

Mental Health of HIV Positive Adolescents in Zambia

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ABSTRACT

Objectives: To assess the mental health of HIV positive Zambian adolescents by comparing with Zambian school sample and an age matched British normative sample.

Design: This was a cross-sectional study of adolescents from school in the age range of 11-15 and HIV positive adolescents from clinics in Lusaka.

Main outcomes: Mental health of HIV positive Zambian adolescents.

Measures: Mental health was assessed using the Strengths and Difficulties Questionnaire (SDQ).

Results: When compared to the school sample it is found that both the groups are almost similar in the SDQ scales. Although the HIV group seem to have more peer problems, the difference does not reach a level of significance. The HIV sample was also less likely to be in the abnormal range for conduct problems (OR = 1.8). But when compared to a British community sample the Zambian HIV positive adolescents had increased emotional symptoms (OR= 3.6) and peer problems (OR= 7.1).

Conclusion: Zambian HIV positive adolescents had increased mental health problems compared to a British Community sample.

INTRODUCTION

Sub-Saharan Africa contains almost two thirds of all young people living with HIV or AIDS¹. Almost 25 years after the first cases of AIDS were recognized, the HIV pandemic continues to pose extraordinary challenges to individuals, families and communities around the world, especially in developing countries. Young people seem to be the fastest growing age group of HIV positive individuals². They make up a segment of the population that is particularly vulnerable to HIV as they are particularly affected in terms of transmission, vulnerability and impact. Factors leading to the vulnerability of young people include lack of knowledge about HIV and AIDS, lack of education and life skills, poor access to health services and commodities, early sexual debut, early marriage, sexual coercion and violence, trafficking and growing up without parents or other forms of protection from exploitation and abuse³.

HIV is a serious health concern among children and young people in Zambia, by the end of 2002, 85 000 children (0-14 years) were reported to be living with HIV⁴. This figure may be an underestimate as numbers may have risen as more children are surviving into adolescents due to the increased availability and quality of antiretroviral therapy⁵. In contrast to prenatal infection, the HIV infection among adolescents has been unconstrained. Although progress in medical research has rendered HIV and AIDS both preventable and manageable prevalence of HIV in sub-Saharan Africa is highly concentrated. Moreover children and adolescents are the most affected group in sub-Saharan Africa; they are at a risk of becoming infected early in life through maternal transmission or in adolescents through risky sexual behaviour⁶.

Keywords: HIV, adolescents, mental health, SDQ, Zambia

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HIV and AIDS meets the criteria for a chronic illness as there is no known cure for AIDS, the treatment can only reduce the viral load but cannot eradicate it⁷. But this transition of HIV and AIDS to a chronic illness does not seem to be evident in sub-Saharan Africa in earlier literature⁸. However, later literature indicated this to be a scenario in sub-Saharan Africa also⁹, and many familial, social and contextual factors seem to determine the psychosocial outcome and neurodevelopmental functioning in children. Due to the chronic nature of HIV infection, psychological distress may be common in HIV positive adolescents. According to a review by Brown et al¹⁰, HIV positive children and adolescents face more subjective distress than uninfected children and adolescents. The distress arises from many stressors related to HIV such as disclosure, stigma, fear of death and family conflict. The social and economic pressure on adolescents, especially girls, to become sexually active at an early age, plays a major role in this¹¹. Adolescents who are HIV positive, together with other challenges of adolescence also have to deal with a chronic illness which may place various restrictions on their life style. Findings such as this may be indicative that although there have been changes in prevalence and treatment in many aspects of HIV and AIDS, children's and the families' reaction to HIV and AIDS may have remained relatively unchanged, including exposure to stigma and discrimination. It is also well recognised that HIV and AIDS has a profound impact on intimate and social relationships, especially in adolescents. The fact that the illness can be transmitted through sexual behaviour may have a profound effect on intimate relationships. The ART regimen is also complex and requires rigid schedule and restrictions to be followed and not equally effective for all patients¹². This may again place restrictions on the life style of the adolescent.

As a result of the increased numbers of young people who are living with HIV, there is also an increased awareness about the social consequences that seems to have resulted from that¹³. A major concern regarding HIV positive young people comes from research evidence from developed countries that indicate that HIV positive children and young people are at increased risk of psychiatric disorders⁴. This is of particular concern since stress and psychological status may affect disease progression

in HIV infected individuals and psychosocial factors have been shown to have clinically significant relationships with immune related outcomes for HIV. However there has been little research into mental health of HIV positive young people, especially in Zambia.

METHODOLOGY

Selection and description of participants

The sample was recruited from schools and clinics in Lusaka. The school sample was recruited from Basic Schools in Lusaka. One of the schools was a girls-only school and the others were mixed schools. The inclusion criteria were that the participants should be attending one of the 5 basic schools in Lusaka which were participating in the study and in school grades 5 to 9.

A convenience of clinic sample was recruited from the Family Support Unit (FSU) at University Teaching Hospital, Lusaka, and from 5 clinics under the Urban Lusaka District Health Team. Children who were HIV positive and in the age range of 11 – 15 years old from FSU and the identified clinics were considered eligible to take part in the study. Initially children were recruited only if they were English speaking but later the translated versions of the questionnaire were used to broaden the sample to include non-English speakers.

Measures

The self-report version and parent report version of the Strengths and Difficulties Questionnaire, a brief behavioural screening instrument¹⁵ was used to assess emotional and behavioural problems in the participants. A structured researcher-completed questionnaire was used to obtain data on age, gender, family circumstances and perceived health status. Additional information was obtained from the HIV positive participants' medical records.

Procedure

School sample were recruited from 5 Basic Schools in Lusaka. The schools were chosen based on their willingness to participate. The participants for the study were recruited through the Heads of the study schools who were sent a letter explaining the purpose of the study before an appointment was made to visit the school. During the initial meeting with the Heads of Schools the information sheets

and consent forms were given for the children to take home to parents/guardians. Parents who did not wish their child to participate in the study were able to withdraw their child by sending back the consent form with their unwillingness indicated in it. A week later, the schools were contacted and appointments were made to collect data from students. The researcher and the research assistant met the students from the pre determined grades who had a free period during the appointed time. The purpose of the study was explained to the participants and informed verbal consent was obtained. SDQ was administered in groups of 20-30 students, grouped according to their year of study (grade). Participants were asked also to complete the demographic questionnaire beside SDQ (US English) and were encouraged to seek clarifications whenever necessary. Standard explanations in simple English were given for some items which did not have a direct equivalent in local dialect and which were unclear to some students (e.g. “nervous” and “fidgeting”).

Clinic sample meeting the inclusion criteria were recruited by clinic staff from Family Support Unit (FSU) at the University Teaching Hospital or from the chosen clinics. The parents/care givers were invited to come to the clinic on appointed day along with their child. After the purpose of the study was explained and consent obtained, the SDQ (parent version) was given to the parent/ care-giver to complete on their own. No discussion of the answers was permitted with the child or other parents. In cases where the parent/care-giver did not understand English, the SDQ was completed with the help of a research assistant using the translated version.

The children were met individually in a private room within the clinic. The participants were given the information about the study and what would be required of them. Confidentiality was assured and verbal assent was obtained from them before data collection. The demographic questionnaire was administered first to establish a rapport and to establish the child's level of English. In every case the researcher offered to read the SDQ aloud to the child in English. If the child had problems understanding English, a research assistant would again read aloud the statements from the translated version.

Data analysis

For the purpose of this paper, the SDQ parent report data was not analysed. Statistical analysis was carried out using SPSS version 11.5 for windows, where recoding and the syntax were applied as recommended by www.sdqinfo.com. Odds Ratio (OR) was calculated to compare the SDQ scores of the HIV positive participants with the school sample and a UK normative sample.

Ethics

Ethical approval was obtained from the University of Zambia Research Ethics Committee prior to the commencement of the study.

RESULTS

Response rates and demographic characteristics

School sample

At the time of the study there were 702 on roll in the targeted year groups of whom 438 (62.5%) were recruited to the study. No child refused to take part, but 18 responses (4.1%) were excluded because of extensive missing data and 245 were absent on the day of testing, giving a useable response rate of 59.8%.

The sample included 227 girls (54%) and 192 boys (45.7%), one participant failed to indicate their sex on the questionnaire and were in grades 5 to 9. The mean age of the sample was 13.1 years (SD= 1.2, range: 11-15). The majority of participants (55.2%) lived with both parents, 105 (25%) with a single parent, 69 (16%) with relatives (including grandparents) and a relatively small percentage 12 (2.9%) with no family members.

Clinic sample:

Of the 143 children identified from FSU and clinics as meeting the inclusion criteria 127 (89%) were recruited. In four cases consent could not be obtained and six children were missed due to time constraints. SDQs were discarded completely for two children (1%) due to a lack of demographic information.

All the participants were HIV positive and majority (73.2%, N=93) were on antiretroviral (ARV) treatment. Most of them (88.2%) visited a health clinic but only 42.5% reported that they had health problems. The majority of the sample did not know

their HIV positive serostatus (58.3%, N=74).The primary care-giver was most likely to be the child's mother (26.8%), followed by a grandparent or aunt. All most all of them (96.9%, N=123) were infected perinatally.

Emotional and Behavioural well being based on SDQ self report scores

Odds ratio was calculated to compare the SDQ scores of the self report of a British sample of 4228 children aged between 11 and 15, and SDQ scores of the self report of a Zambian school sample of 420 children aged between 11 and 15 with the SDQ scores obtained by the participants. Compared to the British sample, it was found that there was over double the chance of scoring in the 'borderline' or 'abnormal' range for total difficulties in the Zambian HIV positive sample. The Zambian HIV positive participants also scored higher on emotional difficulties scale. The odds ratio shows that the group was over five times more likely to have emotional symptoms. The chance of the Zambian HIV positive sample experiencing peer problems was over seven times that of the British community sample. The SDQ scores of the school sample and clinic sample were comparable. Although the HIV group seem to have more peer problems, the difference does not reach a level of significance. The HIV sample was also less likely to be in the abnormal range for conduct problems.

Health problems of clinic sample compared to SDQ self report score

Majority of the sample reported that they had no health problems (57.5%, N=73). Those who reported health problems had higher total SDQ score (median = 12.0) compared to those who did not report health problems (median = 9.0) (Table 2). This was found to be significant (P <0.05, Z= -2.027).

Table 2: Health related problems in clinic sample compared to total SDQ score

Health related problem	Yes Median total SDQ-Y (IQ range)	No Median total SDQ (IQ range)
Taking antiretrovirals (ARVs)	10.0 (7.0-16.5)	11.0 (7.0-16.5)
Any health problems	12.0 (8.0-18.3)	9.0* (5.5-15.0)

* p<0.05

Table 1 Odds ratios for SDQ-Y scores in the sample of Zambian school children (n=420) borderline or abnormal range for the sample compared to an HIV positive Zambian sample (n=127) and UK sample normative sample (n=4228).

	School sample (a) % (n)	UK sample (b)* % (n)	HIV+ve Sample (c) % (n)	Odds ratios
Total difficulties	27.8% (116)	16.5% (698)	29.1% (37)	a vs c OR=0.9 (0.6-1.4) c vs b OR=2.1 (1.4-3.1)
Emotional symptoms	30.1% (126)	11.2% (474)	31.5% (40)	a vs c OR=0.9 (0.6-1.4) c vs b OR=3.6 (2.5-5.4)
Conduct problems	37.7% (158)	21% (888)	25.2% (32)	a vs c OR=1.8 (1.2-2.8) c vs b OR=1.3 (0.8-1.9)
Hyperactivity	7.4% (31)	21% (888)	9.4% (12)	a vs c OR=0.8 (0.4-1.5) c vs b OR 0.4 (0.2-0.7)
Peer problems	34.4% (144)	9.2% (389)	41.8% (53)	a vs c OR=0.73 (0.4-1.1) c vs b OR=7.1 (4.9-10.2)
Prosocial scores	14.3% (60)	8.6% (364)	10.2% (13)	a vs c OR=1.5 (0.7-2.7) c vs b OR=1.2 (0.7-2.2)

*results taken from www.sdqinfo.com

a=Zambian school sample, b=UK normative sample, c=Zambian HIV positive sample

DISCUSSION

HIV and AIDS is now the leading killer in Zambia and as ART is becoming accessible, increasing numbers of children who were infected perinatally are surviving into adolescence. Many studies are suggesting that HIV positive individuals may experience significant amount of stress in living with the chronic illness¹⁶. The participants in this study were at high risk of mental health problems as indicated by the higher score of total difficulties and twice the risk of being borderline or abnormal for total emotional and behavioural problems, when compared to the British sample. Given that HIV prevalence rate is high in Zambia behaviour problems are also more common among adolescents¹⁰.

In accord to earlier studies^{10, 17} we found that the clinic sample also had higher emotional difficulties than that found in age matched UK sample. Physiologically HIV may affect the brain structures involved in emotional and behavioural regulation and psychologically having to cope with a chronic illness, treatment, care factors may lead to psychological distress. The introduction of antiretroviral therapy (ART) needs adjustment to its regimen, therefore with the introduction of ART, not only the survival rate of children has increased but also the psychological problems accompanying it¹⁸.

The clinic sample had over seven times the risk of experiencing peer problems when compared to British normative sample. Although previous studies have not been able to establish the reliability of the peer relationship sub scale¹⁹, it does not appear that over-reporting of symptoms is occurring as seen by comparable conduct problems and prosocial scores. The possibility of stigma experienced by this sample¹⁰ could be a possible explanation for this.

In a South African study to investigate the psychological well being of children orphaned by AIDS using SDQ, it was found that orphans were more likely to perceive themselves as not having any good friend²⁰. The orphans were more likely to experience extreme difficulty in concentrating, but other aspects of hyperactivity were not apparent. They were also less likely to display anger through loss of temper. Our sample also had low scores on

hyperactivity sub scale when compared to the UK sample (O.R. = 0.4).

When comparing the school sample and HIV positive sample, it is found that both groups are almost similar in the SDQ scales. Both groups have similar rates of emotional difficulties. This may be suggest that it may not be necessarily the HIV status that contributes to emotional problems but other circumstances common to both groups such disadvantaged socioeconomic background. This is in agreement with the study by Costello et al²¹ which found higher rates of psychiatric disorder to be associated with poverty and moving out of poverty reduced behavioural problems²¹. Given the high rate of HIV prevalence in Zambia, we cannot overlook the fact that some of the school sample may also have been HIV positive. Therefore, comparing the mental health of HIV positive sample with a sample of school children may reduce the effectiveness of the study to identify differences. Although the HIV group seems to have more peer problems, the difference does not reach a level of significance. The HIV sample was also less likely to be in the abnormal range for conduct problems. However, when compared to the UK matched sample, this group had low scores on hyperactivity sub-scales. Studies also suggest the possibility of HIV positive individuals to develop opportunistic infections²². Therefore being physically sick may be a restrictive factor in determining their physical activity, thereby contributing to low scores on hyperactivity and conduct problem subscale.

CONCLUSION

There have been very few studies on mental health in Africa. The clinic sample consisting of HIV positive adolescents seen to be is at a greater risk of mental health problems than a British community sample. Since the mental health of the school and clinic sample is comparable, mental health may also be determined largely by pressures of life.

Strengths and limitations

The major strength of our study is the use of a large sample and moderately good response rate. However our school sample may not have been a representative sample of Zambian adolescents as most of the participants lived in homes with an earning family member and majority lived with both

parents. The high rate of school sample absent on the day of the study may have had some impact on the representativeness of the sample. There was insufficient data on the actual number of HIV positive adolescents in Lusaka eligible to participate in the study. A high proportion of the children were on ART cannot be taken as representative due to the recruitment process occurring at some ARV dispensing clinics.

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