:**

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