HIV/AIDS programmes: what do learners want?

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We describe how selected adolescent learners experience their current HIV/AIDS programmes in school. The rationale of the instrumental case study was that knowing, appreciating and understanding learners' preferences and experiences should inform future HIV/AIDS curriculum design. Research was conducted at three specifically selected secondary schools (cases). Focus groups and written essays were used as methods for data collection from 90 Grade 11 participants. Whilst learners agreed that HIV/AIDS education is necessary, they suggested that certain changes be incorporated in future HIV/AIDS programmes. They suggested the following innovations: smaller gender-specific groups; outsider presenters; the involvement of parents/caregivers; more variety in the programme format; extended and continuous HIV/AIDS education; acquiring more information about HIV/AIDS care, support and treatment (the current emphasis is on prevention); addressing values and life skills in HIV/AIDS education; utilizing fear-provoking and real-life images and contexts to instil preventive caution. The findings support an integration of HIV/AIDS, life skills and values education into the formal curriculum. This approach is supported in the literature. Further research into learners' preferences and suggestions about the format and content of HIV/AIDS programme development is strongly recommended.

Introduction and background

The purpose in this article is to explain how adolescent learners at three secondary schools in South Africa experienced HIV/AIDS educational programmes presented to them at their schools. It also focuses specifically on what they found beneficial and what their needs would be in future HIV/AIDS programmes. The rationale was that an understanding of how learners experience these programmes could inform future HIV/AIDS education curriculum development.

Whilst the importance of HIV/AIDS education is widely recognised, only 44 of the 107 countries studied in Issues in World Health (2001) included HIV/AIDS education in their school curricula. Even more distressing is what emerged from interviews with 277 secondary school principals in South Africa. They affirmed that while 60% of their learners fall into the moderate or high risk category with regard to HIV infection, only 18% of their schools offered a full sex education programme (Issues in World Health, 2001). Another serious omission is that no current South African HIV/AIDS policies or implementation plans require evaluations of how the learners themselves experienced HIV/AIDS programmes (even though outcomes-based education requires learners to play an active role in creating their personal meanings).

The question that guided this study was: How can learners' experiences of HIV/AIDS education inform curriculum development? But before describing the research itself, we will review both Department of Education policies and curriculum plans and both national and international research into HIV/AIDS education programmes.

HIV/AIDS education

The government's policy on HIV/AIDS education is set out in National Policy on HIV/AIDS (Government Gazette, 1999). It addresses issues such as disclosure and confidentiality, the constitutional rights of learners and educators, non-discrimination and equality, what constitutes a safe school environment. It also mandates that age-appropriate life skills be taught on a regular basis at all schools and institutions to all learners and staff.

Another major policy document is the then Minister of Education, Kader Asmal's implementation plan for Tirisano (Department of Education, 2000). This plan suggests how planners might create the means for understanding how HIV/AIDS is impacting on education. It also aimed to ensure that life skills and HIV/AIDS education would be implemented at all levels, that educators would be adequately trained and resourced, and that awareness would be raised at all levels.

Another important policy document that describes how HIV/AIDS programmes should be implemented in schools is the Gauteng Circular 33/2001 (Department of Education, 2001a).

Kelly's (2002) holistic approach to HIV/AIDS education corroborates the strategy of integration. He emphasises that HIV/AIDS education should engage the whole person, go beyond mere academic and intellectual knowledge, and should include suggestions for real-life action and behaviour. The researchers found that very few programmes throughout the world actually focus on learners' experiences and that the usual emphasis is on changing risky behaviours. Barolsky (2003) notes that this strategy may actually increase the possibility of HIV infection.

Although there is a great deal of research on the impact that attitudes and behaviour has on HIV/AIDS, very few studies in South Africa have investigated the impact of HIV/AIDS education in the formal school sector, and none that the authors encountered focused on the experiences of the participants.

Conceptual framework

The impact of HIV/AIDS on society

Whilst more than 60% of new HIV infections in South Africa occur in the 15 to 25 year-old age group, adolescent girls account for most new infections (Call, Riedel & Hein, 2002). The health of adolescents is determined by their daily experiences and by revolutionary changes in global technologies. These technologies constantly reshape adolescent environments (Call et al., 2002; Giese, Meintjies, Croke & Chamberlain, 2003).

HIV/AIDS is relentlessly changing African demographics. It affects total population loss, population growth rates, crude death rates, fertility rates, life expectancy, age distribution, infant and child mortality, dependency ratios, gender ratios, widow(er)hood, household composition and/or co-residence (Hunter & Williamson, 2001). Whilst this suggests that the role of the family and community is vital in educating young people about HIV/AIDS, the majority of young people in many countries never attend school at all (Giese et al., 2003; UNESCO, 2002).

The literature reveals that parental deaths reduce children's self-esteem and increase the incidence of depression, anxiety, behavioural disturbances, academic problems, somatic complaints and suicidal acts (Rotheram-Borus, Lee, Gwadz & Draimin, 2001). Affected adolescents and their families also experience stigmatisation and discrimination on a daily basis (UNESCO, 2002). Communities and community resources are overextended by large numbers of HIV/AIDS orphans. As communities are increasingly weakened by poverty, hunger and sickness, their participation in self-help activities for schools decreases (Juma, 2001). Hunter and Williamson (2000) note that the vulnerability of children, families and communities is compounded by geographic concentrations of the pandemic.

The impact of HIV/AIDS on the education system

The impact of HIV/AIDS on education is reflected by the number of learners who drop out of school because of the disease. HIV/AIDS keeps children out of school and so prevents the transfer of skills and knowledge (Richter, Manegold & Pather, 2004). The pandemic also
compromises the quality of education because it overburdens all material and human educational resources. A UNESCO study found that in some countries more than one-third of 15-year-olds will die of AIDS-related illnesses. Those who survive will receive an inferior education.

The physical, material, intellectual, educational and psychosocial needs of affected children are radically undermined as they prematurely take over adult responsibilities such as parenting and maintaining households (Giese et al., 2003; Smart, 1999).

Adolescent development and learners' experiences
Because adolescents are economically dependent and socially inexperienced, and have not been taught how to protect themselves from infection, they are more vulnerable than adults in every way (Issues in World Health, 2001). Adolescence is a critical developmental period that has long-term implications for individuals and society as a whole (Call et al., 2001), and adolescence is a time when crucial physical, normative, social, cognitive, emotional and sexual changes occur.

"Experience" is a primary factor in shaping a person's world view (WordIQ, 2004), and adolescents are constantly experiencing developmental changes of every kind. An adolescent's future personal identity depends on how well this stage of development is negotiated (Hendry, Shucksmith, Love & Glendinning, 1993). Although adolescence is a time when adolescents should ideally be attuning themselves to the expectations of society, many adolescents are confused and conflicted because they fail to accommodate themselves to society's expectations during this developmental phase.

Methodology
The researchers adopted a qualitative, interpretivist research approach and a constructivist method for data analysis. They accumulated data on how learners experience HIV/AIDS programmes. This data is rich in descriptive detail about adolescent respondents' actual attitudes and feelings (Morse, 1994). Because the declared research methodology is based on the conviction that human beings construct meaning and knowledge from personal experience, the researchers adopted an inductive approach to their inquiry (an approach that casts researchers in the role of the "co-creator(s) of meaning" (Henning et al., 2004:19).

An instrumental case study was conducted at three secondary schools by using focus groups and written essays to collect data from 90 diverse Grade 11 learners. The selected district contains approximately 200 schools, 60 of which are secondary schools with an average of 400 learners per school. Three of these schools were selected because they had functional HIV/AIDS programmes at various levels. Details about these three schools and their HIV/AIDS programmes are presented in Table 1.

Focus groups of from 10 to 20 Grade 11 learners (totaling 90 Grade 11 learners of 16 to 18 years) from these three schools were selected to take part in interviews. Data were gathered mainly from six focus group interviews, two at each of the three schools, and from written essays by School A learners who wrote a total of 31 essays. The number of learners who participated, and their home language, are illustrated in Table 2.

Responses were audio-taped, transcribed and analysed, and the raw empirical data interpreted in terms of credibility, transferability and dependability. Emergent themes were what learners found beneficial about the HIV/AIDS programme(s) and what they would have liked to see changed.

Discussion of the data
The results will be analysed in terms of three key themes that emerged. These themes were: (1) "There must be new ways..."; (2) "We need to know ..."; and (3) "You have to be scared to get it ....".

All learners in this study agreed that HIV/AIDS education is necessary and there was no expressed opposition to HIV/AIDS education per se. This confirms the findings of Jameson and Glover (1993)
who found that 92% of participants felt that AIDS education could successfully prevent the spread of AIDS. Most respondents felt that unless some interventionist programme is instituted soon, there would be "many deaths", "disaster" and "many innocent victims". This indicated a strong positive belief in the value of education as a means of changing attitudes.

But learners also had very specific ideas about what they wanted and what they did not want in an HIV/AIDS programme. In the following section we discuss these ideas (extracts from learners' contributions are italicised and some are translated from Afrikaans).

"There must be new ways"

Many learner preferences concerned the format of the HIV/AIDS programme.

Most learners felt that the groups were too large to make any useful impact. They also expressed a desire to discuss HIV/AIDS issues in single-sex groups. Girls especially felt that they could have been more outspoken in single-sex groups. Gender issues relevant to gender, power and vulnerability in sexuality and HIV/AIDS transmission were raised by respondents (Human Rights Watch, 2001).

There was a strong desire among learners for a different mode of delivery for HIV/AIDS education. Our education must be more practical. There is no use in just handing out pamphlets. We don't read it. All learners expressed the need for more visual material such as videos and photographs, and a need for personal contact with HIV positive patients. Teenagers should see the suffering. Then maybe they will listen. They wanted fewer facts and more personal experiences and real-life encounters.

The choice of an effective medium determines the success of the HIV/AIDS prevention message. Buseh et al. (2002) emphasise identifying effective channels of communication and developing practical and culturally relevant strategies. All modes of communication should be examined for their potential effectiveness in reaching target audiences.

Participants stated that not enough time had been dedicated to the programme(s). They also felt that HIV/AIDS education should be a regular part of the school curriculum. The programme was too short. I would like to have it every week in school time. Whilst the current outcomes-based curriculum makes provision for Learning Area Life Orientation (of which HIV/AIDS is a part) up to Grade 9 for all learners, and the National Policy on HIV/AIDS is also very clear that a continuing Life Skills and HIV/AIDS education programme should be implemented in all schools, the experiences of learners suggests that this is not happening in all schools.

Jameson and Glover (1993) and Slonim-Nevo (2001) affirm that HIV/AIDS education should take place routinely and frequently in schools. Jameson and Glover also believe that parents, teachers and learners all need continuous education in this field.

Slonim-Nevo (2001:83) states that the Israeli programme was spaced over a period of two or three months. "Such spacing enables participants to digest the material, to experiment with it, and to return to discuss conflicts, experiences, and questions within the group."

The limited role played by parents in the HIV/AIDS programme was discussed as a category in the fourth theme. Many learners felt that their parents could have been more involved in the programme and at home. The education should also start at home so that you can learn to protect yourself ... It is the innocent girl that gets into trouble. Learners wanted their parents to have sufficient information about HIV/AIDS to educate them at home.

Researchers such as Jameson and Glover also believe in the necessity of educating parents. Other studies show that parents themselves believe that they have an important role to play in the HIV/AIDS and sex education of their children (Buseh et al., 2002). Research by Selvan, Ross and Kapadia (2001) among adolescents in India revealed that when parents are better educated and informed, adolescents are less likely to be sexually active.

All focus group interviewees expressed the need for an outside presenter who is HIV positive. We would listen. We don't listen to our teachers. Learners felt that an outsider would make a far greater impact on them. This implies in practice that a variety of outside presenters would have to be utilised so that they would not become "insiders". It would be interesting to speak to someone who has HIV [and to hear] what their lives are like [and] how they feel about it.

Small (1995:25) supports this approach: "It could be argued that teachers are not the most appropriate vehicles for sex education."

Two other studies identify healthcare and social workers as the most suitable presenters in HIV/AIDS programmes. Buseh et al. found that the majority of learners preferred healthcare workers as their main source of preventive messages. Slonim-Nevo (2001) agrees that social work practitioners who have experience of working with adolescents should be the ones to deliver the intervention. This raises the question about the possibility of employing a full-time corps of educators to present the HIV/AIDS curriculum. Current education policy designates teachers as presenters of HIV/AIDS programmes (Department of Education, 2001b). The need that learners have for external presenters is therefore at variance with the Department's instructions. This requires further investigation.

Whilst Slonim-Nevo does not believe in the efficacy of outside presenters, the authors of this paper feel that asking people who are in the initial stages of the disease to present such programmes raises ethical questions, and that great circumspection should be exercised in the selection of suitable presenters.

"We need to know..."

Learners expressed a need for different kinds of information. They felt overwhelmed by too much factual information of a technical kind. We don't want to hear so much about the virus. We know the virus is there. But what must we do [about it]?

Most learners agreed that they had been given more than enough technical information about the HI virus and about other medical matters. What they really wanted was more information about how to cope with AIDS if they or someone known to them were to become infected. It's not only about AIDS. Maybe when you have the virus you have other emotional problems, like getting depression because you know you are going to die. We need to know about this and how to help people who feel that way. These topics interested them intensely, and they are discussed later in the section on care and support. We want to know more about the other things that are related to AIDS once you have it. Like who can help you, where you can go, and so on.

Learners also wanted to know where to go for help. You should also know that when you get it [HIV] there are people who can help you and can teach you to cope with it. This suggests that learners need to feel responsible, useful and empowered rather than merely frustrated and helpless. Barolisky's (2003) view that information about voluntary counselling and testing (VCT) should be included in HIV/AIDS programmes resonates with the need expressed above.

Learners also wanted to know where they could go for care and support. We should get into groups where people have AIDS, and start supporting them. We learn about the blood and so on, but not how to support and deal with someone who has the virus. McNiel et al. (1999) also emphasise the critical role of care and support in assisting people who are HIV positive.

Knowledge about how to care for and support those infected with and affected by HIV/AIDS is required by the whole community and not just by learners at school. Louw, Edwards and Orr (2001:5) believe that all educators should be qualified and equipped to train people to care for and support those infected with and affected by HIV/AIDS. According to the Norms and Standards for Educators, all educators should possess these skills as a part of their "pastoral role".

The main emphasis in the programmes that the researchers examined was on how to make wise decisions in the context of dating and on how to act responsibly in relationships that have a sexual component. Learners were especially interested in how to conduct a relationship with someone who is HIV positive (a fact that once again
demystifies the importance of linking Life Skills and HIV/AIDS education.

Gyarmathy et al. (2002) go further by suggesting that adolescents be taught how to talk to their partners about sex, how to be assertive if necessary, and how to use condoms. They also advocate couple as well as individual education and counselling.

Learners were also very eager to know and see more about treatment, medications and treatment clinics. "We want to see the pills and medicine people who have AIDS must take, and learn about what the medicine does for them."

The Department of Education (2001a) requires that information about treatments be included in the core curriculum of an HIV/AIDS programme.

Providing information on appropriate prevention and avoidance measures, including abstinence from sexual intercourse and immorality, being faithful to one partner, the use of condoms, obtaining prompt medical treatment for sexually transmitted diseases and tuberculosis, and the application of universal precautions when working with body fluids.

Learners also demonstrated a desire to learn about values in these programmes. This correlates strongly with Kader Asmal's emphasis on "values" in education. He says that schools have "an extremely important role to play in supporting the development of our value system and in establishing the regeneration of the ethical fibre of our society" (James, Auerbach & Desai, 2000:3).

Whilst Barolsky supports a return to education based on values, she qualifies this appeal by writing:

"You have to be scared to get it"

We were interested to find that many learners felt that there is a need to instil a fear of the virus. Many learners feel that shocking first-hand visual inputs will make them much more responsible than merely lectures. I think [that] what is important [in] such a programme is to instil fear in learners.

These sentiments are echoed by Gyarmathy et al. They reported that Hungarian teenagers were more likely to use condoms if they were afraid of becoming infected. Rothman and Salovey (1997) call this "message framing", and they believe that effective communications should be "framed" in terms of the possible benefits (gains) or costs (losses) associated with a particular behaviour. Gyarmathy et al. suggest that strong appeals based on fear (coupled with high-efficacy messages) produce the most effective behavioural changes.
In conclusion

Throughout this article we have argued that unless we take cognisance of learners' experiences, the Department of Education's vision will not be realised. Whilst HIV/AIDS programmes and policies for learners have been widely studied and researched throughout the world, the reactions and responses of the recipients (the learners) are seldom acknowledged or accorded the attention they deserve. This research has yielded substantial empirical data from learners, information that could beneficially influence the development of the HIV/AIDS curriculum. With this in mind, we select several significant themes from our data and argue their relevance and appropriateness for the South African HIV/AIDS education curriculum.

We suggest that a comparison of what worked in the programmes to which the learners were exposed, and their expectations of future programmes, could be integrated into recommendations for future programmes. These approaches may be successfully utilised by curriculum developers. Table 3 serves to illustrate one such possible comparison. For practitioners, this overview of HIV/AIDS curriculum content could prove invaluable. Table 3 also illustrates the importance of integrating HIV/AIDS education with life skills education, and the teaching of values in education.

We make no claim that the identified themes are exhaustive or complete, and we suggest the need for further research into various other issues that we identified in our research.

References


Can we avoid a Catastrophe? Issues in World Health, xxix.


Salovey P 2004. The role of fear messages. E-mail received from peter.salovey@yale.edu, 1 September 2004.

Selvan MS, Rose MW & Kapadia AS 2001. Study of perceived norms, beliefs and intended sexual behaviour among higher secondary school students in India. AIDS Care, 13.


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