Chapter 21

The Psychosocial Problems of Children With HIV/AIDS on Antiretroviral Treatment: A Longitudinal Study

Sanne van Gent[1], Daniëlle Winkelman[1], Renée van Gelder[1], Lotte Kraakman[2], Adri Vermeer[3], Rolf Kleber[2], Marcel van Aken[1]

[1] Department of Developmental Psychology, Utrecht University, Utrecht, The Netherlands
[2] Department of Clinical Psychology, Utrecht University, Utrecht, The Netherlands
[3] Department of Pedagogical and Educational Sciences, Utrecht University, Utrecht, The Netherlands

Abstract

This study concerns children with HIV/AIDS who are on antiretroviral medication. Chronic illnesses can have a significant impact on the child's development and social and emotional functioning. Very little research has been done on the problems in social and emotional functioning of children infected with HIV/AIDS who are on antiretroviral medication. This research concerns the first two measurements of a longitudinal study into the social and emotional development of children with HIV/AIDS entered in an ARV treatment programme, provided by the AIDS office of the Southern African Catholic Bishops' Conference at Pretoria, South Africa. In this study, the social and emotional functioning of children with HIV/AIDS (experimental group) will be compared with the functioning of children without HIV/AIDS (control group). In addition, the effects of traumatic experiences and age will be analysed. Social and emotional functioning has been operationalised by means of the varaibles 'depression/anxiety', 'withdrawal' and 'social problems'. For 113 of the 138 original subjects who participated in the first measurement, questionnaires have been completed by the primary caregivers or teachers (experimental group N=58, 30 male and 28 female; control group N=55, 26 male and 29 female). The mean age was 10.5 years old (8.5 experimental group, 10.2 control group). These questionnaires contained a compilation of the scales concerning internalising problems from the Child Behaviour Checklist (CBCL) and the Strength and Difficulties Questionnaire (SDQ). In contrast to results from the first wave, the results of the second wave reveal that children with HIV/AIDS show significant more depression/anxiety, withdrawal and social problems than children without HIV/AIDS on measurement two. Children with HIV/AIDS have significant more traumatic experiences than children without HIV/AIDS, but in contrast to the expectations these traumatic experiences as well as the age of the participants have no effect on their social and emotional functioning. Concluding, these findings indicate that children with HIV/AIDS develop more problems in social and emotional functioning compared to children without HIV/AIDS.

1. Introduction

The purpose of this study is to examine the social and emotional functioning of children with HIV/AIDS entered in a ARV programme after a period of time. The time between the two measurements was nine months. In addition the effects of traumatic experiences and age will be analysed.

HIV/AIDS significantly impair the quality of life and will eventually cause death (Kopnisky, Stoff & Rausch, 2004). Patients with HIV can be treated with Highly Active Antiretroviral Therapy (ARV; Sterne, Hernán, Ledergerber, et al., 2005). Since the introduction in 1996, ARV led to a reduction in mortality and risk of AIDS defining illnesses (Mocroft, Ledergerber, Kaztlama, et al., 2003). As a result of this reduction people with HIV/AIDS can live longer and the disease becomes chronic instead of terminal. For that reason it is important to look at what is already known of the consequences of other chronic diseases.

1.1. Relationship between Chronic Illness and Emotional and Social Functioning

Chronic illness can have a significant impact on the child's development and social and emotional functioning. For instance, children with a chronic illness are at increased risk for a mental illness (Turner, 1998). Evans (2004) found that the ongoing strain of living with a chronic physical condition puts children at increased risk of social and emotional problems. These psychological reactions can also result in a more rapid course of illness.

A common reaction to a chronic illness is depression. The health status of a child is the primary source of psychosocial problems such as depression, diminished self-worth and lower sense of competence (Evans, 2004). Research of Huurre and Aro (2002) found that adolescents with a chronic illness show more depression compared with children without a chronic illness. Depression has a large impact not only for the distress it produces but also because of the negative influence depression has on the experienced symptoms and on the overall prospects for rehabilitation. Patients show less motivation to undergo therapy and are less likely to maintain gains during therapy. Research has also found that depression and negative beliefs about the self and the future have adverse effects on the immune system (Taylor, 2003).

Moussa, Alaeid, Abdella, et al. (2005) found that children and adolescents with a chronic disease had significantly more anxiety and total distress compared to children and adolescents without a chronic disease. Immediately after the diagnosis, many patients become overwhelmed and anxious by the potential changes in their lives and by the prospect of death.

Anxiety may also arise intermittently throughout the disease progress. Anxiety is not only a problem because it is intrinsically distressing, but also because it can interfere with good functioning. The emotional distress of anxious patients may debilitate the anticipation of therapies. Such patients may then cope more poorly with treatment (Taylor, 2003).

Also withdrawal could be a consequence of living with a chronic condition. A five-year longitudinal study found that children with chronic conditions showed recurring and more severe problems with social isolation during that period than children without chronic conditions (Midence, 1994). Others found that children with a chronic illness have the highest risk for psychiatric disorders and withdrawal (Huurre & Aro, 2002; Zimmermann, 1995).

Psychological problems lead to a higher experience of emotional distress. Emotional stress leads to a bad disease progression of HIV infected individuals (Kopnisky et al., 2003). Research findings show that chronic depressed people with HIV have lower CD4+ levels and higher viral loads than non-depressed people with HIV (Kopnisky et al., 2003). Another consequence of the emotional stress caused by HIV/AIDS is the finding that HIV-infected people, who are experiencing high levels of psychological distress, decrease their number of visits to health organizations which can also result in a progression of the disease (Au, Chan, Chung, et al., 2004).

These facts show that social and emotional problems not only lead directly to a decreased immune system but can also indirectly result in a decline of health because of the poor treatment coping, the experience of the symptoms and negative prospects for rehabilitation. Another factor which is very important for the social and emotional functioning of a chronically ill child is age.

1.2. Consequences of Age on Chronic Illness

Although many children who become chronically ill, adjust to the radical changes in their lives quite successfully, others unfortunately do not. A considerable influence on the child's potential to modify the developmental process is the age of the child at the onset of the illness. A toddler faces very different problems and developmental issues compared to an adolescent, even when confronted with the same disease. A child who has lived with an illness since infancy, has different issues than a child of the same age who has recently been diagnosed with a similar illness (Midence, 1994).

Even though HIV/AIDS becomes a chronic disease, still many people die because of the consequences of the disease. Research shows that children in the age of nine have a realistic perception of the meaning of death (Boyd-Franklin, Steiner & Boland, 1995). They realize that the body decomposes and that the person who has died will never return. Children

under the age of nine do not see death as inevitable and final. Research also suggests that young children do not understand the meaning and the consequences of the disease (Taylor, 2003).

The issues mentioned above lead to the suggestion that older children may experience more social and emotional problems, because they understand the meaning and the consequences of the disease better than young children.

1.3. AIDS, Children and Traumatic Experiences

Many studies about children and AIDS had a focus on children who are *affected* by HIV/AIDS and not on children *infected* with the disease. Affected by HIV/AIDS means that important others suffer from or died of HIV/AIDS. Even though the child is not infected, the affection can lead to many problems. These problems could be very traumatic for a child. Children affected by HIV/AIDS are likely to develop mental health problems, because they will not be exposed to several formative influences (Pharoah, 2004). Another aspect of the problems in social and emotional functioning is the trauma caused by the death of one or both parents. The sense of security will decline, which can lead to low self-esteem, depression, anxiety and occasionally aggression. When AIDS is the cause of the death of one or both parents the ordeal will have started earlier, as the parent or caregiver succumbs to illness and loses the ability to support his or her children (Marais, 2005).

Children both infected by and affected with HIV/AIDS have a more negative prognosis for the course of the disease compared to children who are only infected. Research (Taylor, 2003) shows that bereavement, depression, anxiety and a lack of social support leads to a more rapid course of illness and a decline of the immune system.

As a result of the introduction of ARV treatment, children with HIV/AIDS have a higher life expectancy. Before the development of ARVs most children with HIV/AIDS did not survive past early childhood. Because of that the majority of the studies performed on children with HIV/AIDS had a focus on providing comfort in death and dying (Domek, 2006).

Research shows that living with a chronic disease leads to several psychosocial problems. Unfortunately very little research has been done on the psychosocial problems of children infected by HIV/AIDS. Therefore, the purpose of this study is not to focus on the affected children but to focus on the social and emotional functioning of infected children.

1.4. Social and Emotional Functioning

Social and emotional functioning consists of many different aspects. This research has a focus on internalizing problems. The following four features are used and will be described in the next sections: (1) depression, (2) anxiety, (3) withdrawal and (4) social problem (Berk, 2003; Gray, 1999).

Depression

Many people experience depression as a *symptom*: being down and feeling low in spirits. Depression as a *syndrome* is a constellation of symptoms that often co-occur, including feeling sadness and loneliness, as well as worry and nervousness. Depression as a *disorder* (clinical depression) refers to profound levels of these symptoms and has a specific etiology, course and outcome (Wenar & Kerig, 2000). In this research depression as a *syndrome* is used and operationalised through behaviours like crying, feeling sadness, nervousness and loneliness, worry and feeling inferior or worthless. Research shows that HIV-positive children can have a depression as a result of recurrent and cumulative losses and comprehending with their own mortality (Domek, 2006).

Anxiety

Anxiety is usually defined as a normal reaction to an environmental threat. It is adaptive and even essential for survival because it warns the individual that a situation may be physically or psychologically harmful. Anxiety disorders are distinguished from fears on the basis of their intensity (which is out of proportion to the situation), their maladaptiveness, their persistence and their voluntary control (Wenar & Kerig, 2000). Research has shown that children (from the age of six to sixteen) infected by and affected with HIV/AIDS show fear, sadness and anger as most frequent emotions (Mellins & Ehrhardt, 1995). Affected children deal with anxiety because of the loss of family members or other caregivers. Infected children deal with anxiety as a result of the understanding of their own mortality (Domek, 2006).

Withdrawal

Children are called ‘withdrawn’ when they show behaviour as, for example, rather being alone then with others, refusing to talk, being secretive, shy, staring blankly, under-active and worried (University Associates in Psychiatry, 2002). Research shows that school-age children infected by HIV/AIDS exhibit social withdrawal (Wachsler-Felder & Golden, 2002).

Social Problems

Children with social problems can behave in the following ways: acting too young for their age, clinging to adults, not getting along with other children, getting teased a lot, prefers being with younger children, not being considerate of other people's feelings, not willing to share, not being helpful, not being kind to other children (University Associates in Psychiatry, 2002). To the best of our knowledge no research has been done concerning children infected by HIV/AIDS and their ocial problems.

1.5. Research Question

This research concerns two measurements over a period of nine months of the social and emotional development of children with HIV/AIDS entered in a ARV programme. The focus of the first measurement was whether there is a difference in psychosocial problems between HIV-infected children entered in an ARV programme and children without HIV/AIDS. The remarkable conclusion of that measurement was that there was no significant difference between the experimental group and the control group, even after controlling for several possible covariates. It is possible that children with HIV/AIDS will have a different social and emotional development and that the conclusions of the first measurement were due to other factors. For example, children just entered the ARV programme. This could have caused a response bias in the caregivers because of the positive physical effect the medicines had. As a result of the large difference before and after the first medications the caregivers may have evaluated the social and emotional functioning of the child in comparison with their functioning before they started the medication, this instead of evaluating the social and emotional functioning of the child at that moment. For that reason it is important to examine if the results are different almost a year after the start of the medication. Therefore the research question of this study is:

Is there a change in depression, anxiety, withdrawal and social problems in children with and without HIV/AIDS, and is there an effect of age and traumatic experiences?

Because of the supposition that the response bias will not influence the second measurement, the expectation after the second measurement is that children with HIV/AIDS will experience an increase of depression, anxiety, withdrawal and social problems. Many studies describe the negative social and emotional consequences of chronic illnesses. Children without HIV/AIDS are expected to stay stable. This results in the expectation that there is a difference in change of the social and emotional functioning between children with HIV/AIDS as compared to children without HIV/AIDS.

For the effect of age the expectation is that depression, anxiety, withdrawal and social problems will increase with age. Research shows that children at the age of nine have a realistic perception of the meaning of death (Boyd-Franklin, Steiner & Boland, 1995). They realize that the body decomposes and that the person who has died will never return. Children under the age of nine do not see death as inevitable and final. Research also suggests that young children do not understand the meaning and the consequences of the disease (Taylor, 2003). The expectation is that when children become older and begin to understand the consequences of the disease and begin to create a realistic view of death they will experience more problems in social and emotional functioning.

For the effect of traumatic experiences, the expectation is that children with a traumatic experience will have more depression, anxiety, withdrawal and social problems than children without traumatic experiences. Research shows that the sense of security will decline when children are exposed to the death of one or both parents. A decline of the sense of security can lead to low self-esteem, depression, anxiety and occasionally aggression (Marais, 2005). Furthermore, numerous HIV-positive children live in poor households and are often stigmatized and discriminated (Domek, 2006). These children are vulnerable to abuse (Lancet, 2006). Research shows that childhood abuse (sexual, emotional, physical and parent conflict) is an important risk factor for depression (Gladstone, Parker & Mitchell, 2004).

2. Methods

2.1. Subjects

The experimental group of children with HIV/AIDS, consisted during the first wave (T1) of 69 children, age 4-12 year. During the second wave (T2), this group consisted of 58 children, age 4-13 year. The decline of participants was a result of ten children who moved out of the township or finished school, one child past away. Of the experimental group, the mean age is 8.5 (male: 8.3, female: 8.7). These children were recruited from different sites in South-Africa, located near Pretoria, Johannesburg, Tzaneen and Durban (see Table 1). The children were all participating an ARV programme.

Table 1: Participants of the experimental group at T1 and T2

Location	*male, T 1*	*male, T2*	*female, T1*	*female, T2*	*Total T1*	*Total T2*
Nazareth House, Johannesburg	7	6	5	5	12	11
St. Francis, Boksburg	4	4	2	1	6	5

Sizanani Village	9	6	4	3	13	9
Winterveld, Pretoria	4	4	4	4	8	8
Lily of the Valley, Mariannhill	6	4	5	5	11	9
Ethelberth, Mariannhill	2	-	1	-	3	-
Holy Family, Tzaneen	3	3	3	3	6	6
Bela Bela / Warmbath	4	4	6	6	10	10
Total	39	30	30	28	69	58

This group of children was compared to a group of children without HIV/AIDS, the control group. During T1 the control group consisted of 69 children, age 4-13 year. During T2 the control group consisted of 55 children, age 4-14 (mean age of 10.2, male: 9.8, female: 10.5; mean age of the total group is 9.4, male: 9.0, female: 9.7). They were from different primary and elementary schools near the locations of the experimental group (see Table 2). Fourteen children moved out of the township or finished school.

Table 2: Participants of the control group at T1 and T2

Location	*male, T 1*	*male, T2*	*female, T1*	*female, T2*	*Total T1*	*Total T2*
Loreto School, Pretoria	15	9	18	14	33	23
Morekolo School, Mmakau	8	8	8	7	16	15
Primary School, Mariannhill	6	6	5	5	11	11
Lily of the Valley, Mariannhill	1	1	0	0	1	1
Holy Family, Tzaneen	2	2	6	3	8	5
Total	32	26	37	29	69	55

The children who only participated in the first measurement (experimental and control) did not differ significantly from the children who participated in both measurements.

2.2. Instruments

Psychosocial Problems

A compiled questionnaire consisting of components of the Child Behaviour Checklist (CBCL, www.aseba.nl) and the Strengths and Difficulties Questionnaire (SDQ, www.sdqinfo.com) were used.

The CBCL is a questionnaire to obtain caregivers' reports of children's competencies and behaviour problems in the age of four to eighteen years. It includes measurement of the following eight constructs or syndromes: Social Withdrawal, Somatic Complaints,

Anxiety/Depression, Social Problems, Thought Problems, Attention Problems, Delinquent Behaviour, and Aggressive Behaviour (University Associates in Psychiatry, 2002).

The Strengths and Difficulties Questionnaire (SDQ) is a brief behavioural screening questionnaire that can be completed in 5 minutes by the parents, caregivers or teachers of children aged four to sixteen. The SDQ consists of the following subscales: Emotional Symptoms, Conduct Problems, Hyperactivity, Peer Problems and Prosocial (www.sdqinfo.com).

To measure the dependent variables depression, anxiety, social problems and withdrawal, this study included the internalizing and social problem scales of the two instruments. More precisely, this means that for the variable 'depression and anxiety' the scales *Anxiety/Depression* (CBCL) and *Emotional Symptoms (SDQ)* were combined. For the variable 'withdrawal' the scales *Social Withdrawal* (CBCL) and *Peer Relationship Problems* were combined. Finally, the scales *Social Problems (CBCL)* and *Prosocial Behaviour (SDQ)* were combined for the variable 'social problems'. The final questionnaire used can be found in the Appendix.

Traumatic experiences

Traumatic experiences were not measured at wave two. In the first wave the caregivers were able to state anything they thought of as being traumatic to the children. The answers were reduced into the following seven categories, based on their prevalence: (1) severe illness, (2) often ill, (3) parent(s) died, (4) unstable care, (5) abandoned, (6) sexual abuse and (7) parents separated. Children with HIV/AIDS had more traumatic experiences (mean: 1.81) than children without HIV/AIDS (mean: 0.60, see Figure 1). This difference is significant; $t = 9.392$; $df = 131$; $p<.00$ by two-tailed testing.

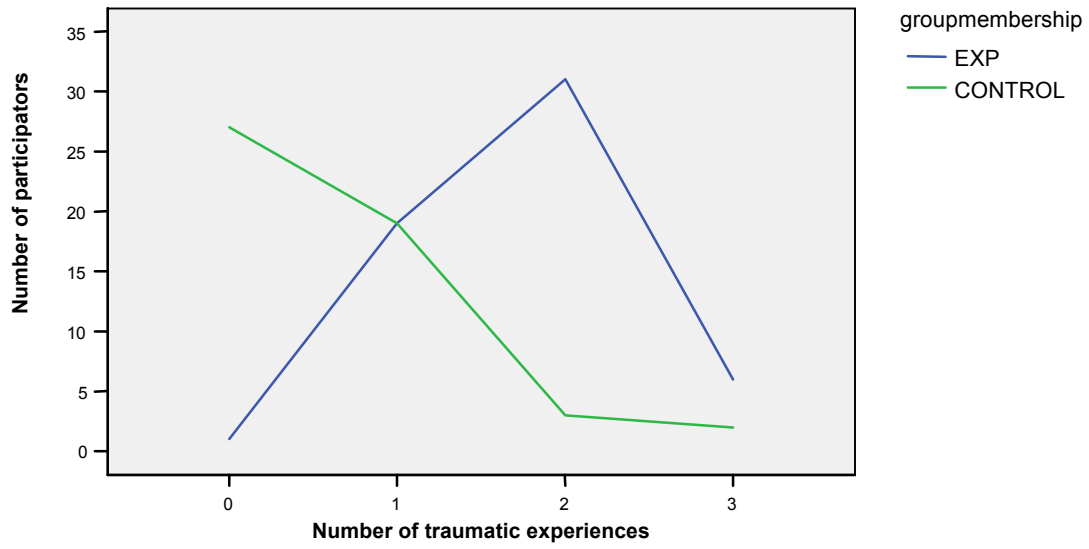

Figure 1: Number of traumatic experiences for experimental and control group

Reliability

To measure the internal consistency of the subscales that represent the dependent variables of this study Cronbach's alpha has been calculated. The Cronbach's alphas of the dependent variables depression/anxiety, withdrawal and social problems are respectively .86, .91 and .80. In other words, the reliability of the three dependent variables proved to be good.

For the dependent variable traumatic experiences, the inter-rater reliability was calculated at wave 1 to secure an accurate alteration of the answers given to the open question about traumatic experiences of the questionnaire into the seven categories. Consistency among the categorizers can be inferred with an inter-rater reliability of 88.4% for the experimental group and 94.2% for the control group.

2.3. Design

A repeated measurement design was used, with an interval of nine months between the first and second measurement. Because of the use of existing groups the participants were not random chosen. For that reason this study has a quasi-experimental design (Baarda & De Goede, 2003).

2.4. Procedure

The questionnaires were filled in by the researchers who asked the questions aloud to the parents, caregivers or teachers of the children. Some of these respondents were at measurement two different from those on measurement one. The questionnaire was written in English. When the respondents did not speak or understand English, a translator accompanied the researchers to translate the questions to them. The questionnaires were filled in at different settings. These settings were school classrooms, orphanages and ARV clinics.

The questionnaire consisted of a few open questions about the HIV-infection, the occupation of the parents and the relationship between the respondent and the child. The other part of the questionnaire consisted of 46 statements about the behaviour of the child. Fourteen statements measured the 'depression/anxiety' variable, fourteen statements the variable 'withdrawal' and eighteen statements the variable 'social problems'. In every statement a behavioural situation is mentioned, for example 'acts too young for his/her age'. The caregiver is asked to answer on a scale of 0 to 2, 0: meaning 'not true', 1: 'sometimes true' and 2: 'very true'.

2.5. Statistics

To analyse the data, the statistical programme SPSS was used. All items were recoded into the same direction.

A general linear model for repeated measures was used to answer the research question. The dependent variables are 'depression/anxiety', 'withdrawal' and 'social problems' with 'time' as a within subject factor, 'group' (with/without HIV/AIDS) as a between subject factor and 'age' and 'traumatic experiences' as covariates. As post hoc analyses an independent sample T-test was used to test the differences between the experimental and the control group during measurement two. The independent variable was 'having HIV/AIDS or not'. In addition to changes in the level of problems from measurement one to measurement two, it is important to look at the stability of the individual differences between these moments. For this reason, a Pearson correlation was calculated for the dependent variables.

3. Results

The means and standard deviations of the dependent variables depression/anxiety, withdrawal and social problems of the experimental and control group at measurement one and two are presented in Table 3.

Table 3: Mean and standard deviation of the experimental and control group at T1 and T2

	T1		*T2*	
	Experimental	*Control*	*Experimental*	*Control*
M depression/anxiety	6.21	5.52	7.13	4.65
SD depression/anxiety	4.05	5.06	5.64	4.74
M withdrawal	6.40	5.27	6.79	4.25
SD withdrawal	3.91	5.31	6.31	5.65
M social problems	6.01	5.31	8.81	6.00
SD social problems	5.05	5.35	5.51	5.40

3.1. Depression/Anxiety

A significant main effect of the factor group was found for the dependent variable depression/anxiety (F=4.973, $p<.05$). The experimental group shows more depression/anxiety than the control group. The main effect of the factor time was not significant. This means that children on measurement two do not show more depression/anxiety than on measurement one. For time and group membership no significant interaction effect was found, but the interaction tends to significance[1] (F=2.159, $p=.15$). This interaction (see Figure 2) seems to imply that children with HIV/AIDS show more depression/anxiety on measurement two than on measurement one, whereas children without HIV/AIDS on measurement two show less depression/anxiety than on measurement one. Results of an independent sample T-test on the group means at measurement two show that the overall effect of the factor group is due to a difference in depression/anxiety between the groups during measurement two ($t = 2.46$; $df = 104$; $p<.05$ by two-tailed testing) and that HIV/AIDS can explain 5% of the differences in depression/anxiety ($d = 0.48$) on measurement two. No significant main effect was found for age. There is no difference in the level of depression/anxiety between children at different ages. Also no main effect was found for traumatic experiences. Children with more traumatic experiences do not show more depression/anxiety than children with less traumatic

experiences. There was no interaction effect for time and age and time and traumatic experiences.

A significant Pearson correlation between measurement one and measurement two was found for the experimental group (r = .39, p<.01) and the control group (r = .31, p<.05). This means that the rank order of individual differences of depression/anxiety seems to be fairly stable in both groups, and that the increase in the HIV/AIDS group is probably not due to a few children showing a large increase, but rather a moderate increase in all children.

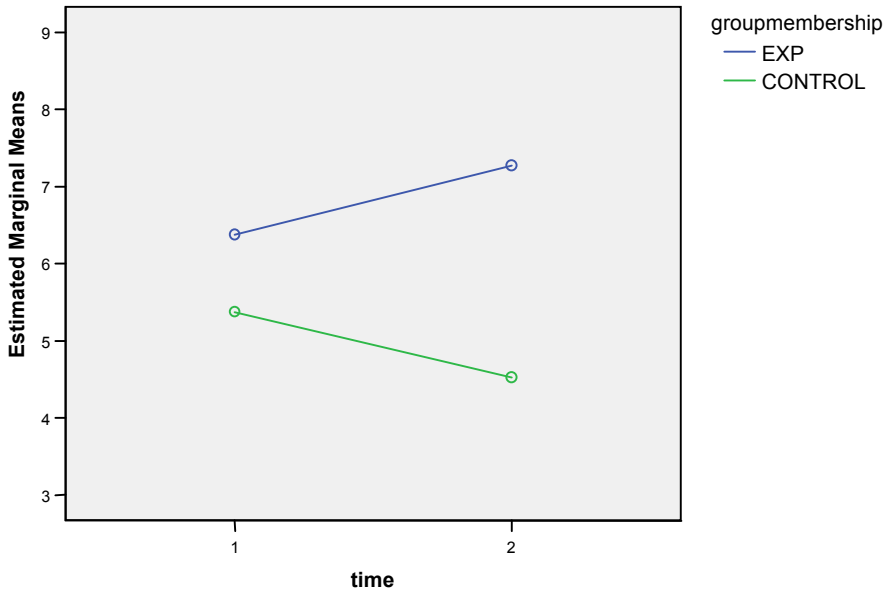

Figure 2: Means of depression and anxiety for measurement one and two

3.2. Withdrawal

For the dependent variable withdrawal also a significant main effect of group was found (F=4.243, p<.05). This means that the experimental group shows more withdrawal than the control group (see Figure 3). There is no significant main effect of time, children on measurement two do not show more withdrawal than on measurement one. Not even a trend towards significance was found for the factors time and group. Results of an independent sample T-test on the group means at measurement two show that the overall effect of the factor group is due to a difference in withdrawal between the groups during measurement two (t = 2.20; df = 105; p<.05 by two-tailed testing) and that HIV/AIDS can explain 4% of the differences in withdrawal (d = 0.43) on measurement two. No significant main effect was found for age, there is no difference in withdrawal between children with different ages. Also no main effect was found for traumatic experiences; children with traumatic experiences do

not show more withdrawal than children without traumatic experiences. No significant interaction effects were found for the factors time and age and time and traumatic experiences.

A significant Pearson correlation was found between measurement one and measurement two for the experimental group (r = .30, p<.05) and the control group (r = .49, p<.01). This means that the rank order of individual differences of withdrawal seems to be fairly stable in both groups, and that the decrease in the control group is probably not due to a few children showing a large decrease, but rather a moderate decrease in all children.

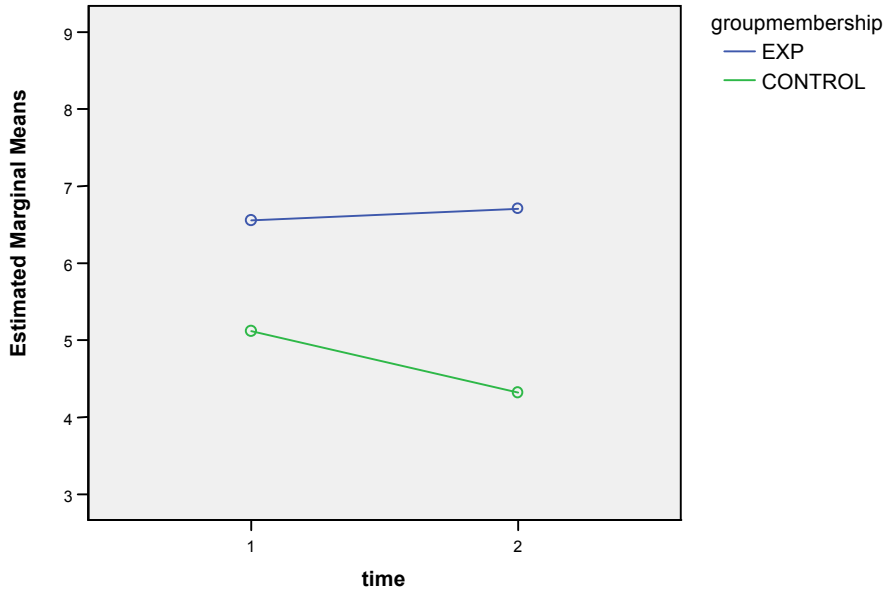

Figure 3: Means of withdrawal for measurement one and two

3.3. Social problems

For the dependent variable social problems a significant main effect of group was found (F=4.887, p<.05). This means that children with HIV/AIDS have more social problems than children without HIV/AIDS (see Figure 4). There is no significant main effect on time; children on measurement two do not show more social problems than on measurement one. Not even a trend towards significance was found for the factor time and group. Results of an independent sample T-test on the group means at measurement two show that the overall effect of the factor group is due to a difference in social problems between the groups during measurement two (t = 2.67; df = 105; p<.01 by two tailed testing) and HIV/AIDS can explain 6% of the differences in social problems (d = 0.52) on measurement two. No significant main effect was found for age, there is no difference in social problems between children with

different ages. Also no significant main effect was found for traumatic experiences. Children with traumatic experiences do not show more social problems than children without traumatic experiences. No significant interaction effects were found for the factors time and group and time and traumatic experiences.

A significant Pearson correlation between measurement one and measurement two was found for the control group (r = .47, p<.01). This means that the rank order of individual differences of social problems seems to be fairly stable, and that the increase is probably not due to a few children showing a large increase, but rather a moderate increase in all children. However, no significant Pearson correlation was found for the experimental group (r = .14). The increase in social problems may be due to a few children showing a large increase rather than a moderate increase in all children. For interpretation of the results this should be taken into account.

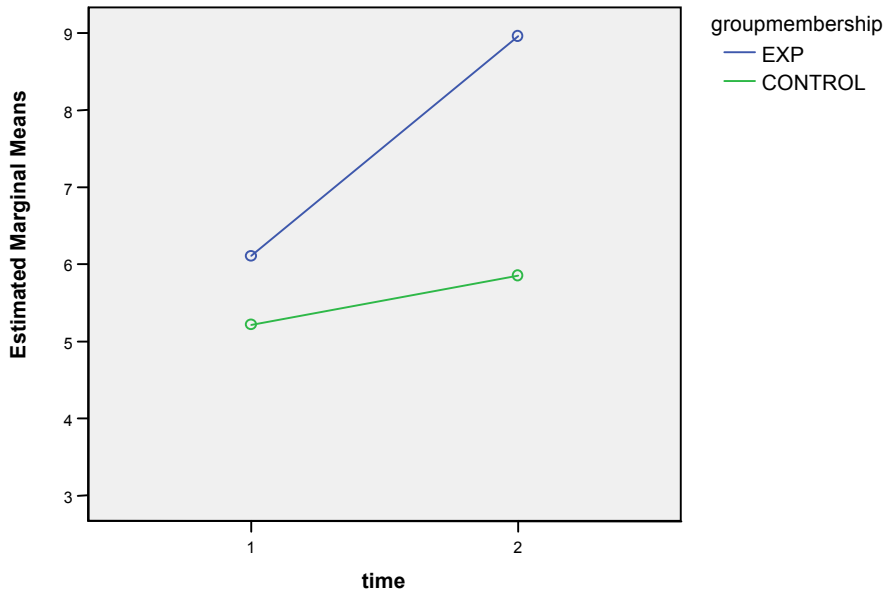

Figure 4: Means of social problems for measurement one and two

4. Conclusions

After the first measurement it was concluded that there was no significant difference between children with and without HIV/AIDS, even after controlling for several possible covariates. The purpose of the second measurement was to examine the social and emotional functioning of children with HIV/AIDS after a period of time, i.c. nine months. Social and emotional functioning was operationalised as depression/anxiety, withdrawal and social problems. The

research question of this study was: *Is there a change in depression/anxiety, withdrawal and social problems in children with and without HIV/AIDS, and is there an effect of age and traumatic experiences?*

Conform the expectation the results reveal that children with HIV/AIDS have more depression/anxiety, withdrawal and social problems compared to children without HIV/AIDS at the second measurement. There is no main and interaction effect of time. Therefore the results are due to a difference between the groups on measurement two. An explanation for this is the response bias at measurement one. At wave one children just entered the ARV programme. This could have caused a response bias because of the positive physical effect the medicines had in a short time. As a result of a large difference before and after the first medications the caregivers evaluated the social and emotional functioning of the child positively in contrast with their functioning before they started the medication. Measurement two was taken almost a year after the first medications. Therefore, children are now evaluated based on their true behaviour instead of making a comparison with their behaviour when they were ill. The expectation is that during future measurements their will be interaction effects of time and group based on the significant difference found on wave two. Also the tendency to significance on the interaction effect of the factor time and group on the variable depression/anxiety on wave two leads to the expectation that during future measurements there will be a significant interaction.

Contrary to the expectation, the results show that social and emotional functioning is not influenced by age. The expectation was that older children will experience more problems in social and emotional functioning because they have a more realistic perception of the meaning of death and a better understanding of the consequences of the disease then younger children. A possible explanation for this lack of difference is that the illness becomes more crucial when children reach puberty. During puberty romantic relationships and sexual activity becomes more important and therefore the virus becomes critically important (Domek, 2006). Presumably, when more participants reach puberty there will be an effect of age.

Another expectation was that children with traumatic experiences such as abuse or dealing with the death of one or both parents can lead to low self-esteem, depression, anxiety and occasionally aggression. Even though children with HIV/AIDS have more traumatic experiences, the remarkable conclusion is that these experiences have no effect on social and emotional functioning.

Concluding, these findings indicate that children with HIV/AIDS develop more problems in social and emotional functioning as compared to children without HIV/AIDS.

Traumatic experiences as well as the age of the children have no effect on social and emotional functioning. There is no interaction effect found for time. However, the expectation is that in future measurements this interaction effect will occur.

5. Discussion

For interpretation of the results some limitations of this study have to be taken into account. The use of the English version of the questionnaire might be somewhat problematic. South Africa has eleven registered languages. Many of the respondents could speak and understand English. However, for most of the respondents it was not their native language. Also a small group did not speak English at all and a translator was necessary. As a result, the questions could be interpreted differently among the respondents.

Secondly, even though the control group consisted of children who live nearby the children of the experimental group, a difference in the social and economical status is possible. Especially most parents of the children of the Loreto School (control group) had a relatively good occupation, this in comparison with the parents of the experimental group. Most parents in the experimental group did not have an occupation or the children were orphans.

Finally, the main effect for social problems of the experimental group may be due to individual differences. This implies that the increase in social problems may be due to a few children showing a large increase rather than a moderate increase in all children. Future research should explore if the difference found between children with/without HIV/AIDS is caused by these individual differences.

HIV/AIDS has a devastating effect on the lives of more than three million children in Sub-Saharan Africa. And the prospects are that the number of infections will increase more and more in the next decades. Fortunately, there are also some positive developments. The number of people infected by HIV/AIDS was stable for the first time in twenty-five years in 2006. Also the AIDS suppression gets better as a result of improved information about the disease and the availability of more money and medications (www.stopaidsnow.nl, 2006). Hopefully the results of this study and future research will be taken into account and lead to more knowledge about the impact of the infection on children and to accurate care in the future.

Note

[1] For the factor group and time the covariate traumatic experiences was not included for each of the dependent variables but the results of the general linear model without this covariate shows the same pattern.

Acknowledgements

Sr. Alison Munro and the staff of the AIDS Office of the Southern African Catholic Bishops' Conference (SACBC), and Prof. D.J.F. Maree PhD, Department of Psychology, University of Pretoria, South Africa.

References

Au, A., Chan, I., Li, P., Chung, R., Po, L.M. & Yu, P. (2004). Stress and health-related quality of life among HIV-infected persons in Hong Kong. *AIDS and Behaviour, 8,* 119-129.

Baarda, D.B., & Goede, M.P.M. de (2003). *Basisboek methoden en technieken: Handleiding voor het Opzetten en uitvoeren van onderzoek (3 ed.)*. Groningen: Stenfert Kroese.

Berk, L.E. (2003). *Child Development*. Boston: Pearson Education, Inc.

Boyd-Franklin, N., Steiner, G.L. & Boland, M.G. (1995). *Children, Families and HIV/AIDS. Psychosocial and Therapeutic Issues.* New York: The Guilford Press.

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

Evans, T. (2004). A multidimensional assessment of children with chronic physical conditions. *Health and Social Work, 29* 247-248.

Gladstone, G.L., Parker, G.B. & Mitchell, P.B. (2004). Implications of childhood trauma for depressed women: An analysis of pathways from childhood sexual abuse to deliberate self-harm and revictimization. *American Journal of Psychiatry, 161*, 1417-1426.

Gray, P. (1999). *Psychology*. New York: Worth Publishers, Inc.

Huurre, T.M. & Aro, H.M. (2002). Long-term psychosocial effects of persistent chronic illness. *European Child and Adolescent Psychiatry, 11 (2),* 85-91.

Kopinsky, K.L., Stoff, D.M. & Rausch, D.M. (2004). Workshop report: the effects of

psychological variables on the progression of HIV-1 disease. *Brain, Behaviour and Immunity, 18,* 246-261.

Lancet, British editors (2006). The devastating effects of HIV/AIDS on children. *The Lancet, 368*, 424.

Marais, H. (2005). *Buckling, The Impact of AIDS in South Africa, 2005.* Pretoria: Centre for the study of AIDS.

Midence, K. (1994). The effects of chronic illness on children and their families: An overview. *Genetic, Social and General Psychology Monographs, 120*, 311-327.

Mellins, C.A. & Ehrhardt, A.A. (1995). The impact of paediatric HIV on infected children and their uninfected siblings. *Women's Health Issues, 5,* 76-77.

Mocroft, A., Ledergerber, B., Katlama, C., Kirk, O., Reiss, P., d'Arminio Monforte, A., Knysz, B., Dietrich, M., Philips, A.N. & Lundgren, J.D. (2003). Decline in the AIDS and death rates in the EuroSIDA study: an observational study. *The Lancet, 362*, 22-29.

Moussa, M.A.A., Alaeid, M., Abdella, N., Refai, T.M.K., Al-Sheikh N. & Gomez, J.E. (2005). Social and psychological characteristics of Kuwaiti children and adolescents with type 1 diabetes. *Social Science and Medicine, 60*, 1835-1844.

Pharoah, R. (2004). *A generation at risk? HIV/AIDS, vulnerable children and security in Southern Africa.* Pretoria: Institute for Security Studies.

Sterne, J.A.C, Hernán, M.A., Ledergerber, B., Tilling, K., Weber, R. Sendi, P., Rickenbach, M., Robins, J.M., Egger, M. & the Swiss HIV Cohort Study (2005). Long-term effectiveness of potent antiretroviral therapy in preventing AIDS and death: a prospective cohort study. *The Lancet, 366*, 378-384.

Taylor, S.E. (2003). *Health Psychology*. New York: McGraw-Hill.The World Almanac and Book of Almanac Books.

Turner, J.L. (1998). Children with chronic illness. *Medical Update for Psychiatrics, 3*, 45-48.

University Associates in Psychiatry (2002). *Review Child Behaviour Checklist, 4-18.* Burlington, VT: University of Vermont, Dept. of Psychiatry.

Vragenlijsten (n.d.). Retrieved March 2, 2006, from http://www.aseba.nl

Wachsler-Felder, J.L. & Golden, C.J. (2002). Neuropsychological consequences of HIV in children – A review of current literature. *Clinical Psychological Review, 22,* 441-462.

Wenar, C & Kerig, P. (2000). *Developmental Psychopathology. From Infancy through Adolescence.* Singapore: McGraw-Hill.

Zimmermann, T.C. (1995). Psychosocial factors and chronic illness in childhood. *European Psychiatry (10)*, 297-305.

Address for correspondence:
Prof. M.A.G. van Aken, PhD
Utrecht University
Department of Developmental Psychology
Heidelberglaan 1
3584 CS Utrecht
The Netherlands
e-mail: m.vanaken@fss.uu.nl

Appendix

In this research the dependent variable depression/anxiety was measured by the following items in the questionnaire: 2, 4, 5, 7, 8, 10, 11, 14, 16, 17, 23, 27, 29, 31. The dependent variable withdrawal by the items: 13, 21, 22, 24, 25, 26, 28, 29, 30, 33, 36, 39, 41, 46; and the dependent variable social problems by the items: 1, 3, 6, 12, 15, 18, 19, 20, 32, 34, 35, 37, 38, 40, 42, 43, 44, 45.

Checklist Child Behaviour and Social Problems (age 4-18)

Child's Name……

Date of Birth…….

Child's Gender:

0 Male

0 Female

Year of HIV-infection…….....

Nature of infection:

0 Mother to child

0 Later in life

Primary caregiver of the child……

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

0 Yes

0 No

If yes, what kind of events?

…….

This form is filled in by: …….

Your relation to thechlid: ……

0 Male

0 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, high strung, 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	Under active, 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 behaviour 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