The Psychosocial Problems of Children with HIV/AIDS on Antiretroviral Treatment in South Africa

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Abstract

South Africa's AIDS epidemic is one of the worst in the world, not showing evidence of a decline. Fortunately, ARV treatment programs are starting and expanding, which results in a change in the disease progress from deadly to chronic. This is the first part of a longitudinal study on behalf of the AIDS Office of the Southern African Catholic Bishops' Conference, that provides antiretroviral medication to a large and growing number of people in South Africa. The purpose is to examine the differences in psychosocial problems between HIV infected children entered in the ARV-program and children without HIV/AIDS. Psychosocial problems has been operationalised as depression/anxiety, withdrawal and social problems. 69 Interviews have been completed with the primary caregivers of HIV infected children on treatment (age 4-12; 39 male, 30 female). Another 69 interviews were held with the teachers of the control group, consisting of 69 children that were not infected with the virus (age 4-12, 29 male, 37 female). These interviews contained 46 questions, a compilation of the scales concerning internalising problems from the Child Behaviour Checklist (CBCL) and the Strength and Difficulties Questionnaire (SDQ). The HIV/AIDS infected children were expected to have more psychosocial problems than the control group. The results did not confirm this expectation: no significant differences where found between the two groups, even after controlling for several possible covariates. Significant differences were found in the amount of traumatic experiences between the two groups; the experimental group had encountered more trauma. Remarkably, this does not appear to have an effect on the psychosocial problems experienced by these children. In addition, the orphaned children living within the extended family system experienced significant more psychosocial problems than children living with their parent(s) or in an orphanage. Concluding, these findings indicate that the HIV/AIDS infected children experience approximately the same amount of psychosocial problems as the control group, in spite of the large difference in traumatic experiences or environments they live in.

Keywords: South-Africa; HIV/AIDS; Depression; Anxiety; Withdrawal; Social problems; Orphans; Trauma; Children

Introduction

Since the beginning of the Acquired Immuno-Deficiency Syndrome (AIDS) epidemic in the late 1970s, more than 25 million deaths worldwide have occurred due to illnesses associated with the virus (UNAIDS/WHO, 2005). Of these deaths, many were children. More than half a million lives of children were claimed by the virus in 2005. Southern Africa remains the worst affected sub region in the world, and South Africa has, along with India, the highest number of people living with Human Immunodeficiency Virus (HIV) worldwide. In 2005 there was an estimated number of 5.5 million people (18.8% of the adult population) living with HIV in South Africa. Unfortunately, South Africa's AIDS epidemic – one of the worst in the world – shows no evidence of a decline (UNAIDS, 2006).

AIDS is the final stage of infection with the retrovirus HIV. This virus gradually impairs the immune system which is crucial for the suppression of infections, viruses and bacteria. As the immune systems weakens, HIV infected patients become infected with opportunistic infections. HIV/AIDS is a chronic disease and without treatment patients will eventually die. New advances for treatment of HIV using Highly Active Antiretroviral Therapy (HAART) have dramatically improved disease prognosis (Tate et al., 2003). Antiretroviral therapy (ART) in children preserves or restores immune function; provides sustained suppression of the viral load; promotes or restores normal growth and development; improves the quality of life; prevents complicating infections and cancers; and prolongs the child's life. Yet an outright cure remains elusive, leaving patients with the challenges of living with a chronic medical condition (Tate et al., 2003).

A number of cross-sectional studies have found that chronically ill children are at increased risk of psychosocial problems. These children have been reported to have lower self-esteem, poorer body-image and more problems in psychological well-being, behaviour and social adjustment than those without chronic conditions (Huurre & Aro, 2002). HIV-positive patients can live a longer life because of medical and social advances like ART, but treatment programs have not been able to eradicate the virus and cure the disease. As a result, patients are living longer with a chronic condition that continuously presents social, physical, and psychological challenges (Capaldini, 1999; Tate et al., 2003). Consequently, HIV-infected patients, like all patients with chronic medical disorders, are at increased risk for specific psychiatric and psychosocial problems. Various studies have linked HIV/AIDS with a number of psychosocial problems, depression being the most common one (Capaldini, 1999; Lichtenstein, Laska & Clair, 2002; Tate et al., 2003; Wachsler-Felder & Golden, 2002).

Children are affected in different ways by the HIV/AIDS pandemic. Many children are infected with HIV, and all children in regions with high HIV prevalence are likely to be affected by the ensuing deterioration of services, the weakening of social institutes and high levels of stress. Another category of children affected by HIV/AIDS are children who lose a parent or parent-substitute; children who live in a household in which one or more people are ill, dying or deceased; children whose caregivers are too ill to continue to look after them; children living with very old and frail caregivers (Richter, Manegold & Pather, 2004). So in addition to dealing with HIV/AIDS, due to the severity of the epidemic in Southern Africa, many African children face recurrent losses among family members and guardians, as well as the loss of familiar surroundings and schooling. Thus, the psychological impact may also be recurrent (Atwinea, Cantor-Graae & Bajunirweb, 2005). The worst affected children – those in deeply impoverished households – are losing their health (through infection, inadequate nutrition and poor health care), their livelihoods (through the illness and death of breadwinners and working adults), their parents (to illness and death), their families (as they are separated from caregivers and siblings) and their social networks.

Children suffer tremendously when their parents are infected, and the needs of children with infected parents are often neglected. According to Wood, Chase & Aggleton (2006), AIDS-related bereavement is likely to be particularly complicated and difficult to accommodate. Grief may precede the actual death in the form of 'anticipatory loss', and AIDS-related death may be more stigmatised. Children often witness debilitating illness and may experience compromised parenting. In many African societies there is no tradition of talking to children as equals and on an intimate basis, and caregivers often report seeing 'the suffering of children, (…), seeing and hearing everything but never addressed directly' (Van Dyk, 2001, p. 219). In many contexts in southern Africa, children's emotional needs are not responded to in ways which help children to cope. Children are, for example, seldom told about their parent's death in an effort to protect the child (Richter et al, 2004). Death is considered to be an inappropriate topic for children. During her research, Posel (2004, p.18, in: Wood et al., 2006) was told by her adult informants in rural South Africa that children were often simply told that someone had 'gone away'.

Numerous children lose their parents and become orphans. Eleven countries in Africa have an orphan prevalence rates of 15% or more with AIDS responsible for up to three quarters of parental deaths. In sub-Saharan Africa, most children who are 'double' orphans have lost both parents because of AIDS (Foster, 2006). Traditionally, the extended family system would have provided support for these orphans. But because this system is greatly overextended in those communities most affected by AIDS, it can often no longer take care of its orphaned children

(Foster, 2000; Van Dyk, 2001, p. 269). In addition, many families don't want to look after AIDS orphans because of the stigma associated with AIDS deaths in many communities (UNAIDS, 2004). Aids-related stigma and discrimination remain the greatest obstacles to people living with HIV infection or Aids. Stigma and discrimination increase people's vulnerability, social isolation, deprive them of their basic human rights, care and support, and worsen the impact of infection. Stigma and discrimination also intensify violations of the rights of AIDS orphans – in particular their access to education, social services and community and familial support (Kang, Rapkin, Remien, Mellins & Oh, 2005; Van Dyk, 2001, p. 269).

Previous research on the impact of HIV/AIDS has focused generally on adults. Richter et al. (2004) argued that, particularly where children are concerned, HIV/AIDS needs to be treated as a broad developmental concern rather than as a narrow health or even public health issue. However, the majority of the studies performed on children have been conducted by researchers working for the medical discipline. This research consists mainly of the immunological, medical, and neurological consequences of the disease and tends to neglect the psychosocial effects (Wachsler-Felder & Golden, 2002). The purpose of this study is to extend research that has been done so far and to emphasize a psychosocial point of view.

Theoretical developmental models concerning the psychosocial consequences of HIV/AIDS as a chronicle disease are not yet available, given that antiretroviral therapy is relatively new. Despite all the published paediatric findings concerning children's understanding of illness and pain and the effects of hospitalisation, the ideal of a developmental psychology of illness is nowhere in sight (Wenar, 1999, p. 284). Additionally, these paediatric findings may be culturally biased because of the dominance of western research populations.

This research has been done on behalf of the AIDS Office of the Southern African Catholic Bishops' Conference (SACBC) that provides antiretroviral medication to a large and growing number of people. This office funds clinical programmes in the southern African region, for instance small NGO projects, home-based care programmes, training programmes and capacity building at local level. A special focus lies on building the response to AIDS in the region. The positive influence of the antiretroviral therapy on the physiological well-being of patients is evident, but little is known about the psychological impact. Consequently, the main question in this study is*:* Is there a difference in psychosocial problems between HIV infected children entered in the ARV-program and children without HIV/AIDS?

Within the capacity of this study, it was decided to focus on internalising psychosocial problems only. Therefore, the main question results in three research questions. These

questions are based on the internalising scales of the Child Behaviour Checklist (CBCL) and the Strengths and Difficulties Questionnaire (SDQ). These scales measure three psychosocial factors, respectively depression and anxiety, withdrawal and social problems. The first three research questions are based on these factors.

1. *Is there a difference in the level of depression and anxiety between HIV infected children entered in the ARV-program and children without HIV/AIDS?*
2. *Is there a difference in the level of withdrawal between HIV infected children entered in the ARV-program and children without HIV/AIDS?*
3. *Is there a difference in social problems between HIV infected children entered in the ARV-program and children without HIV/AIDS?*

Obviously, there are several conditions apart from the HIV status of a child that can influence these psychosocial factors. HIV positive children have to deal with their own mortality and uncertain future, suffer from trauma and grief as they watch their parents die, lose siblings and other family members, are often stigmatized and discriminated against, and numerous children live in poor households – with HIV often perpetuating the vicious cycle of poverty (Domek, 2006). All these circumstances could be described as extremely stressful and traumatic. Therefore, trauma will be taken into account as a covariate in this study. Furthermore, the role of primary caregivers is important, as many orphaned children live with different kinds of primary caregivers in South Africa. Normally in African cultures the extended family network adopts these children, but as mentioned by Foster (2000), this system is eroded and many child homes and orphanages take this responsibility. Because these caregivers play different roles for the HIV infected orphaned children, and institutionalisation comes with different socio-economic circumstances, these influences will be included as a covariate as well. Apart from these issues, a number of key demographic dimensions mediate the impact of HIV/AIDS on children, families and communities. These contain for instance gender and ages of affected children (Richter et al., 2004), and will therefore be included as covariates in the study. By including relevant covariates in the statistical analyses, the results will give more accurate answers on the main research questions mentioned above. Accordingly, the four issues mentioned above result in the following research questions:

4. *Does the amount of traumatic experience a child has encountered relate to the level of depression and anxiety, withdrawal, and social problems?*
5. *Does the age of a child relate to the level of depression and anxiety, withdrawal, and social problems?*

6. *Does the gender of a child relate to the level of depression and anxiety, withdrawal, and social problems?*
7. *Does the type of primary caregiver of the child relate to the level of depression and anxiety, withdrawal, and social problems?*

It is clear from the research to date that psychosocial problems exist in many children infected with HIV. In this previous research HIV/AIDS has been linked with a number of psychosocial problems, like lower self-esteem, more problems in psychological well-being and social adjustment, and depression (Capaldini, 1999; Huurre & Aro, 2002; Lichtenstein et al, 2002; Tate et al, 2003; Wachsler-Felder & Golden, 2002). Therefore, our main expectation is that there will be a difference in psychosocial problems between the two groups, to the detriment of the HIV infected children.

Methods

Subjects

The experimental group consists of 69 children, age 4-12 year. Among them, 39 are male and 30 female. The mean age of the experimental group is 7.66 years, with a standard deviation of 2.33 years. These children all have AIDS and are involved in an antiretroviral treatment program. The participants are recruited from different sites in South-Africa, located near Tzaneen, Johannesburg and Durban. At these sites antiretroviral medication is provided by the AIDS Office of the Southern African Catholic Bishops' Conference (SACBC). A breakdown of age and gender for each location is shown in Table 1.

Table 1. Participants Experimental Group.

Location	Males 4-12	Females 4-12	Total
Nazareth House, Johannesburg	7	5	12
St. Francis, Boksburg	4	2	6
Sizanani Village	9	4	13
Winterveld, Pretoria	4	4	8
Lily of the Valley, Mariannhill	6	5	11
Ethelberth, Mariannhill	2	1	3
Holy Family, Tzaneen	3	3	6
Bela Bela / Warmbath	4	6	10
Total	39	30	69

The experimental group will be compared to a group of 69 children that are not infected by HIV/AIDS, the control group. This group includes 32 male and 37 female participants. Among them the mean age is 9.17 years, with a standard deviation of 1.96 years. These children are approached at different elementary schools and orphanages near the locations of the experimental group (see Table 2).

Table 2. Participants Control Group.

Location	Males 4-12	Females 4-12	Total
Loreto School, Pretoria	15	18	33
Primary School in Mmakau	8	8	16
Primary School in Mariannhill	6	5	11
Lily of the Valley, Mariannhill	1	0	1
Holy Family, Tzaneen	2	6	8
Total	32	37	69

Procedure

Experimental Group

The contacts with the different ARV-providing sites were established by the Aids Office staff members of the SACBC. At every site the researchers explained their needs and offered to help out the caregivers in return for their time. The questionnaire needed to be answered by a caregiver of the child, someone with sufficient knowledge of the child's well-being and behaviour. When feasible a parent or other family member was contacted, in other cases the interviews were held with the professional caregivers (e.g. home-based care workers). Most of the childcare workers were able to answer the (English) questionnaire and helped translating the questions for other caregivers when necessary. If possible, the researchers tried to interview the caregivers in a quiet surrounding without the child present. To insure a correct understanding it was sometimes necessary to offer further explanations of the questions or examples.

Control Group

To get in touch with participants for the control group several schools were visited. Through different acquaintances, the researchers made contact with a number of primary schools that were willing to help. At these schools, a current teacher of the child was questioned. The interviews took place in either the staff room or an empty classroom. To prevent any selection bias from the teacher the children were chosen randomly.

Since this is the first measurement in a longitudinal study, a non-response was out of question. All children have been included in this study.

Instruments

Psychosocial problems

To measure the psychosocial problems a compiled questionnaire was used, consisting of components of the Child Behaviour Checklist 6-18 (CBCL) and the Strengths and Difficulties Questionnaire 3-16 (SDQ). Both the CBCL and SDQ have been developed to carry out a brief behavioural screening to measure behavioural and underlying problems of a child. For the purpose of this study, the parent/caregiver rating forms have been used. The reliability of both questionnaires has been proven in different countries (Achenbach, 1966; Goodman, 2001).

Although the reliability of the CBCL has not been measured in African countries, the instrument has been used in Kenya by Weisz and Sigman (1993), and by Lansford and colleagues (2005). Furthermore, Crijnen, Achenbach & Verhulst (1999) concluded that standardized, empirically based assessment in terms of Child Behavior Checklist syndromes

can give clinicians a solid baseline for evaluating syndrome scores obtained by individuals from different cultures.

In the Netherlands experiences with the SDQ are positive and the reliability is considered to be of good quality (Muris et al., 2003). The SDQ has been translated in many languages, including the South African language Xhosa, indicating that the SDQ is designed to be used in African countries as well. Although for both tests no specific data is available for South Africa, adequate reliability is assumed based on the findings in other countries.

As shown in table 3, specific CBCL and SDQ scales regarding internalising problems were selected to obtain answers to the first three research questions. For question 1 these scales were 'anxiety/depression' (CBCL) and 'emotional problems' (SDQ). To answer question 2 the CBCL scale 'withdrawal' was selected. Finally, the CBCL scale 'social problems' and the SDQ scales 'peer relationship problems' and 'prosocial behaviour' were chosen to explore question 3.

Table 3. CBCL/SDQ scales used in study and corresponding items.

Research question concerning:	**CBCL scale used:**	**SDQ scale used:**	**Items in compiled questionnaire:**
Depression/Anxiety	'anxiety/depression'	'emotional problems'	2, 4, 5, 7, 8, 10, 11, 14, 16, 17, 23, 27, 29, 31
Withdrawal	'withdrawal'		13, 21, 22, 24, 25, 26, 28, 29, 30, 33, 36, 39, 41, 46
Social Problems	'social problems'	'peer relationship problems' 'prosocial behavior'	1, 3, 6, 12, 15, 18, 19, 20, 32, 34, 35, 37, 38, 40, 42, 43, 44, 45

All the scales selected to answer the three research questions combined became a questionnaire consisting of 46 statements. Which items attend to the different questions is illustrated in table 3 as well. In every item a behavioural situation is mentioned, for example 'gets teased a lot'. The primary caregiver is requested to answer on a scale of 0 – 2, 0 meaning 'not true', 1 'sometimes true' and 2 'very true'.

Traumatic events

The first page of the questionnaire consists of various questions on demographic data, including year and nature of HIV infection and possible exposure to traumatic events. The question considering traumatic events is a qualitative, open question. It was not possible to know on forehand what kind of traumatic experiences these children had encountered. To reduce the risk of missing an important issue, the caregivers were given the opportunity to

state anything they thought of as being traumatic to these children. After completing the data collection, the raw data about trauma has been reduced into seven categories. The following categories were selected based on their prevalence: severe illness, often ill, parent(s) died, unstable caregiver/situation or neglect, abandoned, sexual abuse and parents separated. To secure an accurate alteration of the answers given to the open question used in the questionnaire into these seven categories, an inter-rater reliability was calculated. Consistency among the categorizers can be inferred with and inter-rater reliability of 88.4% for the experimental group and 94.2% for the control group. The questionnaire used in this study can be found in appendix 1.

Statistics

The statistical program SPSS has been used to analyse the data. The items have all been recoded through this program into having the same direction; a low score on any question means a low score on the factor measured (differing per scale). The reliability of the questionnaire is established using a homogeneity measure, Cronbach's alpha.

To measure the differences between the groups a MANOVA has been used. To be able to control for the effects of age, traumatic experiences, sex and the differences in primary caregiver a MANCOVA was carried out. Exploratory analyses will be conducted on the covariates trauma and primary caregiver, to obtain more insight in the role they possibly play for these children.

Results

Reliability

To measure the homogeneity of the three subscales in the questionnaire, consisting of statements from both the CBCL and SDQ (see table 3), Cronbach's alphas have been calculated. Cronbach's alpha was established at respectively .81, .80 and .80 for the scales 'depression/anxiety', withdrawal' ands 'social problems'. According to usual standards, these reliabilities can be considered sufficient.

Internalising problems

To assess the differences in the levels of depression/anxiety, withdrawal and social problems between the experimental and the control group a MANOVA has been completed. The F-value was 1.121(p= .343), which means that no significant differences between the two groups were found. A MANCOVA has been used to control for the effects of age, traumatic experiences, sex and the differences in primary caregiver. This resulted in a F-value of 0.213 (p= .887) which is not significant.

Although the specific group comparisons within these non-significant models should not be considered because of the risk of chance, they do give a clear insight in the differences between the two groups. However, even then no significant differences in the levels of depression/anxiety, withdrawal and social problems between the experimental and the control group were found. In Table 4 a summary is given of these results, including an overview of the means.

Table 4. MANOVA and MANCOVA: overview of the means per group.

		Group		Means MANOVA		Means MANCOVA	
Depression/Anxiety		HIV/AIDS		6.25		6.25	
		Control		6.07		6.09	
		F	*sign.*	0.043	*.835*	0.105	*.746*
Withdrawal		HIV/AIDS		7.06		7.10	
		Control		6.00		6.05	
		F	*sign.*	1.46	*.229*	0.006	*.938*
Social problems		HIV/AIDS		6.30		6.35	
		Control		5.23		5.28	
		F	*sign.*	1.457	*.230*	0.322	*.571*
Model	*(Wilks' Lambda)*	F	*sign.*	1.121	*.343*	0.213	*.887*

The effects of traumatic experiences and different caregivers

As can be seen in Figure I, there is a significant difference in the amount of traumatic experiences between the group of children with HIV/AIDS and the controls (F=88.215, p<.000).

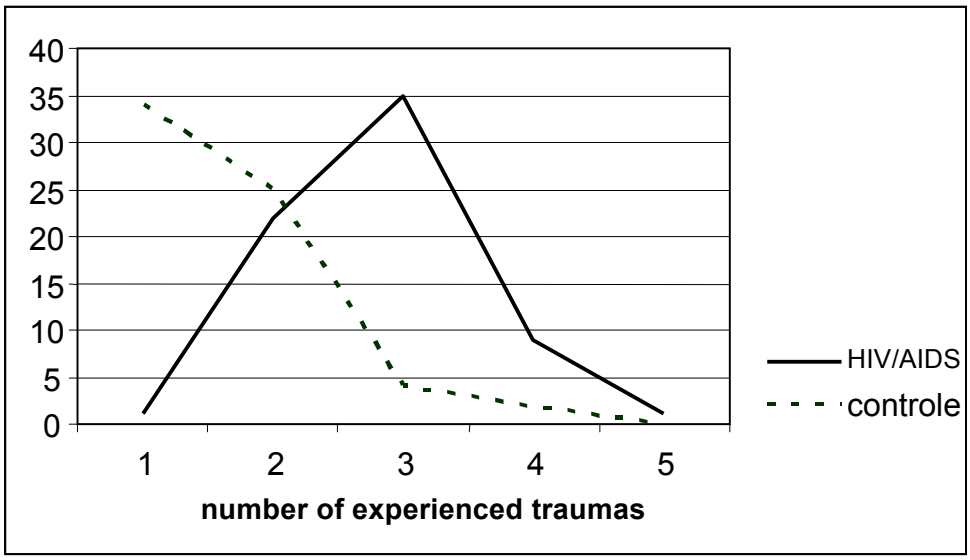

Figure I: The number of experienced traumas by the children in the two groups

Furthermore, figure II shows that the HIV-infected children who are living with family/ other relatives have higher scores on the psychosocial problems than when living with their parent(s) or in an orphanage. For depression, this effect was found to be significant (F=7.895, p<.001). This indicates that the group of HIV-infected children who have been adopted by their family/other relatives after their parents died, experience more depression/anxiety than the children living with their parents or in an orphanage.

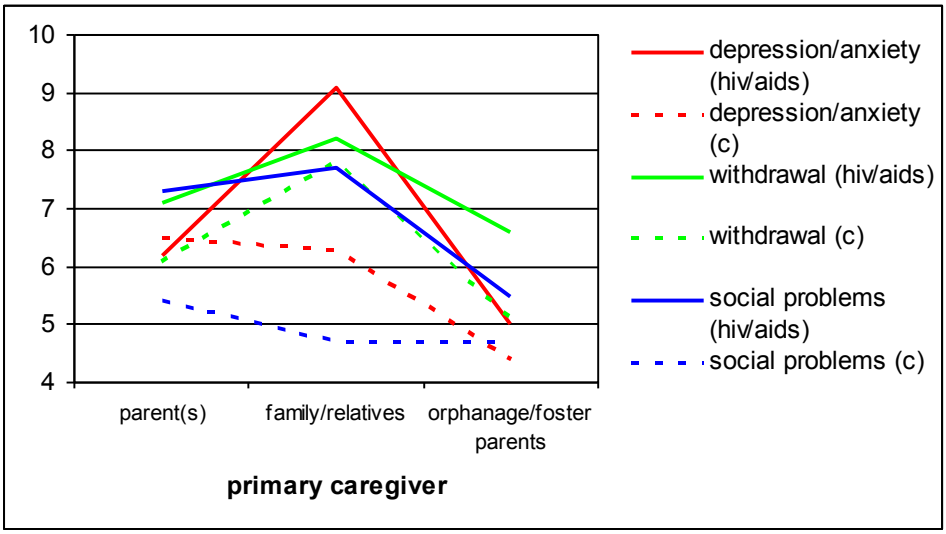

Figure II: An overview of the relation between differences in caregiver and the experienced psychosocial problems.

Discussion

The intent of this study was to look at the differences in psychosocial problems between HIV-infected children receiving medical treatment and children that are not infected with the virus. These two groups of children were compared on three scales: depression and anxiety, withdrawal, and social problems. Our findings revealed that no significant differences exist between the two groups on any of these three scales. As such, this study did not find confirmation for the first three research questions. Even when controlled for several factors that could influence the results of the two groups differently (trauma, age, gender and primary caregiver), no differences were found. Based on these results, research questions 4-7 cannot be substantiated; no significant relation appears to exist between the factors mentioned above and the scales depression and anxiety, withdrawal, and social problems. However, the groups did differ significantly on the amount of traumatic experiences they had encountered; the HIV-infected children had experienced significantly more trauma. Remarkably, this appears to have no impact on the level of psychosocial problems; in other words these children, while having experienced more traumas, do not differ from the control group on depression/anxiety, withdrawal or social problems.

A possible explanation for this lack of difference between the two groups could be the positive effect of the medication the children with HIV/AIDS are receiving. A large number of the children in our experimental group have entered the ARV treatment program approximately a year ago. In South Africa, the children are not able to receive free treatment until the virus has already developed into full blown AIDS, meaning that they are seriously ill. As a result of the medication, their health suddenly improves enormously. This could influence their results on our questionnaire in two ways. Firstly, it's possible that the children actually experience less psychosocial problems, feeling happy being healthy again; they are able to go to school, play with their friends, etc. This is in accordance with the findings of Richardson et al (2001), who concluded that it's not the seropositive status or CD4+ levels, but visible disease symptoms and progression that are correlated with depressed affect. Antiretroviral treatment reduces or even eliminates these 'AIDS defining illnesses' with a decrease of possible depressive feelings. Secondly, there could be a response bias from the caregivers answering the questionnaire. They compare the child's well-being in a 'before-after' fashion, and in comparison the child is now doing very well. Often the researchers got responses that point into that direction, e.g. 'She used to cry a lot because she was very ill, now she is alright.' In this case, it is possible that the child still cries more than average. Therefore, actual differences between the two groups may be underestimated.

In addition it could be concluded that among the children in our experimental group, those who are living with extended family are experiencing more psychosocial problems than children living with parent(s) or in an orphanage. This surprising result might point to the overburdening of the extended family. Often, it's already hard enough for the aunts, uncles or grandparents to take care of their own household. They suffer from health problems, housing issues and financial problems. Taking in the children of their deceased sister or child may cause extra stress and even more difficult living conditions. Compared to these extended families, the orphanages visited in this study appear to function as a stable and safe environment for the children. Crawley (2001) gives in his research some insight in this situation around the extended family shortcomings. While most people answered the questionnaires used in this study by saying that orphaned children should be cared for by relatives, most family members caring for the AIDS orphans said they preferred institutionalising the children. Here lies a cultural challenge which can contribute to better geared health care services in the future. A number of studies found that orphans had higher levels of psychological distress (depression, anxiety and anger) than non-orphans when other factors were controlled (Atwinea e.a., 2005). Our results nuance these findings and provide renewed inside in the needs of the AIDS orphans in South-Africa.

Results from the present investigation should be interpreted in the context of some possible limitations. First of all, doing research in a country with eleven officially registered languages, like South Africa, is not easy. Unavoidably, now and then language difficulties were experienced during the interviews. There were large differences in the ability to speak and understand English properly between the interviewees. When needed, the researchers used translators or tried to ensure comprehension of the questions by giving examples or further explanations. According to Matsumoto (2003), cultural nuances may be encoded in language in ways that are not readily conveyed in translation. The translation may not have exactly the same nuances, contextualized meanings, and associations. Because of the pervasive influence of culture on the encoding of both verbal and nonverbal signals, conflict and misunderstanding are unavoidable in inter-cultural communication. A complete understanding and open communication could therefore not be assured at all times. A possible solution for a part of this problem is to use the same translator throughout the whole research, who is able to interpret all eleven nationally accepted languages. Besides contributing to enhanced communication, an improvement of the internal validity of the research could be an additional consequence.

A second shortcoming of this study can be the discrepancy between the experimental and control group concerning the person who answered the questionnaire. These were

respectively family members or professional caregivers and teachers. This may have influenced the responses to our questions because the setting in which the child is known and observed obviously differs for a caregiver and teacher. This setting may affect the behaviour of the child and therefore the image a caregiver or teacher holds of the child. In addition, Wood et al. (2006) argues that internalised signs of not managing emotionally are less likely to be noticed by significant adults in children's lives. Verhulst and colleagues (2003) compared problems reported by parents and youths themselves from 5 different cultures, by means of the CBCL and the Youth Self Report (YSR). For all cultures, the YSR yielded higher 'Total Problems' scores, indicating a general tendency for youths to report more problems than their parents. This implicates that the present findings possibly give an underestimated view of the actual situation. A final limitation to the instruments used in this study is that both questionnaires that were used are designed to execute brief behavioural screenings. It is possible that these brief screenings are too general to uncover the more specific psychosocial problems. Consequently, future research should include a less biased and more specific questionnaire (e.g. Impact of Event Scale [IES]).

Finally, all the children infected with HIV/AIDS were included in a treatment program when tested. Information about when they started receiving the medication was not included in this study. The duration of the treatment may influence the children's health, knowledge about their disease and the adherence. Since this study is part of a longitudinal research, several measures will follow. Subsequent research will and has taken the described limitations into account.

It has become clear that the HIV/AIDS epidemic challenges the constitutional and conventional rights of children affected by AIDS; their rights to a home, care, health and education. As Desmond and Gow (2002, in: Richter et al., 2004) put it: "Every child in South Africa will feel the impact of HIV/AIDS, whether first-hand or in the changed nature of the society in which they grow to maturity." So far, research has linked HIV/AIDS with several psychosocial problems (Capaldini, 1999; Huurre & Aro, 2002; Lichtenstein et al., 2002; Tate et al., 2003; Wachsler-Felder & Golden, 2002). However, psychosocial support continues to be one of the most neglected areas of support for vulnerable children. The HIV epidemic has increased the necessity to address psychological problems of children in equal proportion to other interventions. The long term consequences for children who experience profound loss, grief, hopelessness, fear and anxiety without assistance, can include psychosomatic disorders, chronic depression, low self esteem, low levels of life skills, learning disabilities and disturbed social behaviour (Richter et al., 2004). Nonetheless, the previous studies didn't focus on the influence of antiretroviral treatment on the children's psychosocial well-being.

Now that these drugs are available to a great deal of South African children that are tested HIV-positive, the impact of the disease will inevitably alter. These children can now stay relatively healthy and live longer, which is a great development. This puts a positive light on the substantial work done by the SACBC and similar organizations. But in reality antiretroviral therapy does not prohibit the social, economic and psychological consequences of HIV/AIDS as yet. Moreover, living with a chronic disease brings along its own challenges. For this reason it is of greatest interest to monitor these developments in the treatment of HIV/AIDS and the impact it has on the psychosocial functioning of children. Only by expanding our knowledge of these influences it is possible to offer children infected and affected by HIV/AIDS the care they need.

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References

Atwinea, B., Cantor-Graae, E., Bajunirweb, F. (2005). Psychological distress among AIDS orphans in rural Uganda. *Social Science & Medicine, 61*, 555–564

Capaldini, L. (1999). Psychosocial Issues and Psychiatric Complications of HIV Disease. In Sande, M.A., Volberding, P.A. (1999) *The Medical Management of AIDS* (6th ed.) (241-263). Philadelphia: Saunders.

Crawley, M. (2001). Cribs and hugs for Africa's AIDS orphans. *Christian Science Monitor, 93 (173).*

Crijnen, A.A.M., Achenbach, T.M., Verhulst, F.C. (1999) Problems Reported by Parents of Children in Multiple Cultures: The Child Behavior Checklist Syndrome Constructs *Amarican Journal of Psychiatry* 156, 569-574

Domek, G.J. (2006) Social consequences of antiretroviral therapy: preparing for the unexpected futures of HIV-positive children. *The Lancet, 367(9519), 1367-1369*

Evers, A., Vliet-Mulder, J.L. van, Groot, C.J. (2000). *Documentatie van tests en testresearch in Nederland.* NIP Dienstencentrum, Assen: van Gorcum.

Foster, G. (2000). The capacity of the extended family safety net for orphans in Africa. *Psychology, health and medicine 5 (1)* 55-8

Foster, G. (2006). Children who live in communities affected by AIDS. *Lancet (North American edition), 367 (9511)* 700.

Goodman R (2001) Psychometric properties of the Strengths and Difficulties Questionnaire (SDQ). *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 1337-1345.

Huurre, T.M., Aro, H.M. (2002). Long-term psychosocial effects of persistent chronic illness. *European child & adolescent psychiatry, 11 (2),* 85-91.

Joint United Nations Programme on HIV/AIDS (UNAIDS) (2004). *Report on the global HIV/AIDS epidemic.* Geneva: UNAIDS.

Joint United Nations Programme on HIV/AIDS (UNAIDS) (2006). *Report on the global AIDS epidemic.* Geneva: UNAIDS.

Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization (WHO) (2005). *Aids epidemic update: December 2005. Special report on HIV Prevention.*

Geneva: UNAIDS.

Kang, E., Rapkin, B.D., Remien, R.H., Mellins, C.A., Oh, A. (2005). Multiple dimensions of HIV stigma and psychological distress among Asians and pacific islanders living with HIV Illness, *AIDS and behavior, 9 (2).*

Lansford, J.E., Chang, L., Dodge, K.A., Malone, P.S., Oburu, P., Palmérus, K., Bacchini, D., Pastorelli, C., Bombi, A.S., Zelli, A., Tapanya, S., Chaudhary, N., Deater-Deckard, K., Manke, B., Quinn, N.(2005) Physical Discipline and Children's Adjustment: Cultural Normativeness as a Moderator. *Child Development, 76 (6)*, p1234-1246

Lichtenstein B., Laska, M.K., Clair, J.M. (2002). Chronic Sorrow in the HIV-Positive Patient: Issues of Race, Gender, and Social Support. *AIDS patient care and STDs, 16 (1),* 27-38.

Matsumoto, D.R. (2000). *Culture and psychology: people around the world.* San Francisco: Wadsworth.

Muris, P., Meesters, C., Van Den Berg, F. (2003). The Strengths and Difficulties Question – naire (SDQ). Further evidence for its reliability and validity in a community sample of Dutch children and adolescents. *European Child & Adolescent Psychiatry, 12,* 1-8.

Richardson et al. 2001, In: Aranda-Naranjo, B., Faan, R.N. (2004). Quality of life in the HIV positive patient: implications and consequences. *Journal of the association of nurses in AIDS care, 15 (5) 1,* 20S-27S.

Richter, L., Manegold, J., Pather, R. (2004). *Family and community interventions for children affected by AIDS.* Cape Town: HSRC publishers.

Sande, M.A., Volberding, P.A. (1999). *The Medical Management of AIDS.* 6th ed. Philadelphia: Saunders.

Schuman, P., Ohmit, S.E., Cohen, M., Sacks, H.S. Richardon, J., Youg, M., Schoenbaum, E., Rompalo, A., Gardners, L. (2001). Prescription of and adherence to antiviral therapy among women with AIDS. *AIDS and behavior, 5 (4).*

Tate, D., Paul, R.H., Flanigan, T.P., Tashima, K., Nash, J., Adair, C., Boland, R., Cohen, R.A. (2003). The impact of Apathy and Depression on Quality of Life in Patients Infected with HIV. *AIDS patient care and STDs, 17 (3),* 115-120.

Van Dyk, A. (2001). *HIV/AIDS care & counselling. A multidisciplinary approach*. Pearson Education, South Africa.

Verhulst, F.C., Ende, J. van der, Koot, H.M. (1996). *Handleiding voor de CBCL/4-18*. Sophia kinderziekenhuis /AZR/ Erasmus Universiteit Rotterdam.

Verhulst, F.C., Achenbach, T.M., van der Ende, J., Erol, N., Lambert, M.C., Leung, P.W.L., Silva, M.A., Zilber, N., & Zubrick, S.R. (2003). Comparisons of problems reported by youths from seven countries. *American Journal of Psychiatry, 160,* 1479-1485.

Wachsler-Felder, J.L., Golden, C.J. (2002). Neuropsychological consequences of HIV in

children: A review of current literature. *Clinical Psychology Review, 22,* 441-462.

Weisz, J.R., Sigman, M.(1993) Parent reports of behavioral and emotional problems among children in Kenya, Thailand, and the United States. *Child Development*, 64 (1), 98-109

Wood, K., Chase, E., Aggleton, P. (2006). 'Telling the truth is the best thing': teenage orphans' experiences of parental AIDS-related illness and bereavement in Zimbabwe. *Social Science & Medicine,* In press.

Appendix 1*: Checklist Child Behavior and Social Problems (age 4-18)*

Child's name…….

Date of Birth……..

Child's Gender

- ❑ **Male**
- ❑ **Female**

Year of HIV-infection……...

Nature of infection:

- ❑ **Mother to child**
- ❑ **Later in life**

Primary caregiver of the child……

Has the child been exposed to traumatic events (e.g. personal abuse, exposure to violence)?

- ❑ **Yes**
- ❑ **No**

If yes, what kind of events?

……

……

This form is filled out by…….

Your relation to the child……

Your gender:

- ❑ **Male**
- ❑ **Female**

This checklist consists of two parts, A and B. Please be sure to fill out both parts. The personal information you share will remain just that, personal. Your confidentiality will be respected.

A. Below is a list of items that describe children and youths. For each item that describes the child **now or within the past 6 months**, please circle the **2** if the item is **very true or often true** of the child. Circle the **1** if the item is **somewhat or sometimes true** of the child. If the item is **not true** of the child, circle the **0**. Please answer all items as well as you can, even if some do not seem to apply to a child.

	Not True	Sometimes True	Very True	
1	0	1	2	Acts too young for his/her age
2	0	1	2	There is very little he/she enjoys
3	0	1	2	Clings to adults or too dependent
4	0	1	2	Complains of loneliness
5	0	1	2	Cries a lot
6	0	1	2	Doesn't get along with other kids
7	0	1	2	Fears he/she might think or do something bad
8	0	1	2	Feels he/she has to be perfect
9	0	1	2	Feels or complains that no one loves him/her
10	0	1	2	Feels others are out to get him/her
11	0	1	2	Feels worthless or inferior
12	0	1	2	Gets teased a lot
13	0	1	2	Would rather be alone than with others
14	0	1	2	Nervous, highstrung, or tense
15	0	1	2	Not liked by other kids
16	0	1	2	Too tearful or anxious
17	0	1	2	Feels too guilty
18	0	1	2	Overweight
19	0	1	2	Poorly coordinated or clumsy
20	0	1	2	Prefers being with younger kids
21	0	1	2	Refuses to talk
22	0	1	2	Secretive, keeps things to self
23	0	1	2	Self-conscious or easily embarrassed
24	0	1	2	Too shy or timid
25	0	1	2	Stares blankly
26	0	1	2	Sulks a lot
27	0	1	2	Suspicious
28	0	1	2	Underactive, slow moving, or lacks energy
29	0	1	2	Unhappy, sad, or depressed
30	0	1	2	Withdrawn, doesn't get involved with others
31	0	1	2	Worries

B. Below is a list of items that describe children and youths. For each item, please mark the box for **Not True**, **Somewhat True** or **Certainly True**. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behavior over the last six months or this school year

	Not True	Somewhat True	Certainly True	
32				Considerate of other people's feelings
33				Often complains of headaches, stomach-aches or sickness
34				Shares readily with other children (treats, toys, pencils etc.)
35				Rather solitary, tends to play alone
36				Many worries, often seems worried
37				Helpful if someone is hurt, upset or feeling ill
38				Has at least one good friend
39				Often unhappy, down-hearted or tearful
40				Generally liked by other children
41				Nervous or clingy in new situations, easily loses confidence
42				Kind to younger children
43				Picked on or bullied by other children
44				Often volunteers to help others (parents, teachers, other kids)
45				Gets on better with adults than with other children
46				Many fears, easily scared