

Primary School-Going Children's Understanding of HIV/AIDS: A Narrative Analysis

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ABSTRACT The aims of the study were to investigate how primary school-going children understand the HIV/AIDS pandemic and the effect of HIV/AIDS on them. Children's narratives were obtained via four focus groups with a total of 36 children of primary school-going age (average age 7). The results of the study indicated that children's knowledge and awareness was generally adequate for their developmental age as described by Piaget's cognitive developmental theory. However, children from the urban area seemed to have a broader and more accurate knowledge of HIV/AIDS than their rural counterparts. Children from the rural areas also seemed to hold more myths about HIV/AIDS than those from the urban areas. Since parents were an important source of HIV/AIDS information as far as children were concerned, it was recommended that more HIV/AIDS educational programmes should target parents. Also, those involved in the design and implementation of HIV/AIDS educational programmes must ensure that they incorporate accurate and positive African traditional beliefs system.

INTRODUCTION

Research indicates an increase in children infected and affected by Human Immunodeficiency Virus infection / Acquired Immunodeficiency Syndrome (HIV/AIDS) in southern Africa (Joint United Nations Programme on HIV/AIDS 2010). In South Africa, the South African National HIV prevalence, Incidence and Behaviour survey (Human Sciences Research Council 2014) indicated that in the province of KwaZulu-Natal there has been an increase in HIV prevalence in children aged 2 to 14 years. This situation will bring trauma to these children in a number of ways. They are likely to suffer trauma resulting from possible prejudice and social exclusion as societies continue to associate AIDS with promiscuity and drug usage (Walton et al. 2011).

Children affected and infected with HIV/AIDS also have to face and deal with the trauma of witnessing the lives of parents and/or significant adults gradually fading away due to illnesses and eventually dying of AIDS. The psycho-

logical impact on children who witness their parents suffering and eventually dying of AIDS can be more severe than for those whose parents die from more sudden causes (Campbell et al. 2014). The increasing death of adult population is also threatening the traditional family structures. Many children will end up with adoptive families (Carver et al. 2014). Many will also end up in the streets and many of them will end up taking the responsibility of heading their families and looking after their younger siblings (Mangwaya 2013).

The rapid spread of HIV/AIDS pandemic has focused the attention of health professionals and educators on the critical importance of responding to the psychosocial needs of children. In order for interventions to achieve maximum effectiveness and sustainability, research must be informed by an understanding of how mental health issues are understood within a local context (Betancourt et al 2011). Such efforts to match programmes designed to help children is enshrined in the United Nations Convention on the rights of the Child. In South Africa it is also encoded in the South African Constitution, which protects the rights and health of children and ensures that in matters affecting the child, the child's view be heard and given due weight in accordance with the age and maturity of the child (The Republic of South Africa 1996).

Research on HIV/AIDS education for children has long indicated that effective and efficient educational programmes that promote re-

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silience are often those that, firstly, embrace cultural beliefs and behaviours (Mangwaya 2013; Campbell et al. 2012; Gwandure 2008). Reaction to illness and adversities appeared to be influenced by specific social practices and local cultural beliefs and worldviews (Campbell et al. 2012). Secondly, effective and efficient developmental programmes are those that are developmentally based, and that take into account ways in which children of different ages understand HIV/AIDS (Duyan and Duyan 2009). It is therefore important that curricular should incorporate cultural beliefs and should be adapted to the different needs and cognitive abilities of children and adolescents (Walsh and Bibace 1991; Armistead et al. 1999; Tarakeshwar et al. 2006; Ansell 2008).

Joint United Nations Programme on HIV/AIDS (2010) noted the importance of acknowledging that children are different from adults in that they have not yet fully developed their sets of beliefs, rituals, and values. It is therefore recommended that in order to know how children experience the world, individuals who work with children must be guided by children's own behaviours and expressions. In line with this opinion, Walsh and Bibace (1991) developed a cognitive developmental model for describing children's understandings of illness that parallels Piaget's (1936) stages of cognitive development. Bibace and Walsh's model suggests that children's various accounts of the definition, cause and treatment of an illness could be subsumed by three developmental stages, each consisting of two major conceptions/categories, from the least to the more cognitively mature conceptions.

Firstly there is a pre-logical Stage (2-6 years) which is seen as parallel to Piaget's preoperational stage. According to Piaget (1936), children at this stage of development are unable to distance themselves from the environment. This results in them describing cause and effect relationships in terms of immediate spatial and/or temporal cues that dominate their experience. During this stage children would either describe illness in terms of any phenomenon that they have experienced as being associated with illness without any clear differentiation of cause and effect, or they would associate a specific cause with the illness and describe specific symptoms/ effects, but cannot explain how the cause leads to the illness. Walsh and Bibace (1991) call this contagion. An example of phenomenism

would be: 'How do people get colds?' 'From the sun.' How does the sun give you a cold? 'It just does, that's all' An example of contagion would be: How do people get colds? 'From outside.' How do they get them from outside? 'They come when someone gets near you. How? 'I don't know – by magic I think.' (Walsh and Bibace 1991: 36).

The second stage is concrete-logical (7-10 years). The major developmental shift that occurs at this stage is the ability of a child to distinguish self from others. They can also differentiate between what is internal to the self and what is external to the self (Vreeman et al. 2014). Less mature children at this stage describe illness in terms of experienced symptoms, that is, contamination. They can also explain the manner in which the illness is effected. Bad or harmful objects external to the child are viewed as the cause of illness. Children can also explain how a sequence of causal events is effected through physical contact of the child with the person or object or through the child's physical engagement as a whole. An example of contamination would be, What is cold? 'It's like in the winter-time.' How do people get colds? You're outside without a hat and you start sneezing. Your head would get cold, the cold would touch it, and then it would go all over your body' (Bibace and Walsh 1981: 36). Older children in the concrete-logical stage describe illness in terms of internal symptoms or organ malfunction, while its ultimate cause is still seen as external. This external cause, which can be either a person or an object, is linked to the internal effect of illness through the process of internalization, for example, inhaling or injecting. Even though the illness is described in terms of symptoms, it is described in vague terms, which indicates that there is confusion about internal organs and functions. An example of internalization would be: What is cold? 'You sneeze a lot, you talk funny, and your nose is clogged up.' How do people get colds? 'In winter, they breathe in too much air into their nose, and it blocks up the nose.' How does this cause cold? 'The bacteria get in by breathing. Then the lungs get too soft, and it goes to the nose.' (Bibace and Walsh 1981: 37).

The third stage is called formal-logical (11 years and older). During this stage there is a greater amount of differentiation between self and others and between the internal and the ex-

ternal world. Although the source of illness is described as being located within the body, the ultimate source is always described as the external agent (Bibace and Walsh 1981). The explanation of illnesses is based on the interaction between physiological and psycho-physiological causes. Younger children at the formal-logical stage of development, describe the cause of illness as being triggered by external events. However, the source and nature of the illness is described as lying in internal structures and functions. They give a step by step sequence of events involving the interaction of multiple causes and effects that lead to the functioning or non-functioning of an internal organ or process (Walsh and Bibace 1991). An example of a physiological explanation would be: "What is a cold? "It's when you get stuffed up inside, your sinuses get filled up with mucus. Sometimes your lungs do too, and you get a cough." How do people get colds? "They come from viruses, I guess. Other people have the virus, and it gets into your blood stream and it causes a cold" (Bibace and Walsh 1981: 37). The explanations given by the more mature group of children during this stage shows an awareness that a person's thoughts and feelings can interfere with a person's well being. An example of a psychophysiological explanation would be: "What is a heart attack?" It's when your heart stops working right. Sometimes it's pumping too slow or too fast." How do people get a heart attack? "It can come from being all nerve-racked. You worry too much. This tension can affect your heart" (Bibace and Walsh 1981: 38).

Although a study by Hoppe (1995) conducted in the US demonstrated that the number of misconceptions decreased with age in a group of children in Grades 3-6, they also found that children from ethnic minorities, who were most at risk for HIV/AIDS held more misconceptions than their White counterparts. This they attributed to the differences in socio-economic status. Campbell et al. (2012) support this in the study they conducted with the African American children of HIV-infected and HIV-non-infected mothers. Their results also revealed that inner city ethnic minority communities who were economically disadvantaged had limited understanding of HIV/AIDS. This was in line with a more recent study conducted by Zhao et al. (2011), which indicated that children in the rural china also did not have adequate knowledge of

HIV/AIDS. This is an unfortunate situation since HIV/AIDS tends to be more prevalent in low socio-economic status communities (Goodall et al. 2011).

The present study aimed at investigating primary school-going children's narratives of their understanding of HIV/AIDS and the effect of HIV/AIDS on them, by exploring whether these children have knowledge of the disease, exploring the kind of knowledge these children have, and exploring their sources of information about the disease. While previous studies have provided a quantitative analysis of children's understanding within a southern African context, there does not seem to be a study presenting children's narratives.

METHODOLOGY

The researchers utilized a qualitative research paradigm because the study was exploratory by nature and intended listening to the participants' narratives and then formulating an understanding based on their ideas (Miles et al. 2014). As Cresswell (2013) argues, a qualitative researcher learns from the participant's perceptions and experiences, and the way they make sense of their lives.

A total of 32 participants with an average age of 7 years were recruited from two randomly selected primary schools in Pietermaritzburg, KwaZulu-Natal province. Half of them were from a school located in a township in the semi-urban area, and the other half was recruited from a rural school about 100 km from the city of Pietermaritzburg in South Africa.

Data was collected using focus groups. Focus groups with children acknowledge them as experts (Dowling 2014). They therefore help the researcher to discover children's views of their world and, consequently, the results are likely to have high face validity and can be useful in the development of programmes, services or conceptual models (Heary and Hennessy 2002). Focus groups are suitable for exploring how points of view are constructed and expressed. They are particularly suited to the study of attitudes and experiences around specific topics (Miles et al. 2014).

The researchers recruited ten children in each focus group, as per convention, which states that ten participants are ideal for a focus group to effectively serve its purpose (Bloor et

al. 2001). However, eventually each of the four focus groups ended up with eight children participating. Such size was found to be acceptable because the researchers felt that it was conducive to order and attention, particularly considering the average age of the participants. In an attempt to accommodate the particular demands of these participants, each focus group ran for about 45 minutes because all the participants were under 10 years (Hennessy 2002). During each focus group, chairs were arranged in semi-circles to facilitate discussion. Proceedings from all focus groups were recorded using an audio recorder.

Four focus groups, two in each school, were conducted by one of the researchers. The questions asked during each focus group were adapted from the concepts of AIDS protocol used by Walsh and Bibace (1991) in their study on children's understandings of HIV/AIDS in the United States. For the sake of convenience and simplicity to children HIV/AIDS was referred to as AIDS throughout the focus group interviews. The first 5 questions addressed the definition, cause, treatment or prevention of AIDS. Questions were: Have you ever heard of AIDS? What is AIDS? How do people get AIDS? What do doctors do for people with AIDS? What can people do so that they won't get AIDS? By looking at the person, how can you tell if they have AIDS? The last question was added to investigate the children's understanding of the impact of the HIV/AIDS pandemic on them. The question was; How does AIDS affect you as children?

The researchers translated the protocol into isiZulu because all participants were from isiZulu speaking community and the language of teaching and learning in their schools was isiZulu. The advantage here was that two of the researchers' home language is isiZulu, which meant that the researcher had a much better chance of achieving equivalence of meaning. The translated version was then piloted before the final draft was produced.

After being granted permission by the principals and the governing bodies of the two schools, the researcher made appointments to meet the principals and Grade one educators to schedule times to meet with the participants and explain the study and its purpose to them. All the children who volunteered to participate in the study were given short consent letters writ-

ten in isiZulu for their parents to sign and to indicate whether the child could participate in the study. Among those who returned the parents' signed consent form, twenty participants from each school were randomly selected to participate. Four participants from each school were absent from school on the day of data collection. Before the interview, children were given a chance to give verbal assent. The researcher also emphasized to the children that they could stop the interview at any time with no questions asked. Participants were also reassured that their names would remain anonymous. The researcher also explained why she needed to use an audio recorder and again children had to give verbal assent to be recorded. Focus groups were run in isiZulu. At the end of each focus group the researcher conducted debriefing and used the opportunity to provide accurate information where misleading information regarding HIV/AIDS was provided by the participants during the focus group process.

All written transcriptions were then translated by the researchers from isiZulu to English. In order to ensure accuracy in the translation, another first language isiZulu speaker was asked to back-translate from English to isiZulu. The data was then coded. For each question a thematic content analysis was conducted by examining categories linked to meaning units in the text. The themes were then explored across cases. The following guiding questions were asked of the data and used in the process of identifying emerging themes: What did the participants say? How did they say it, and on what bases did they make their statements? How much difference of opinion existed within the group, and what seemed to lie behind these differences? The researcher then moved from description into interpretive analysis (Robson 2006).

RESULTS

Regarding the definition of HIV/AIDS, all participants defined AIDS as a life threatening, an incurable and a terminal disease. Mostly they defined AIDS in terms of its end result, which was perceived to be death. For example, they said;

"(AIDS) is a disease that kills lots of people..."

"(AIDS) is a bad disease, which kills people..."

"...a disease that cannot be cured"

In addition, some participants described HIV/AIDS in terms of opportunistic diseases associated with it. For instance;

"AIDS is TB"

"...it is a non-stop flu"

On the subject of symptoms, the majority of participants from an urban school reported some fairly good and accurate knowledge of the physical symptoms associated with HIV/AIDS. For instance they said;

"People with AIDS get thinner and thinner and eventually become very thin"

"They become regularly tired and sometimes cannot even get out of bed"

"People with AIDS cough a lot"

"People with AIDS get sores all over their bodies and lose a lot of weight"

"People with AIDS always have running stomachs"

On the other hand, even though most participants from a rural school showed correct understanding of the physical symptoms, their knowledge did not seem to be as broad as that of participants from the urban focus groups. Their comments were to a large extent confined to weight problems, instead of many other physical symptoms likely to be evident in a person sick with AIDS. For instance, to a large extent, their comments were;

"They become very thin"

"They lose a lot of weight"

"Their faces become very thin"

"A person's face become hollow and you can see bones"

In addition to physical symptoms, some of the participants also mentioned emotional symptoms. For instance;

"People with AIDS are always angry"

"... because they are always angry, they always keep quiet"

"... they are sad and want to kill themselves"

Concerning the modes of transmission, participants showed an accurate awareness of how a person can get infected. Many of them mentioned both sexual and blood on blood transmission. Examples are;

"If you touch blood of another person who is hurt, you get AIDS"

"If you sleep with someone who has AIDS.."

"If you make a baby with someone who is (HIV) positive"

However, many of the comments regarding blood on blood transmission had elements of imprecise and inaccurate information on how HIV/AIDS get transmitted. Examples are;

"When a person cuts himself and blood comes out, and they touch you, you get AIDS,"

"When they touch you, their AIDS gets into your body and spreads all over your body"

Also, more participants from the rural school than those from the urban school explained transmission of HIV/AIDS from the African perspective of illness. For example they said;

"...if you step on the medicine spread by people who hate you...your will become sick and will eventually die of AIDS"

"Some people are jealous... and they bewitch you and then you get AIDS"

"You can get sick because you are training as isangoma and nurses will say you have AIDS"

Furthermore, unlike the participants from the rural school, most of the participants from an urban school mentioned accurate precautionary measures to be taken in order to avoid becoming infected. Examples are:

"You must never touch blood of a person who is hurt"

"Sick people must be taken to hospital because they will make you sick"

Needs to physically avoid people with HIV/AIDS was the dominant misconception among the participants from the rural school. For example;

"You must never come close to a person who has AIDS because he/she will infect you"

"You must not share a room with someone who has AIDS"

The majority of the participants in this study reported awareness that AIDS is an incurable disease. Their responses also indicated a detailed awareness of the progression of the disease:

"Doctors give them injections and they get better for a while and get sick again"

"Hospitals give them drips and they get better for a few days and get sick again"

"... instead of getting better.....sickness become worse and worse until they die"

Participants in all groups also reported mixed opinions regarding the usage of traditional medicines:

"some people get better but some (people)become worse and worse after drinking (traditional medicine)"

“ ... (they) get better after drinking (traditional) muti¹ because it is stronger than the injections they get from hospitals”

“You must not give them muti when they have AIDS, because muti kill them”

Participants from a rural school mentioned television and radio as the source of information about HIV/AIDS, more often than any other sources. For example;

“I heard from TV that AIDS kills many people”

“I heard from TV that AIDS is a bad disease which kills people”

“I heard from the radio that if you touch the blood of a person that is hurt, you get AIDS”

On the other hand, the participants from the urban school mentioned significant adults more as source of information. For example;

“My mother told me that I must never touch blood of a person that is hurt”

“My father said I must never play with people who have AIDS”

Many of the participants also reported not getting information directly from adults, but through overhearing adults conversations. For example:

“I heard my uncle at home talking about AIDS”

“I heard my aunt and uncle talking about people who have AIDS..”

DISCUSSION

The results of this study indicate an improvement in both the amount of knowledge as well as the level of accuracy of HIV/AIDS-related knowledge in children, than was indicated by the previous studies (Armistead et al. 1999; Duyan and Duyan 2009; Zhao et al. 2011). Various reasons could account for such improvement in children's knowledge about HIV/AIDS. Firstly most of the located previous studies were conducted during the periods when HIV/AIDS prevalence was not as high as it presently is. By then not many children were directly affected and/or infected with the disease as it was not as pervasive as it was in children's environments when the present study was conducted. Second explanation could be that the mass media has been increasingly aggressive in giving out information about HIV/AIDS today.

The level of knowledge that children in this study had about HIV/AIDS is generally consist-

ent with the theory that children's understanding of illness tends to be relative to their developmental stage and that, as indicated by Hoppe et al. (1995), children's misconceptions about illness tends to decrease with age. Children involved in this study were around seven years of age. As expected from children of their age, they were able, for instance, to define HIV/AIDS symptoms and the manner in which people, which was in line with Bibace and Walsh's (1981) theory of contamination. However, even though the amount of understanding of illness displayed by children tends to be in line with their developmental stages, as indicated in this study, the information cannot be expected to be completely accurate. In line with Carver et al. (2014), this could be due to the fact that their sources of information, such as the media and their parents, cannot always be reliable sources to disseminate accurate information. For this reason it is important that formal HIV/AIDS education is offered in schools, where formal assessment measures are in place to assess whether children are getting accurate and adequate knowledge.

The intensity of understanding of HIV/AIDS tends to reflect the differences in children's socio-economic backgrounds. In line with a study by Zhao (2011), the results of this study indicates that children in rural areas who arguably come from a disadvantaged socio-economic background, and who seem to be sharing similar background to those from ethnic minorities in a study by Campbell (2014), tend to have less knowledge than those from urban areas. This may be due to the disparity in resources, with children from urban areas having better access to sources of accurate information. As a result parents tend to be the primary source of information for children in rural areas. It is pleasing that in some countries recognize the crucial role played by parents in empowering children with knowledge in their policies on HIV/AIDS. For instance, in South Africa, parent's role is recognized and included in the South African National Education Policy Act (Department of Education 1996).

In line with Gwandure 2008 the results of this study also indicated that the African view of illness appears to be influential in children's understanding of HIV/AIDS. As Gwandure (2008) indicated, positive cultural beliefs and behaviors that are beneficial should not be discarded. In this way, other cultural myths that

may be contributing to the spread of this disease can also be corrected in children while they are young.

CONCLUSION

The design for this study was informed by Bibace and Walsh's (1981) model for children's conception of illness. The findings suggest that children have knowledge of HIV/AIDS illness. Children's knowledge is appropriate to their developmental stages and appears to be relative to whether they are from urban or rural areas. An interesting finding was also that children's understanding of HIV/AIDS is also informed by the African traditional view of illness.

RECOMMENDATIONS

Sample size in this study limits the generalizability of the results to larger populations. Also, only those children whose parents gave consent for participation took part in the study. Since parents are the significant source of HIV/AIDS, particularly in rural areas, it could be that those parents who refused consent neither discuss HIV/AIDS openly with their children nor allow their children access to mass media information on HIV/AIDS. Follow-up studies using a larger sample and with children at wider range of developmental stages will be able to give a bigger picture of children's understanding of HIV/AIDS.

NOTE

1. Muti is a word in isiZulu language that is used to refer to traditional African medicine.

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